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Disability and Challenging Behaviour in Schools: the necessity for a Culpability Model of Disability.

I declare that this submission is my own work and that I have correctly acknowledged the work of others. I have not submitted it elsewhere for academic credit.

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Abstract

Key Words: Culpability, disability, discrimination, exclusion, SEN, understanding.

This research contributes to the field of disability studies, and that of education, by challenging the continued practice of holding accountable persons with a neurodevelopmental disability for the behavioural manifestations of that disability. This is a tendency found inadequately explained by either established or emergent models of disability. This study also identifies that in the wider field there is limited parental narrative available to offer an embodied perspective of the implications of neurodevelopmental disability, nor the childhoods these produce. This is considered a primary barrier toward understanding the reality of challenging childhood and the scope of disability accountability in the UK.

Neurodevelopmental disabilities have expanded both in range and prevalence throughout the previous four decades, they now affect 3-4% of all children. Disproportionate tendency to accord blame within this population is revealed by both the reasons cited for official school exclusions and the population most vulnerable to exclusionary sanction. Differentiation is made in this thesis between blame and accountability, as it is contended that whilst all persons with a behavioural impairment are accountable in principle for the manifestations of their disability, blame per se, refers to specific individual acts and is impacted upon by wider social indices.

This thesis introduces the term 'challenging childhoods', and refers to childhoods which exceed the normal excesses of childhood, typically witnessed during key developmental miles stones (for example adolescence). Rather this thesis privileges childhoods which through disability, defy control, and are as a result overwhelming, both for schools and for parents. Throughout this thesis I refer to discrete diagnostic classifications as medical labels, this is a strategic term which acknowledges that disability classifications are contested as is the medical model to which they are aligned.

This thesis offers an original contribution to knowledge through the development of a Culpability Model of Disability. This model highlights the vulnerability to accountability referenced above, and charts the juncture where physical and psychological disabilities digress. This is termed the twin pathways of attribution

and charts how persons with physical disabilities are protected from discrimination under the Equality Act 2010, whilst for those with psychological disabilities, these rights are qualified in law. The primary reason identified for this digression is based upon potential or actual impact on others, and this is cited to be key to the disavowal of equality rights.

Two incompatible responsibilities are identified in the school context, serving to exacerbate accountability tendencies. These are a need to maintain and improve standards, through summative output, alongside also the need to be inclusive as demanded legislatively. The Culpability Model posits it to be the resolution of these tensions which is fundamental to both accountability and to exclusionary response.

This research, inspired by my own parenting experience and research output from a prior study, adopts an analytical autoethnographic approach to interrogate the nature of disability challenge and accountability in the UK school context. Three areas of challenge were highlighted through experience, firstly the medical legitimacy accorded to a disability classification, secondly, perceptions around the accuracy of diagnosis and finally accountability for the behavioural effects of a disability which are considered medically to be diagnostic criteria. Using qualitative methods, the study engaged three main groups, teachers, SENCOs and families. Methods included self-complete diamond ranking exercises and guided face to face and free narrative interviews. Further data was generated from two longitudinal volunteering placements in the special sector, alongside individual interviews with Baroness Warnock and Leslie Henderson, founder of a North East autism charity.

Blame emerges as a pervasive theme and is revealed through ongoing causal discourses, framed around a nature versus nurture distinction. I concluded that psychological disabilities are stimulating of punitive responses when 'behaviour' is an issue, alongside an increased tendency to confer personal and familial blame. This thesis concludes that accountability and disposition to accord blame are illogical under the tenets of a medical understanding of disability, and as such are considered to be discriminatory.

Dedication

This research is dedicated to my family: my children, partner and sister, all of whom have contributed by various means to enable the completion of this project. Most specifically for their faith that I could and would complete it and for the many different ways that they have shown me that they care. This study was founded upon my family life and it is apt therefore that it is dedicated to my family.

Acknowledgements

This research acknowledges the countless families that struggle daily to understand and manage the dark side of disability. Facing challenges that are compounded through a conferring of accountability in the public and private domains of their lives. Behind every sensationalised media headline, staff room vent and playground gossip, is a real life story. Personal tragedy, which in an era of heightened equality might speak of help and understanding.

Unfortunately humanitarian inclinations appear lost when behaviour is an issue, consigning many young people and their families to the margins of social life.

A special acknowledgement is offered to all of the respondents who engaged with me during the years of data collection. Through sharing openly their experiences and opinions the shape of culpability was revealed; and through such exposure hopefully, the seeds of its negation. The Culpability Model of Disability offers potential to highlight public and private disablement in a manner parallel to changes effected through the Social Model in respect of physical disability.

A debt of gratitude is owed to my family, not least my sons, whose personal tragedies founded this study, and whose ongoing challenges have directed my thoughts beyond the personal. Equal gratitude is offered to my daughters whose lack of challenges have kept me sane and my pug whose presence is forever a comfort. As Benjamin Franklin (1706 – 1790) stated “out of adversity comes opportunity”. This thesis has accorded such opportunity, aiming to salvage hope from despair.

Finally my thanks are extended to the academic staff at Newcastle University who have shared their expertise and by extension fostered mine. A specific acknowledgement is offered to my supervisors Pam Woolner and Jill Clark for their advice and patience. Special gratitude is extended to Janice McLaughlin who has kindly advised on this research during its various stages and to Liz Todd whose input during the earlier stages of my PhD has held specific relevance toward its final conclusions.

Prologue

It was hoped that my own narrative would have a happy ending that hope could triumph over experience and lead to a better place. Sadly not, it just leads to more disappointment, greater loss and awareness of what can never be attained. Intellectual competency inside a social and communicatively impaired body summons up a duel tragedy of deficit with tantalising glimpses of what might have been.

The social structures surrounding such persons appear incapable of conceptual reconciliation to such incongruences and hence respond to intellectual potential not underlying often 'hidden' impairment. Until there is a tipping point, at which time responses appear directed by accountability and a conferring of culpability. Does this lead to rehabilitation? Often not, for too many, personal impairments become evidence of inability to change and a pathway to management under the Mental Health Act. An unfortunate minority drift in and out of custody, unable to break the cycles established in childhood of inclusion and exclusion.

Is this reflective of a fair and just society, one mindful of disability equity? Not for the persons involved, forced to carry baggage accrued from countless acts of injustice. This thesis determined to unpick the understandings toward disability that justify such management, for my sons and the many documented similarly. What was discovered was a conceptual framework that employs accountability as a rationalisation for responses that are just not good enough. Its presence accepted without challenge, a silent guest with deadly impact. Such subtlety belies real effect, a compounding of tragedy: particularly for families who bear witness as their children stumble from one catastrophe to the next.

The culpability paradox requires urgent address: to separate culpability from response is not to offer a free behavioural pass, to put risk into the educative and wider public domain. It is however to demand response that offers hope that recognises the root of difficulties: roots beyond the choice of the individual or the families that surround them. Hope to change, hope to learn and belief that change is possible are markers of a developed and civilised humanitarian society. One committed to egalitarian principles. As a society, we are far from this and it is hoped foregrounding a Culpability Model will extend a preliminary first step in that direction. It has been said that the longest journeys begin with a single step and I submit this thesis as that first step.

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List of Abbreviations

AA	Ambitious about Autism
ADHD	Attention Deficit Hyperactivity Disorder
AET	Autism Education Trust
ASD	Autistic Spectrum Disorders
BESD	Behavioural, Emotional and Social Difficulties
BFI	British Film Institute
BIBIC	British Institute for Brain Injured Children
CAF	Common Assessment Framework
CAF	Contact a Family
CDS	Critical Disability Studies
CEREBRA	Charitable Foundation for Brain Injured Infants and Young People
CLA	Child Law Advice
Daslne	Database of Children with Autism Spectrum Disorder Living in the North East
DMDD	Disruptive Mood Dysregulation Disorder
DSM	Diagnostic and Statistical Manual of Mental Disorders
DPO	Disabled Persons Organisations
ECHR	European Convention of Human Rights
EFDS	English Federation of Disability Studies
EHRC	Equality and Human Rights Commission
ESRC	Economic and Social Research Council
HCC	House of Commons Committee
HL	House of Lords
ICD	International Classification of Diseases
IPSEA	Independent Panel for Special Educational Advice
ITTP	Integrated Threat Theory of Prejudice
MRI	Magnetic Resonance Imaging
NAS	National Autistic Society
NASUWT	National association of Schoolmasters and Union of Women Teachers
NFER	National Foundation for Education Research
NICE	National Institute for Clinical Excellence
NUT	National Union of Teachers
OCC	Office of the Children's Commissioner
ODD	Oppositional Defiance Disorder
ONS	Office for National Statistics
PDB	Persistent Disruptive Behaviour
PTA	Parent Teacher Association
QCC	Quality Care Commission
RM	Resistance Model
SDR	Secondary data respondent
SEMH	Social, Emotional and Mental Health
SEN	Special Educational Needs
SENTASS	Special Educational Needs Teaching and Support Services

SI	Symbolic Interactionism
SR	Social Representation
PDA	Pathological Demand Avoidance
PRT	Prison Reform Trust
PT(r)	Papworth Trust
PT	Positioning Theory
TCA	Thematic Content Analysis

My kind of day

“Every day I wake to the drum drum drum of my fish tank and I hear these dreaded words, mum calling 'time to get up', and I make this dash for the bathroom and eureka I have beaten my brother to the bathroom', that is the joyous part of my day and then there is this terrible part of the day when my mum says 'time to get in the car' and I would look up and see my brother in his bedroom waving at me and I felt so sad... then I got into school, mum gave me a kiss and I dragged myself off slowly, I do everything slowly, I crossed the field to the torture chamber where we are lined up platoon by platoon and the jailers come out to take us in and that final door crashes, and my fate is sealed”. *(Courtesy of family 1: daughter [then] age 10, ADHD, OCD and mental health problems)*

Chapter One. Introduction

This thesis seeks explanation for disability accountability and disability challenge, drawing upon both maternal experience of childhood disability and previous academic research. As an interjection at this point I will take the opportunity to reveal that I am a mother of eleven children, of which several have been given a neurodevelopmental disability diagnosis, following social and behavioural atypicality. They can be summed up collectively as challenging, hence my experience is both expansive and I hope illuminating. This doctoral research seeks explanation for why children and young persons who display challenging behaviours due to a known or suspected neurodevelopmental disability are held accountable for the manifestations of such disability.

Practices of accountability in this guise are considered contrary to the stated definition of disability 'as a physical or mental impairment which has a substantial and long-term adverse effect on ability to perform normal day-to-day activities (Parliament 2010, Pt. 2, Ch. 1, section 6). This definition by inference is taken to imply that the symptomatic manifestations of a disability are beyond the control of the person affected, and therefore blameless. Nevertheless blame appears common practice, and most tellingly observed through the increased vulnerability to school exclusion that pupils with special educational needs are found to hold. Equally telling is that 'persistent disruptive behaviour' is the most common reason cited for exclusion (O'Regan 2009; 2010, DfE 2015b; 2016).

Neurodevelopmental disabilities are particularly common in children and known to stimulate behavioural difficulties (CEREBRA 2013); however the manifestation of these 'symptoms' in school and indeed the criminal justice system frequently results in within-school segregation, exclusion (legal and illegal) and at times criminal prosecution (Jull 2008, Hughes 2012, OCC 2013, AA 2014, Wasik 2015, DfE 2015b; 2016). This thesis also finds that there are qualifications to educational rights embedded within both Education and Inclusion legislation (Parliament 1996; 2001; 2014), of which the 2014 Families and Children's Act is the most recent example. Within this act it is stated that entitlement to mainstream provision is compromised where there is an adverse effect on the 'proficient' education of other children (Chapter 6, part 3, and point 35). Equally it is found that there are serious negative

implications to disability being invoked as mitigation in the judicial system (O'Connell 2016). Taken in conjunction it would appear that all disabilities are not equal, nor equally protected from disadvantage. It is contended that such disadvantage amounts both within and without the education system as institutionally ratified discrimination, and as such necessitates urgent address. This thesis subsequently seeks to discern explanation for the disadvantages outlined, drawing upon the implications of wider political and educational priorities, intersections of disadvantage and relationships of power.

Chapter one commences with reference to an extract written by a respondent's daughter (aged ten). The extract illustrates a young girl's perspective toward her school context and also emphasises her sense of powerlessness. It serves to remind us that the child's perspective is paramount, even though discourses of diagnosis and response remain rooted to the adult domain. This is followed by an expansion on the researcher's personal and previous research context, outlining why in conjunction they acted as an impetus for this research. An overview of the study follows, introducing its underpinning ontology, theoretical influences, methods of data collection and analysis. This introduction then progresses to outline the ethical implications stemming from drawing upon the personal and familial context for professional purposes. The chapter concludes with an introduction to the nature and significance of culpability in the education context, its centrality and why such centrality suggests the need for a further model of disability.

1.1 An unequal relationship

The preface to Chapter one, 'my kind of day' was penned by a girl, who following many educational struggles, was identified as having several recognised disabilities during the latter years of secondary schooling. Her words show how oppressive school can appear when you are the recipient of its services, not the architect. Indeed for all children, the reality of school and the relationships it engenders, are relationships of inequality. Unequal in relation to teacher/pupil relationships, peer/peer relationships and unequal for many pupils in relation to summative achievements (Benjamin 2002, Black-Hawkins 2008, Youdell 2006, 2010, 2011).

School based education results in unequal positioning, conjuring inequalities which appear both immutable and fundamental to the foundation of contemporary mass education systems (Bourdieu 1977, Ecclestone 2009, Robinson 2011, OCC 2013,

Kulz 2015). Problematically power imbalances are heightened for children and their families when disability is a factor, and problematized further when disability results in behaviour which is viewed as challenging. Rogers (2013) refers to this as 'difficult difference' (pp 132), a manifestation of disability which is not only disadvantaging, but can be definitional of a pupil's identity (Bailey 2009).

The difficulties my children experienced were not only constitutive toward their personal and school profiles, they extended into the family domain with deleterious effects both practical and emotional. In addition the negative profiles generated, exceeded their immediate childhood and were formalised (for future reference) through the bureaucracy of school, social services and criminal justice records. It is thus of concern that current statistics and research attest to similar vulnerabilities for other children and families (OCC 2013, DfE 2015b, Kulz 2015) similarly affected by neurodevelopmental disability. Such impact was thus considered suggestive of an unequal hierarchy within the disabled community as a whole.

This research adopts the definition of childhood disability proffered by McLaughlin (2016). 'Children and young people whose minds- bodies interact with the world in a different way; a difference that places them in recognised categories, established in medicine, validated by state institutions, and maintained by how others in society, known and unknown, engage with them '(pp 2). Toward a broad definition of what constitutes a 'behavioural difficulty' this research accepts O'Connell's (2016) description, which holds that behavioural difficulties may be understood as 'the range of socially challenging behaviours that might be seen as a disability' (pp, 2).

Seeking a finer appreciation of the nature of disability as well as the sites of disability challenge and accountability, my thesis explores not only medical understandings of disability, but also constructivist and relational explanations. This broader engagement is found to alter in integrity explanations for 'challenging' and disability; render in regards of constructivist and relational explanations, both states to be emergent from collective engagement, rather than medically determined on the basis of individual child factors.

1.2 Beginnings – from personal circumstance to a research impetus

The duality of the personal and the professional domains, inherent to autoethnographic research, poses a preliminary dilemma; whether to foreground innate research interests, accomplishments and ongoing endeavours firstly, or to

ground the reader in the personal context which is equally foundational to the research focus. Indeed the absence of any prescriptive protocol adds complexity to the writing process (Wall 2008) and after due consideration I considered it appropriate to introduce my personal context firstly, as its research value was primary to both my decision to use an autoethnographic approach and to pursue the research avenue I engaged in.

Without further hesitation I will introduce myself primarily as the mother of an improbably large family (eleven in number); a challenge simply by numbers, but additionally so as five of my younger children hold the neurodevelopmental diagnosis of autistic spectrum disorder (ASD) and of these diagnosed children, they are also known to have additional comorbid conditions, including Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiance Disorder and Dyslexia/Dyspraxia. They are by character and nature children and young people who can aptly be described as 'challenging': a description which is consistent with the criteria for diagnosis contained within the latest version of the diagnostic and statistical manual of mental disorders (APA 2014). It has also been a constant personal reality, irrespective of ongoing medical debates around causation or diagnostic criteria.

The theme of challenging has been a central feature of my parenting experience, although the fashion for diagnosis may be seen as a more recent activity. The childhoods of my older children pre-dated the fashion of medical diagnosis and as they entered school in the mid to late 1980s, before claims to inclusion and routine diagnostic surveillance protocols were common discourses. In contrast, my younger sons entered formal education at the turn of the millennium amidst a very different culture, both politically and medically. This has offered a unique opportunity to contrast the effect of both inclusion and medical explanations for 'behaviour' in the school and familial context, addressing the question of what, if anything, has changed.

It is widely acknowledged that parents (particularly mothers) of disabled children suffer multifarious disadvantages (Kingston 2007, Rogers 2007; 2011, McLaughlin 2008 a; b; 2016, Carpenter and Emerald 2009, Gallagher 2010b). Nevertheless as Cologon (2016) found, parents resisted the inevitability of disadvantage as a biological given and emphasised awareness that many of theirs and their children's disadvantages were resultant from social barriers. I too would concur with these

parents; nevertheless, practically there are differences between what may be viewed as the traditional markers of average child development and those faced by parents of children with both physical and neurodevelopmental disabilities. Notably bureaucratic systems do not reflect these differences, which serve to erect further barriers for both the child and the family.

Overall, the challenges my children present have necessitated disproportionate parental time and emotional energy (in excess of that which their chronological ages would commonly indicate). For example the age of eighteen is the legal start of adult independence, yet for some children, mine included, this is a juncture in name only. Another pressure resultant from 'challenging childhood', surrounds the familial and child personas fostered, particularly where parental identity is not congruent with agency dependency and thus either results in resistance to support, or a denial by agencies of support needs. These challenges were experienced by both my partner and myself, as we both held higher degrees, had a professional standing and presented as socially competent. Over time it was revealed to me that as a family we did not fit the anticipated profile of a 'troubled family' (Casey 2012 a; b). Such a revelation did, however, underscore the attributions of familial deficit which were typically associated with 'challenging childhood'.

Practically as a family we have navigated a range of difficult behaviours in school (and at times the wider community). This has resulted in numerous exclusions, (both legal and illegal), a creative range of school sanctions, management protocols and regular 'review' meetings. These experiences have extended across three decades, straddling fundamental shifts in educational thinking, and hence have accorded a unique insight into organisational practices, publicised change and actual change.

Looking objectively with the benefit of hindsight, my role as advocate and that of a mother has at times led to tensions that most mothers are fortunate enough never to face. It is also fair to suggest that decisions taken during periods of school crisis were driven too frequently by a narrow focus on the academic prize, rather than the vulnerabilities I knew my children to hold. Similarly so in retrospect, I can identify that when my older children were of school age, I held a deference to the sanction protocols of my children's schools and felt shame that my children did not comply. With the onset of medical explanations for the challenges my children posed this attitude began to shift and I became more critical of the structures that appeared to contribute to the difficulties posed. Reflexively I can now see my former deference

and acceptance of responsibility were deflating of any institutional challenge. Not least because school priorities and expectations were repeatedly emphasised and embedded in the majority of school communication and unquestioningly accepted as fundamental to school and adult success. The emergence of medical understandings of 'challenging childhoods' challenged this orthodoxy and resulted in for me a resistance to school driven priorities, alongside a demand for school accommodations, in line with the then dominant disability discrimination act (Parliament 1995). However at this point I was unaware that there was a tipping point where equality rights concede to criminal and educative law (O'Connell 2016).

Practically my son's difficulties in education have ranged from minor conduct infraction, abstract thoughtlessness to major meltdowns, frequented by aggressive and abusive behaviours. Typically they have begun with minor misdemeanours and escalated upon school remonstrations into major incidents. Looking back now at the 'facts' of these instances, they could be reasonably described as reflective of the criteria for medical diagnosis that founded my younger children's medical labels. However both prior to the expansion of childhood diagnosis and following it, my own experience suggests that there were parallel explanations in circulation (notably explanations which were led by personal accountability and the rightness of individualised blame).

In practice these dual discourses worked to found school and community understandings of the drivers of 'challenging behaviours' and although a medical diagnosis would logically suggest a negation of accountability and blame in working practice, this was never axiomatic. Thus the challenging dispositions my younger sons displayed were inconsistently viewed as symptomatic of a diagnosed disability. Rather they were more generally held to be deliberate and accountable acts, resulting in frequent internal and external exclusions. With the luxury of reflection and a more objective critical eye, these responses were not only incongruent with a medical model of disability and the legal protections such model confers, they amounted to under the responsibilities accorded from equality legislation (Parliament 1995; 2010), acts of discrimination.

1.3 Changes and underpinning explanations

Contrasting the school experiences of my older sons with those of their younger brothers suggests that irrespective of the consolidation of educative vision and

disability rights, little had changed (Warnock 1978, UNESCO 1994a; b; 2008, DfES 2001b, DH 2001, Parliament 1995; 2001; 2003b; 2010b, 2014). This was considered (from a professional perspective) to signal that a deeper reliance on accountability was operational beneath the level of policy, but one whose guise was shrouded by contemporary social rights rhetoric. Looking at wider explanations for these tendencies, two main explanations were prominent. The first was that individualised accountability was intrinsic to sustain a mass education system, particularly one whose guise was most generally founded upon the schooling needs of the industrial era (Robinson 2011; 2015). The second possible explanation surrounds the surveillance and stratification functions served by mass educational systems, in particular the perpetuation and legitimation of existing social inequalities (Foucault 1973; 1977, Bourdieu 1977, Kulz 2015).

Certainly both explanations were persuasive, particularly against a backdrop of disproportionate vulnerability to exclusion for particularly groups. Most particularly for those with a disability or an SEN (DfE 2013b, DfE 2014b and DfE 2015b).

Problematically, however, disadvantage was found to extend more widely, intersecting with other indices, such as socio-economic status, culture and ethnicity (Rogers 2007 a, b, c, 2012, Runswick – Cole 2009, 2011, Slee 1993, 2001, 2013, Tomlinson 1982, 1985, 2012, 2014), suggesting disadvantage to be a more general trend rather than local to disability. Nevertheless within the disabled school population, pupils with ‘challenging behaviours’ were rapidly becoming recognised as being subject to a repeating pattern of disadvantage and exclusion (CEREBRA 2013; OCC 2013, AA 2014, NAS 2015). As the National Autistic Society’s (2015) caution examples:

“Children with autism are particularly vulnerable to being excluded from school. Sometimes behaviour associated with this hidden disability can be confused with disobedience because of a lack of awareness of the condition by both pupils and adults in school” (NAS cited in Patterson 2014, pp 17).

These observations resonate with my own experience, although such simple association has been challenged most recently research by Kluz (2015), who working on behalf of the Communities Empowerment Network suggests that the procedural exclusion process of schools may themselves be contributory to this increased vulnerability. In particular Kulz finds “the statutory guidance asking head teachers to consider overrepresented groups prior to exclusion is ineffective in practice” (pp.7), similarly so the level of expertise available to manage or redress challenges exhibited. These findings suggest it is not difference or presenting challenges which

prompts exclusion; rather it is organisational inability to manage or respond efficaciously. Which of itself prompts deeper questioning toward the reasons underpinning such lack.

1.3.1 Returning to the personal

Looking back, accountability was levelled towards me in respect of the challenges my younger children posed as robustly as it was to their older brothers; who whilst posing similar challenges held no medical explanations to legitimate mitigation. Notably, however one important difference was noted, namely that a medically deterministic attitude was observed toward my younger children and it was this which regularly was invoked as reason by school to place them alternatively (either segregated with the mainstream) or outside of it. This logic conjures for children who are of 'normal' or 'above intellectual ability' a placement dilemma, as there are few placement alternatives in the special sector for children without physical or intellectual difficulties. Even though my older children were not exposed to medicalised explanations for 'challenging childhoods', they were neither more nor less, accountable. In a sense their placement was more secure, as being of average or above intellect, they were expected to remain and be educated in the mainstream.

Nevertheless logically and indeed legislatively, medical understandings of 'challenging childhood' and its invocation as mitigation should have been both conceptually and legally game changing. Not least because replacing the understanding of behavioural difference from 'naughtiness' to symptom has been described as the introduction of labels of forgiveness (Slee 1995, Lloyd and Norris 1999, Riddle 2007). Nevertheless in working practice it was notable that my younger son's challenges were rarely viewed or managed as symptoms; nor effecting of remediation or accommodations in the school or community context. It was (and remains) questionable as to why not, when medical discourses maintain 'challenging' behaviours to be a core diagnostic feature.

1.3.2 Safeguards or challenges?

In addition to accountability, my younger sons were also subject to repeated disability challenge within their school system, a complication my older sons evaded. Looking back towards an understanding, these challenges could be understood as emanating from a limited understanding of the range of presentations contained within the rapidly expanding autistic spectrum. There was an even lesser understanding (and at

one point pre DSM-5 lack of recognition) of the common comorbid interaction of ADHD. Such a challenge was experienced directly in respect of one son in particular and emanated from his diagnosis of Atypical Autism. This unfamiliarity led to a direct diagnostic challenge by teaching staff, which in the arguments presented for challenge was justified on the basis the expectations of classic autism did not present in my son. Notably this attracted a swift rebuttal by the diagnosing psychologist, who replied with a dictionary definition of what 'atypical' was.

1.3.3 Reflections

Such experiences were fundamental to an eventual unwillingness to internalise or accept the academic priorities and accountabilities conferred toward my children and family by their schools. Thus despite the benefit my younger sons may have assumed from being historically and geographically situated in an era of equality, the school response demonstrated that inequalities and prejudice remained active and in relation to disability challenge were heightened. These disadvantages were unobtrusive and throughout the daily exposures of school life and unavoidable peer networking, it became apparent that they were disproportionately levelled toward children who were 'challenging'. Such disadvantage unsurprisingly rebounded into the privacy of our family life, mainly through incursion into both our time and emotions. Most typically this took the form of phone calls home, alongside requests to attend school, or more recently to withdraw our child, alongside an unstated (but implicit) demand that something be done.

Looking objectively at the circumstances of disadvantage, it is fair to suggest that my sons challenging behaviours did challenge. This made school concerns practically understandable, hence suggestion of their incompatibility with the mainstream might not have appeared as questionable, had such a conclusion been accompanied by an entitlement to an appropriate alternative. Notably an alternative which lacked the stigma of exclusion and held promise of behavioural and social supports; as indeed as parents we were having to manage equally (if not more) behavioural challenges with no support.

Severe adverse personal circumstances following an agreed funded move for one of my sons revealed the scope of financial supports that had been available to school to support the challenges being posed. The financial cost (met by school) also reinforced to me that the incompatibility school cited as justification for a move was

not resource driven. To the contrary, it appeared to extend from the school's lack of desire to retain, a factor which only surfaced after there were significantly serious consequences leading directly from the alternative placement which at one point nearly cost my son his liberty. Without alluding to specific details, it is sufficient to state that throughout the past few years, there has been serious concerns surrounding the exploitation of vulnerable young people in large city centres. Through circumstance and lack of chaperoning, our son was introduced to this scene and because of vulnerabilities held, engaged with it to highly deleterious effects. In short, far from being recognised as vulnerable and supported in the protected environment of school, the school's unwillingness to retain added to the difficulties already held.

The serious lack of safeguarding which had been sanctioned, led to meetings with the funding authority, it was at this point I was made aware of the funding provisions available to school and the protocols for securing it. Nor could I rationalise the schools desire to revoke my son's placement simply on the basis of challenges faced, as I was aware that equal or indeed worse challenges were being (successfully) managed in the specialist sector. I thus concluded that the disadvantages levelled, stemmed directly from the individualised accountabilities my son's mainstream school had considered it appropriate to accord, which deflected from them the vulnerabilities he was also documented as having on account of the medical diagnoses he held.

1.3.4 The illogical nature of blame

Over time the persistence of accountability and the disadvantages endured were considered not only illegal, but also illogical: running counter to the concept of disability as a medical state of being, productive of symptoms, beyond the control of the host. Accountability was also considered incongruent with both the working definition of a disability and the responsibilities metered by equality legislation (Parliament 1995, Parliament 2001, Parliament 2010b).

Of equal concern was that accountability was unconsidered as an act of discrimination; particularly as there are qualifications to educational entitlements persistently stated in disability and equality legislation (Parliament 2001, 2014). These qualifications offset the right of a child to be educated in the mainstream and pertain to perceived impact on the 'proficient education' of the wider pupil cohort (Parliament 2014, Chapter 6, part 3, point 35). Through these qualifications,

accountability for challenging behaviours is stated to be reasonable. However in working practice, it may be seen as reactive and disavowing of the individual pupil's needs or vulnerabilities. For my family accountability was constitutive; and generated for our son (and at times ourselves) a negative profile which actively shaped the meaning given to all subsequent difficulties our son displayed. These effects resonate strongly with Foucault's (1982) writing on objectification, most specifically of how individuals become embroiled in relations of subjection that are constitutive of their personhood. My son's identity, through a series of personal crises, (the result of educational decisions), altered his profile from one of vulnerability, to one of risk. As such my son was no longer welcome in education, yet it was the one environment best placed to support him. The accountabilities cited also suggested that teaching staff were sceptical toward medical explanations for psychological/behavioural disabilities and such action did was a professional rebuff to their disability status. There appeared an unspoken consensus that the behavioural symptoms commonly deemed as diagnostic criteria by psychologists, were for identified children, a personal choice. It was therefore the persistence of accountability over time, despite the emergence of medical understandings which prompted this research. I particularly wanted to probe the uniqueness, or wider recurrence of these personal challenges and accountabilities, as well as the logic blameworthiness extended from. This research was further informed by data generated from a previous research project (Watson 2010) and this is now outlined in the following section.

1.4 Testing the water - secondary supporting data

Data collected as part of a prior research project (Watson 2010) supported the need for my doctoral research project. Of itself, it produced data which could offer explanation for some of the previously referenced difficulties my children had experienced. This study probed whether common collective meaning, or multiple individual meanings were typical in respect to the personal understandings educational inclusion conjured amongst teachers, parents and children. Although my data confirmed multiple meanings across all respondent groupings, it was secondary school teachers responses that emerged as directly relevant to this study, particularly to the accordance of blameworthiness.

This small scale research was prompted by the experience of pursuing a school disability discrimination complaint at tribunal; which when considered in retrospect, offered indication that in dialogue, school and I were discussing different

conceptualisations of what inclusion represented. This research comprised a single question, requesting spontaneous definition of what inclusion represented to respondents personally.

Overall respondents suggested strongly that not all disability types or presentations of SEN were accepted equally. There was also an intimation that some disability/SEN presentations were contested and the children concerned were being subject to considerations of whether they were deserving or undeserving. Such opinion is exemplified by the following teacher's annotation:

"I would differentiate between the inclusion of students with real special needs e.g. physical disability and those with behavioural problems, the latter rob others of their educational rights because of constant disruption" [secondary data respondent 6 (SDR 6)].

A similar theme of deserving and undeserving is detected in this further comment, referring not to the type of disability held, but to the innate motivations of those with a disability:

"Inclusion offers excellent chances given to those who really need it and most importantly – want it, otherwise it's no good" [SDR 3].

Both examples may also be considered illustrative of the dividing practices Foucault considered central to the institutional exercise of power (1982). In addition, the idea of merit suggests there to be a hierarchy of legitimacy active within the broader status of disability. The idea of deserving and undeserving can also be understood by drawing upon Kelly's contention that humans make meaning through oppositions. Hence the notion of a deserving disability is revealed only through equal appreciation of its opposition, undeserving. Kelly (1963) entitles this tendency as Constructive Alternatism and states it to be central to the development of Personal Construct Theory.

Certainly the meanings generated from the oppositions of deserving and undeserving were evident within this small research project. Serving to frame not only the validities of need and motivation, but also the legitimate use of staff time, the following teacher's comment is illustrative:

"The current state of inclusion results in staff having to spend too much time on a small number of pupils to the detriment of the main class" [SDR 2].

This sentiment suggests that the practical demands of attending to the needs of 'challenging' pupils is disproportionate and unjustifiable. It is also illustrative of the qualifications to entitlement previously noted (see point 3.2.5) and found echoed

through wider research projects (NASUWT 2008, 2012a, b, NFER 2012, Neil 2013). If levelled against disability without any differentiation, these sentiments would in probability be dismissed, not only as callous and indefensible, but also as discriminatory. Nevertheless they can be seen to alter in their guise where the indicators of disability manifest as behavioural challenge, notably reframed as disruptive and thus sanction worthy (Parsons 2005, Jull 2008, O'Regan 2009; 2010). Poor behaviour is also linked to teacher resignations and wider pupil disadvantage (Smithers 2003), heightening its appearance of unreason. Thus despite suggestion that there are educative benefits deriving from inclusive schooling (Alur 2009), for some those benefits are unseen, for as Lea (2015) asserts, 'socio-emotional difficulties are often poorly understood and engender negative responses in schools' (pp. 242).

1.4.1 Associations

It was illuminative that this research had focused specifically on the policy of inclusion and its enactment as educative practice. It contained no overt reference to disability, yet respondents overwhelmingly made such a connection, albeit stated to be SEN rather than disability. Teachers differentiated consistently those pupils which were viewed as a problem, not least burdensome and impeding of the progress of their peers, this was summed up thus:

"Inclusion for me means that I have to tailor my lessons to small number of pupils which then disadvantages the rest of the pupils" [SDR 15].

On closer inspection, however, this sentiment was not alluding to practical time needed to support a struggling pupil, it was typically framed around behavioural impact. It thus offered a first glimpse of the primacy of the collective in the mainstream school sector. A primacy which by its opposition was disavowing both of the needs and rights of the minority, essentially the antithesis of the sentiment expressed by Booth in the Index for Inclusion (2002). Nevertheless such sentiment did offer explanation for my own children's negative experiences and tenuous placement security. However, this was considered insufficient to explain fully, why similar discord was not extended toward other forms of disability which warranted equally demands on time.

Teachers within this study intimated that at times, 'inclusive placements' were forced upon the mainstream, schools rather than representing a core pupil right. Such

sentiment was accompanied by indication of local resistance to remaining legally compliant with the policy of inclusion. As this teacher states:

“Inclusion involves taking students out of mainstream lessons so this avoids external exclusion and consequent government penalties” [SDR 4].

This teacher’s claim clearly indicates the functions served by internal exclusionary practices (OCC 2012; 2013), one which is mirrored more generally across schools. Thus, despite official statistics suggesting a downward trend to the rates of school exclusion, McCluskey (2015) found that exclusionary practices remain buoyant, albeit in less overt forms. It is also found that students with disabilities remain as disproportionately vulnerable to what I term ‘within system exclusionary practices’, as they are known to be in relation to formal exclusions (DfE 2015b; 2016). ‘Within system exclusionary practices’ are defined as practices which mask a segregationally motivated intent behind a rhetoric of benevolence. McCluskey (2015) draws attention to the detail of such practices, citing the practice of offering managed moves as a means of preventing formal exclusion, as well as ‘cooling off periods’ out of school and bespoke timetabling.

Ironically I rarely dismissed the practicalities faced by schools in relation to managing my children’s complex behaviours, even during protracted periods of discontent. To the contrary, the real frustration felt alongside confusion, extended from the seeming lack of necessary supports to cater for their particular needs. A lack Kulz (2015) reports to be an ongoing issue, ‘mainstream educational institutions frequently lacked the staff expertise, financial resources and time to accommodate SEN students (pp. 7). These omissions of support contrast markedly with other European practices, particularly those common to the Italian system which claims absolute inclusivity alongside a zero school exclusion rate (Arnold 2009).

1.4.2 Challenging the direction of accountability

Kulz’s concerns lead to the question as to why the effects of lack of support within the secondary data were most frequently levelled toward pupils, given that pupils, and similarly their parents, have little influence over the distribution of school resources. It is equally worthy of note as to why inclusion held a negative association, not with disability per se, but rather with pupils posing management problems. Interestingly Cook (2000, 2001) and Klehm (2014), similarly to Lea (2015) found that behaviour was frequently disassociated as an indicator of disability, thus amenable to alternative attributions and response. This suggests there to be a

restricted range of presentations that trigger association with disability, and that behaviour is infrequently one of those triggers.

The data teachers produced suggested two explanations for teacher's negative attitudes toward challenging behaviour. These surrounded the adequacy of training and the accessibility of supports to maintain pupil placement as this teachers comment illustrates:

"I fully support the idea of giving each child the same educational opportunities however for this approach to succeed teaching staff need to be empowered with effective training, have access to appropriate resources and be well supported in class"[SDR 16].

Although the issues raised are practical in orientation, they link to decisions made at a political and higher professional level. They thus widen the locus of responsibility for exclusionary response beyond the immediate school setting.

It is equally of concern that 'behaviour' emerged within this data as undifferentiated in its causal factors, despite an expansion of medical labels to explain patterns of challenging behaviour. Until the introduction of the new SEN code of conduct (DfE 2015a), pupils displaying behavioural and emotional challenges were grouped under the common descriptor emotional and behavioural difficulties (EBD). This grouping has also resulted in the legitimisation of specialist schools tailored to this pupil group's needs, although it remains unclear as to what extent such grouping generates or deflects identity or association with disability. However, although the generic grouping of EBD has generated wider concerns (Hardwood 2006, Cross 2011), there are also concerns indicated toward medical understandings of challenging behaviours (Slee 2013a, Hardwood and Allen 2014). Notably the new code does not challenge the ongoing blameworthiness of behavioural presentations in the light of its amendment and is hence considered insufficient to address disability inequality fully.

Although the data generated in this small study cannot generalise to teachers associations generally, or their dispositions to conceptualise pupils challenges within a disability frame: official statistics suggest that individualised blame is consistent across schools and links disproportionately to disability and SEN (DfE 2015b; 2016), as the following comment states:

"Inclusion is an attempt to keep students within a school environment as long as possible despite their behaviour. It can only work if students are treated fairly and sanctions are imposed in accordance with their misdemeanours" [SDR 3].

Notably closer consideration to the sentiment exposed in this comment reveals a deeper meaning. Typically that behavioural infractions, irrespective of disability are

blameworthy and disassociated from any conceptualisation that they may be symptomatic of a disability and as such entitled to reasonable adjustments. It is thus interesting that the concept of fairness was invoked by this teacher to support a parity of sanctions, without any corresponding acknowledgement of fairness in relation to misdemeanours that may accrue as the result of a disability or SEN.

Overall teachers who participated in this study consistently referred to 'behaviour' as a negative, a standalone descriptor. This tendency acted to divide those who were worthy from those who were not:

"Where inclusion involves students with physical disabilities/learning difficulties it has been a positive teaching experience -where inclusion has meant that students with emotional/behavioural difficulties have been allowed to hamper the life chances of a significant number of other students, it has been the single most demoralising aspect of the job" [SDR 18].

Such sentiment operates not only to demarcate a specific group, but also hints to the reasons for such demarcation; chiefly their impact in the school domain, effecting not only a negative impact on the collective, but undermining of the teaching role generally.

The demarcation of certain pupils as burdensome, impacts not only in the immediate, stimulating negative response, but rebounds on their future life outcomes, particularly as disassociation with school remains a predictor of lower achievement into adulthood (Henry 2012, Allardyce 2013). Similarly looking more closely at the words used in the previous excerpt, the use of words such as 'allowed', holds itself the implication that this particular group of pupils are both imposed and resisted. Such opinion in working practice is not only descriptive, but positioning and summoning of a negative identity.

Overall the data generated by this previous study resonated with my personal experience, although was found to be somewhat shocking at times in terms of the strength of negative feelings displayed. As the mother of several 'behaviourally challenging' children, this data raised as many questions as it answered. Not least as to whether it was reasonable to expose a child to such a hostile environment; one liable to compound difficulties, rather than address them.

1.4.3 Implications

This data supported the need to explore more fully the locus of challenge: both in terms of rationalisation and internal logic. Of specific interest was intimation that behavioural challenges were being viewed outside of a disability frame of reference,

hence disregarded as indicative of any underlying etiology. Indeed it was rare within this data-set to find any acknowledgement that challenging behaviours were being viewed as symptomatic of a medical disability. Furthermore responses suggested that inclusion as an educational policy, engendered negative association with the management of pupils exhibiting challenging behaviours, not disability per se. This stimulated further a research interest toward the understandings that disability prompted amongst teachers, particularly toward discrete medical labels.

Notably secondary teachers responses were found to contrast heavily with colleagues in the primary and special sectors, who had indicated a lesser negativity toward challenging behaviours as well as a lesser frustration toward pupil management). Nevertheless the consistency of these findings are challenged as most recent exclusion statistics suggest an increase in exclusions in the primary sector, alongside a corresponding decrease in secondary (DfE 2015b) school exclusions.

In summation the negative attitudes exhibited toward behavioural challenges, both personally and within this small study were summoning of deeper questioning toward how disabilities of a behavioural nature were understood. Particularly whether in the wider school context medical disability labels attracted equal legitimization, or if some were subject to legitimacy challenge, as had been personally experienced. Wider intimations of deserving and undeserving, alongside conferment of accountability offered suggestion that many behavioural challenges were viewed as a conscious choice, rather than symptomatic of an underlying disorder. This viewpoint was considered incongruent with the medicalised classifications of disability commonly employed in schools. Particularly as these are classifications that teachers are entrusted to identify, and which also act as primary evidence to support resource allocation (Hobbs 1975, Florian 2013). Overall, data generated from this study, in conjunction with personal experience supported assertion that challenging behaviours generated differential understanding and were heavily imbued with the notion of blameworthiness. These factors above all others were directive of my doctoral research foci.

1.4.4 Key findings from supporting personal and secondary data

- Differential disability understandings generated from discrete disability types
- Tendency to accord culpability for disability effect

- Distinction between deserving and undeserving disability presentations
- Impact of individual on teaching/organisation
- Limited appreciation of organisational (school) impact on the pupil or presenting differences/challenges.

1.5 Introducing the Research Study

1.5.1 Making sense of disability personally

I felt it an important principle of 'insider research', to consider the outlined research arena equally as an 'insider (a mother) as well as a researcher. I hence felt it useful to consider what childhood disability had come to mean personally, given my sons were, and still are, challenging, the narrative offered on page 19, details not only the experiences and difficulties faced, but also why as a mother I considered there to be a need for this study.

Overall this research aims to explore the justification for disability disadvantage and particularly the accordance of accountability in the school context. I was further mindful of the effects such disadvantage can have across the life course; effects which were found to impact on personal and familial identity, employability and social and financial wellbeing (Home 2002, Holt 2010a, McCrystal 2007, CAF 2013). It was also considered notable that the longevity of these disadvantages are rarely captured within school statistics or employment records. They are in essence the silent effects of what I consider the last vestiges of overt disability discrimination (BIBIC 2005, 2007, Kingston 2007, Rogers 2007, Runswick-Cole 2007, McLaughlin 2008b, Runswick-Cole 2008, Gallagher 2010b, McLaughlin 2011, Rogers 2011, PT 2014).

Looking across space and time outside of specific events that acted as mapping referents, the following thoughts (offered below) emerged, and represented how my own parenting challenges could best be summed up. This sentiment highlights the potential for not only external accountability, but also its inversion: blame directed inwards in an attempt to make sense of a situation that defies 'typical' parenting expectations (Kingston 2007, 2007a, Rogers 2007, Landsman 2009, Gill 2011, Curran 2013). As Doubet and Ostrosky (2015) note, the dual direction of accountability (emergent from self and the wider social arena) generates increased susceptibility to an acceptance of such accountability. This is a process which is reminiscent of Cooley's (2010) notion of the looking glass self, whereby persons take on their sense of self as it is projected by others.

The following thoughts are shared with the reader, demonstrating how personally disability is understood as a relational concept, founding not only recognition, but understanding, liability and familial experience.

“Can you imagine what it is like to tear yourself apart, to interrogate every aspect of your conduct in order to answer that one burning question of what went wrong? What you did, didn't do, when and how? Only to surface with no answers, just a gnawing feeling of responsibility...And then throughout engagement with professionals, professionals who are trusted to deliver answers, culpability is again a dominant lens. Signifying move from personal flagellation to external scrutiny, which extends into the core of private family life. Such intrusion has frequently been endorsed through reference to issues of attachment, 'refrigerator mothering', too harsh or too soft parenting, the list is extensive. That has been my reality of childhood disability, the foundation of social engagement, extending from professionals to strangers in the street. Adding insult to injury have been the intimated and indeed often open challenges both to the application of disability diagnosis and the very core of the diagnostic category itself. A response that renders the recipient and their families in a state of flux, unable to fully accept explanations so sought, introducing an element of doubt that erodes and undermines ability to face their child's disability with confidence and dignity.

Disabled childhood is a fight; a quest for answers, recognition, access to services and exoneration from culpability. All of which frequently result in an excess of regret. By far the biggest regrets surround bearing witness to both large and small acts of injustice, executed frequently with good intention, informed wisdom or plain desperation. This also has too often been my reality of childhood disability.

Behavioural disabilities introduce into the mix issues of personal complicity, lack of restraint, malevolence or plain badness. Triggering a duality of response, involving feelings of powerlessness to protect, whilst simultaneously invoking drive to explain. To position your child so he/she is recognisable to others, in order that others responses may reflect understanding and acceptance of your child's condition and inability to 'self-heal'.

All of the above play out amidst the general trials and tribulations of 'normal childhood', yet generate a sense of bereavement for the 'normal childhood' that is lost and will never be realised. To parent a disabled child requires ability to accept such loss, igniting a drive to procure gains for your child, to shore up their adulthood, so that too will not be lost”.

Tania Watson

In retrospect, it was never the challenges our sons posed that were our primary difficulties, rather they derived from the response and understanding (or lack of) of others, most frequently in the school context. Typically a belief that something drastic could be done to remediate their challenges effect on others. Furthermore that the absence of such 'something' was indicative of either complicity or ineffectiveness. The real life implications of such logic are too numerous to list, however overall the effects were socially excluding, extending stigma across the family and compounding of an already fraught situation. In addition, blameworthiness contained within itself an internal logic, the logic of undeserving. Serving to inhibit the delivery of supports needed to remediate many of the most pressing effects my sons' disabilities posed.

Paradoxically blameworthiness also set in motion a cycle of defence, generating counterproductive resistance to either seeking or accepting help. This momentum was itself generative of a familial tendency to conceal need, a tendency that is not always in the child's best interest.

As a family we were fortunate to have a reasonable capacity to cope; the benefit of professional identities and aligned resources and skills to hand. Nevertheless such challenge exacted its toll in multifarious ways. Practically limiting professional advancement, social activities or home based social engagement, not only for ourselves as adults, but more troublingly for our sons siblings. Indeed, despite the benefit of reflection the strain child disability is found to exert particularly on mothers (Whalen 2011, Dykens 2014) was a revelation to me, similarly so the consideration that my own challenges may indeed be viewed as a gendered issue (Kingston 2007). These considerations stimulated reflection on my own situation from a different and previously unconsidered perspective. Nevertheless, my personal experiences and indeed the secondary data outlined, lend a sense of urgency to the need of an indiscriminative support system for vulnerable families. Similarly so a more critical deconstruction of the assumptions that underpin presentations of disability and difference. The identification of a need to seek the sites of challenge and to probe for the existence of similar experience on the basis of extended parenting experience across three decades, attests to longevity of spoiled identities (Goffman 1968b), which accrue from identified dispositions to accountability and blame. Toward fulfilment of this need, this study probes the wider discourses underpinning notions of accountability, blame and entitlement and it is toward the logic of these sentiments that this research is directed.

1.5.2 The study outline

The data outlined in the previous section, strengthened my resolve to direct my doctoral research to address whether discriminatory practices and opinion were part of a wider trend. This research needed to engage with the range of adults prominent in the school context, these being SENCOs, teachers and parents. Firstly I engaged with SENCOs toward an appreciation of the range of medical disability labels presenting in mainstream schools. I was also interested in any practical implications extending from disability in the classroom and whether there were any school protocols for response. Finally I wanted to explore with SENCOs schools identification procedures and the jurisdictions of school staff. SENCOs (through their

role) were considered to be a prime source of information and I was also keen to explore whether they held any concerns in regard to teachers opinions or response to specific disability labels.

The second phase of my research endeavoured to explore whether all disability classifications (labels) were considered equally valid by teachers and if not, why not. I was conscious that such a question was controversial and as such there may be professional tensions which might act as a barrier to open responses. It was necessary therefore to consider which data collection methods would be able to encourage the sharing of subjective opinions. Two methods were considered; the repertory grid interviewing method and diamond a ranking exercise, however upon further determination I decided that the repertory grid method was unfeasible, due to limited resources as a sole PhD student and the time constraints that the teachers emphasised.

Thirdly as my study was drawn from personal experience, it was necessary to explore whether this was part of a more general trend or specific to ourselves. As a result, an invitation to participate in one 'to' one interviews was made to families of children with a range of disabilities, through the Contact a Family charity network. I found that families emphasised great faith in the special sector and it was considered useful to develop a naturalistic impression of how teachers developed and shared meanings toward disability in the daily activity of school life in the special sector. I was interested to observe these processes outside of formal data collection activity in both class-based and non-classroom contexts. I felt that such observation could build upon data returned through more formal means in the mainstream context. Nevertheless the overriding consideration in both contexts was whether accordances of accountability were common; if so, what rationalisations, if any, were invoked to legitimate blame within the medicalised understandings of difference utilised in UK schools?

Finally, I extended interview invitations to two prominent individuals who have had a significant influence on the lives of disabled children and their families. Firstly I approached Baroness Warnock, chair of the former Committee of Inquiry into the Education of Handicapped Children and Young People, and secondly Leslie Henderson, who following the diagnosis of her son with autism founded the northern autism charity the Henderson Trust.

Overall I wanted to produce a snapshot of the contemporary understandings and opinions held by adults holding jurisdictions over a child's educative life. Not least because adults were considered primary to how challenging differences are understood and equally importantly, responded to. In design, the rounds of data collection were sequenced in a layered format, each designed to inform the next phase, working toward an overall profile aimed at explicating both disability accountability and disability challenge.

A qualitative study was considered the most appropriate approach to explore individual and collective subjectivities (Bryman 2008). Furthermore the stable of methodological approaches available within this tradition offered accepted means to embrace personal experience as formal data (Sikes 2013). My research employs a methodological approach known as analytical autoethnography. This is a method which has been expanded by Anderson (2006) and endorses the use of personal experience as data in the first instance, which is then systematically tested in the wider domain. I felt that the analytical autoethnographic method mirrored most closely my own situatedness and wider research intent, making it a more compatible method than an evocative autoethnographic approach, founded upon personal data alone.

The wider methods of data collection involved field note observations generated from two separate periods of voluntary work (one and a half years in a pupil referral unit and a further year in an independent special school); face to face open and guided interviews with SENCOs; families and key individuals of note. In addition a self-complete diamond ranking activity was completed by teachers both in and out of institution, followed by a further concise self-complete questionnaire designed to probe previous findings further. The data collection methods chosen were responsive to the particulars and circumstance of each respondent group and aimed to facilitate the generation of a dynamic and comprehensive snapshot of opinion.

1.5.3 The research questions

RQ1. "Why do behavioural disabilities appear less tolerated and accountable in British mainstream schools when other presenting disabilities are not?"

RQ2. "What forms does accountability take"?

RQ3. “What are the implications of accountability for aspirations of disability equity and inclusion in the school context and wider social domain”?

1.5.4 Overall topic guide

TG1. What are the range of presenting childhood disabilities in schools and what are their practical implications in regards to mainstream inclusion?

TG2. To what extent are all medical labels (disabilities) considered equally valid by teachers and what factors account for their determinations?

TG3. What forms of knowing coalesce around children exhibiting challenging behaviour in the school and family context?

TG4. What factors can be found to impact on understandings across the respondent groups?

TG5. How do understandings of disability inform pedagogical practice in the special sector of education?

TG5. To what extent is disability accountability considered by teachers and parents to constitute an act of discrimination?

TG6. What barriers can be identified to inhibit disability equity in the school context?

1.5.5 Theoretical underpinnings – introducing the tool box

Whilst acknowledging that philosophical purity is often impractical in the research field (King 1994), I cautiously determined my ontological position to be placed within the broad spectrum of Social Constructionism (albeit from a ‘qualified’ platform). This stance is founded upon belief that the social world is founded upon and responsive to individual and collective agency, essentially a negotiated consensus.

Individual/collective agency is also considered bounded by the effects of social expectation, differential relationships of power at a micro level and demands of pre-existing structure and collective will at a macro level.

When choosing philosophical referents I considered it vital that they were congruent with the aforementioned position; this necessitated an eclectic mix of philosophies. Firstly my research was influenced at a transactional level by the tenets of Social Constructionism (Mead 1934, Blumer 1969 and Cooley 2010) and Positioning Theory (Harre 1990 and 1999). Whilst toward a more detailed understanding of the exercise of power in the school context, the contributions of the social theorists Foucault

(1977a, 1980, and 1982), Derrida (1978) and Bourdieu (1977, 1991, 1998) were consulted.

Symbolic Interactionism (SI) elucidates the practical dynamics of human communication; particularly of how phenomena in the social world develops tangible collective meaning, founded upon conventions of 'normal' and 'abnormal' (Mead 1934, Blumer 1969, Cooley 2010). The processes detailed offered means to understand how medical labels can through collective consensus claim scientific status, even where there is a lack of tangible evidence to support such claims (Smalley 1991, Blatt 2011, Lewis 2010, Cukier 2011). SI is also a useful frame from which to map how negotiated meanings in the school context generate the truths, surrounding disability classifications.

Positioning Theory (PT) extends this understanding and balances a transactional conceptualisation of social engagement with the impact of unequal relationships of power which are deemed inherent to all social exchange. Positioning is stated to be not only the mechanism through which social stratification is established, but also as foundational to individual and collective motivations to engage. PT asserts all instances of social engagement represent a play for power, at both macro and micro levels. Notably PT acknowledges there to be varying resources available to individuals and groups, hence it is as pertinent toward everyday power differentials as it is toward those at the level of structure. As unequal power relations were a defining feature of my children's school lives, PT offered means to unpick these dynamics, sidestepping issues of the rightness or error of discourses of accountability or psychological determinism.

Equally although contemporary schooling asserts equal opportunity for all based on the principles of meritocracy, inequalities persist (DfE 2014a) and present both as consistent and particular to certain groups in respect of disability and SEN (DfE 2011b, DfE 2012a, DfE 2012b, DfE 2013a and DfE 2013b). Indeed the statistics referenced invite a closer consideration of how power acts not only to position, but to replicate relationships which intersect negatively with a range of socially considered differences.

Bourdieu's (1977) contention that the school system is foundational toward the maintenance of social inequalities was considered central toward an understanding. Nevertheless such a view runs counter to the dominant and very public claims of

inclusion, particularly as it pertains to mainstream placement (Booth 2002). This suggests a duality of intent, that which is operative in the public gaze, and that which is shrouded from view. Toward a conceptual reconciliation of what appear to be opposing motivations as well as their seemingly limited recognition, the work of Foucault is relevant. Foucault's (1973) notion of 'Gaze' and delineation of the self-regulatory dimension to power, extends a means of rationalising the reconciliation of these oppositions. Foucault's work also offers explanation for the absence of public recognition of its exercise, without any dilution of its intent. Essentially Foucault's (1977) writing challenges the surveillance role school systems actively engage in, similarly so the primacy of notions of normalised child development and educational pace (Winance 2007, Campbell 2008, 2009, Heir 2002 and 2009). This serves to raise uncomfortable questions around whose interests are being served and why. The method of deconstruction (Derrida 1978) offers practical and conceptual means to interrogate educational and social agendas, essentially involving a stepping back from what is stated, to a deeper consideration of what is sought and whom it benefits most. Towards a consolidation of the aforementioned social theorists contributions Francis's (2013) micro political framework was adopted to guide focus, informed further by an analytical template developed by Willig (2008) which was directed to disturb the relationships of power underpinning formal relationships.

1.5.6 Respondent groups

Three main respondent groups were identified as central to my own parenting challenges (teachers; SENCOs; parents) and were also identified as the main adult groups comprising the school organisation at the local level. Although the research interests towards each group varied, it was felt that the opinions held by teachers toward discrete medical labels were of central significance. Teachers enjoy a central jurisdiction toward how behavioural challenges are interpreted and managed; similarly so the identities that medical labels can engender in the educational domain. I was also keen to question how engaged teachers were with the ongoing medical debates, especially those concerning the criteria for, and configuration of, medical labels.

SENCOs through their role were viewed as intermediators, acting in an advisory capacity towards both teaching staff and families. Their knowledge was considered foundational to the meanings made of pupil difference, particularly challenge. SENCOs also have a central role in co-ordinating information, equally so brokering

the supports available to both teachers and families. SENCOs were a primary source of information, offering elucidation of the most common types of disability presenting in their institutions, alongside the strategies schools employed to accommodate these pupils. Families in contrast were viewed as both the recipients of professional understandings and the architects of primary disability identification. As the child's primary advocate, families are centrally positioned, able to articulate the impact of their child's disability in school and also the effect of school responses on the child and family. They offered in essence a test of whether my own experience was unique to me or part of a wider pattern of response.

1.5.7 Implementing the research

A layered approach was employed involving several rounds of data collection, designed to inform the next layer in sequence and offering the possibility in analysis of a deep impression of how childhood difference and disability is experienced and understood in the school and family contexts. This approach necessitated flexible data collection methods and finely nuanced research foci responsive to each group's role and relationship to the child. In addition an overall research ambition was to discern whether accountability and blame were routinely part of school and familial discourses. The research process in total amounted to ten discrete data collection stages, each stage holding specific address as shown in my appendix.

1.5.8 Ethical Issues

Founding a research project upon personal and familial experience poses particular ethical problems. These surround not just issues of informed consent and capacity to give consent, but toward the wider rights to privacy of all family members, both in the immediate and longer term who might be identified. Similarly ethical issues emerge in relation to the emotional effect of the research process on the researcher (Lee and Renzetti 1990, Bahn and Wetherill 2012, Emerald and Carpenter 2015). Rogers (2003) and Cooper and Rogers (2015), found both strengths and weaknesses to the 'insider' approach. The strengths being a detailed understanding of the area under study and ability to gain access as an insider. The weakness being that familiarity may serve to foster complacency founding of unstated assumptions. These were complexities which required resolution prior to the inception of the research process.

Central to this process was engagement with other researchers embracing similar methods (Cooper 2015, Ellis 2000, Rogers 2003), alongside general ethical

conventions within the social sciences (Beauchamp 2001, Medford 2006, Campbell and Groundwater – Smith, 2007). In the final analysis, ethical issues in relation to respondents outside of the family were resolved according to the principle of ‘do no harm’. Problematically ethical issues in relation to the family evolved to be in essence a negotiated process, laden with emotive undertones. Hence the roles and priorities of mother and researcher did not always sit compatibly. In the final analysis despite carte blanche agreement to utilise what has essentially been our lives, editorial resolution decisions were made on the basis of the longer term interests of all respondents and involved a blending of familial data, to reduce the possibility of personal attribution through the script of individual circumstance.

1.5.9 Analysis

Thematic content analysis (TCA) was employed, guided by the five stages of analysis proposed by Braun (2006), whilst diamond ranking responses were processed using the software package SPSS. This enabled an overview of ranking dispositions to be compiled. Overall TCA enabled common means of analysis, generating in the first instance themes indigenous to each discrete group. Cross reference of these themes then culminated in the identification of Meta-themes (themes which extended across the individual data sets). These themes are directive of the thematic chapters and conclusions drawn. Overall findings were congruent with my personal experience and expanded upon the secondary data previously referenced.

1.5.10 Accountability and blame

A distinction between accountability and blame was revealed; showing that accountability for disability effect was commonly accorded to all pupils presenting with challenging behaviours, whilst blame was levelled in regards to specific events. Hence although all were accountable, the conferment of blame was more complex and found to be heightened or reduced depending upon the resources available to parents.

Accountability was considered contrary to the working definition of disability, termed by the Equality Act as a physical or psychological impairment which has a ‘substantial or long term negative effect’ (Parliament 2010b, part 2, ch.1, point 6 a,b). This definition was considered to imply disability was of impact on the individual, not a lifestyle choice made by that individual. As a result the conferment of accountability

was considered contrary to the status of behavioural disability as a protected characteristic.

Diagnostic expansion far from simply reflecting 'labels of forgiveness' as many have suggested (Slee 1995, Lloyd and Norris 1999, Riddell 2007) emerge as unequal labels, which may be seen to exist on a continuum, ranging from the sentiment of unforgiving to absolute forgiveness. Yet their integrity and utility is found to be tangibly different where a label pertains to behaviour. In this instance as Lloyd and Norris (1999) note, 'not all disabilities are created equally' (pp 507). Hence it is more apt to suggest neurologically based labels foster the impression of the right to forgiveness. In contrast, labels with uncertain causal factors which cite the environmental context to be equally implicated, hold a tendency to compound vulnerability to blame, not only for the presenting problem, but equally for its remediation. In working practice differentiating between the causal factors contributory to behavioural difficulties has revealed ongoing challenge as the academic literature reveals (Timimi 2004, Timimi and Taylor 2004b, Timimi and Leo 2009, Timimi and McCabe 2010) and it is this division which opens spaces for blame and accountability in the first instance. This stands in stark comparison to physical disabilities which tend toward sympathy as is shown through charity events such as 'children in need'. Such division serves to highlight the impact of tangible evidence as a means to substantiate legitimacy, it also speaks to a general disposition to seek such legitimisation. Overall such divide was considered indication that disability as a state of being was subject to processes of bifurcation: based upon distinction between physical and psychological disability presentations. These differentiations also hold implications in respect of the level of control the child is perceived as able, or indeed expected, to exert over symptoms that act as diagnostic criteria. Notably even where expectations are low, lack of control acted as impetus to exclude, rather than accommodate, predicated upon perceived risk to self or others. Overall I concluded that indeterminate causal attributions were a significant factor serving to legitimise will as a cause of challenging behaviours thus forth, disassociating it as a legitimate indicator of disability.

1.5.11 Recurrent themes across the data sets: Blame; Lack; Causation, Training and Inclusion.

Analysed data revealed many initial codes which were then consolidated into themes which were typically linked to context and role. These were consolidated under five main descriptors (for a more detailed breakdown see appendix).

Blame: was endemic and emerged in various guises across the respondent groupings, it operated in within a culture of accountability and was itself fluid and responsive to individual deflection. Overall accordances of blame and accountability was chiefly directed at pupils and parents by teachers, levelling regards to child control and familial culture. There was also intimation of wider discourses framed around within and without child factors (nature versus nurture). Familial accordances of blame emerged as a defensive response, typically to deflect negative attributions families considered conferred by schools. Blame was also displayed through instances of personal and/or institutional accountabilities, triggering responsive deflection. The externalisation of blame is a disposition Weiner (2001) refers to as interpersonal attribution, as opposed to internalised accountability which is classically directed toward the self.

Lack: was most commonly described by teachers as child/familial deficit, nevertheless teachers also made reference to a lack of wider resources, although rarely as a critique of their own school. Institutional and/or professional deficits were most commonly expressed by parents. Indeed emphasis on wider external lack typically surrounded a lack of service provision; funding; effective training and day 'to' day support. Parents extended this sentiment indicating their children lacked appropriate recognition and empathetic appreciation of the effects of both their disability and the school context. These effects were stated by families to manifest chiefly in the home context.

Personal lack was manifested as an absence; a child's distance from the norms of physical, psychological or academic development. In relation to disability this was formally stated to be a medical lack, whilst in the case of unattributed 'challenging behaviours', lack emerged as an indication of a lack of control, support or efficient nurture. Lack was thus a foundational explanatory tool for difference and central to the legitimisation of blame and accountability.

Causation: was foundational to explanations for difference and was most frequently based on medical and social factors. Although active discourses were found to be

ongoing within the medical profession, there was little evidence that they had any significant effect. Interestingly, disability status alone did not confer immunity from school exclusion, as paradoxically at times, identification of disability was used as justification to exclude. This was typically rationalised on the basis of pupil need and mainstream schools inability to meet that need.

It was at this juncture that the 'specialness' of special provision was invoked by mainstream staff and parents and indeed observed to be celebrated by special school teachers. Notably medical explanations underpinned parents understanding of their children's differences, framing child and familial identities, social networks and perceptions of school based rights. Essentially attributions of causation, legitimated or negated disability identity, it was also implicated in the forms of 'lack' identified.

Training: Teachers and parents expressed concern toward the level and quality of training that teachers received in relation to types of disability. For parents, appropriate training was seen as vital for teachers ability to both respond to, and understand the difficulties their children faced and presented. Teachers likewise indicated concerns in regards to the comprehensiveness of training provided, both during initial teacher training and also as part of continuing professional development. However, whilst training was viewed by teachers to be a key factor influencing both professional empowerment and confidence, parents expressed concerns towards the content of training, emphasising concern that teachers failed to engage with parents as part of their training, hence lacked appreciation of the reality of childhood disability, most notably its practical effects and the effect of school on the child.

Inclusion: inclusion was heavily associated at a conceptual level with disability and social right. Practically this was framed around the types of pupils who were considered able to be 'managed' rather than 'included' in the mainstream and conjuring questioning around 'challenging' pupils placement entitlement. Although the majority of teaching staff intimated support for inclusion in principle, practically there were tensions intimated. Notably these qualifications were also expressed by families, although the direction of criticism was directed at the mainstream, rather than the child or family.

1.5.12 Meta-themes

Looking at the delineated themes two Meta themes were implicated in the varied themes that emerged prior to and post consolidation, these were **knowing** and **accountability**.

Knowing: Knowing is defined as the knowledge that a person draws upon to form assumptions of an individual's actions and intent. Knowing is also stated to be the means by which the other is revealed and is identifiable. Overall the individual themes which emerged from the data sets, presented as vital components of knowing. Furthermore, knowing was itself found to be heavily impacted upon by 'seeing'. Seeing is defined as the underpinning assumptions that channel attributions; most specifically in relation to teachers, whether the child's presentation is viewed from a disabled lens or one of deviance and intent.

Accountability: Was found to be pervasive across all the data sets, although it presented in varying guises. Accountability was intrinsically intertwined with knowing, which in combination, substantiated specific accordances of blame which were directed toward young persons and their families where behaviour was an issue. Neither was behavioural disabilities found to be a valid mitigation when compared with other (physical) manifestations of disability, as the protections accorded by equality and educational legislation conceded in influence to criminal law and exclusionary discourses centred on impact on others.

Thus, knowing and accountability revealed that behavioural disabilities were viewed differently and judged blameworthy for specific acts or transgressions, even though such acts may be alternatively explained as symptomatic of clearly defined medical labels. Thus these tendencies were considered contrary to the 'knowing' defined in official documents which cite disability to be an unwarranted state of being, which inhibits general physical and psychological functioning (Parliament 2010; 2014). Notably it is this definition which underpins social support and policy, yet this research finds that an accountability and identity division exists between disabilities of a physical nature and those of psychological origin, which impact on behaviour. This division of status was found to be entrenched, not only in equity and educational legislation, but also in criminal law.

1.6 The pervasive nature of culpability

Accountability was identified as central to this thesis and fundamental to the model of disability that emerged out of the study's findings. Overall findings confirmed a culture of accountability in the school context which was similar in nature to my own personal experience. This was evident in all contexts, although responsive to both group context and the causal attributions formed in relation to presentations of difference. Accountability was also found to be implicated in a child's educational entitlements, particularly in relation to exclusionary sanctions. In relation to disability challenge, although there was evidence of differential validation of medical labels, most frequently teachers expressed challenge to the legitimacy of individual diagnosis, rather than the label itself.

Disability inequality was found to extend from barriers in the school context, not least school sanctions which were framed as reasoned response to blameworthy incidents. These instances were disproportionately levelled against child factors that were difficult to manage in the classroom and school, despite such response also being known to effect a negative impact on children's future life chances (Henry 2012, Allardyce 2013 and Trust 2013), lending to even greater injustice.

Although the propensity to accountability and blame was resisted by families, there was no indication that these were seen as acts of discrimination by either families or teachers. Indeed, behavioural and psychological difficulties were not referenced within a disability frame by either families or schools in the same manner physical differences were. This was considered perplexing as families and to an extent teachers, sought and embraced medicalised understandings and indeed such identifications were key to accessing wider support resources.

A bifurcation of disability was found channelled by the symptomatic manifestations of physical and psychological disability. Process this research diagrammatically depicts as the twin attributions of disability (pp 40). This differentiation is notably absent from other models of disability and was taken to indicate there to be a different understanding of behavioural/psychological disabilities in comparison to those generated by disability of an organic, physical nature. This distinction was also found to be understated within the academic community and unrecognised by the groups who participated in this study. Toward address this study introduces a Culpability Model of Disability (pp 36-40).

The Culpability Model delineates the foundations of accountability and the resolution of tensions accountability is considered derived from. These tensions were identified as school requirement to adhere to the core tenets of inclusion alongside corresponding need to maintain behavioural complicity and deliver ever improving academic productivity. These demands were found heightened by governmental scrutiny and suggested to be foundational towards a culture of accountability. Overall resolution of these tensions was found to be based upon the utilitarian principle of the greatest good. Thus in the school context, a child's impact on his peers, or indeed school resources, appears as the measure of placement entitlement (Parliament 2014, Chapter 6, part 3, point 35). Similarly it offers means to reconcile the school tensions identified. Thus forth, individualised accountability permits an exclusionary response which is compliant with the philosophical tenets of inclusive education and social equity. What is not stated, however, is how individualised accountability is reconciled with the status of neurodevelopmental disabilities as being equal to disabilities of a physical or organic nature.

1.6.1 A Culpability Model of Disability

The culpability model emerged from a desire to develop an explanatory frame to account for the disadvantages (as noted in the previous sections), found levelled toward psychological/behavioural disabilities. Not least for the accordance of accountability in response to the practical manifestations of behavioural disabilities. Notably, accountability was found to be unrecognised by teachers as either unfavourable treatment or discriminatory tendency, despite statistics indicating such accountability was disproportionately levelled toward children and young people presenting with both a diagnosed disability and or SEN which was of impact on their behaviour. Thus forth, practices of accountability were found to manifest as a silent but legitimated form of prejudice.

The Culpability Model emerged from the identification of tensions inherent to mainstream schools in the North East of England. Two main tensions were identified, both found to be longitudinal in nature; namely governmental requirement of schools to deliver both inclusivity and higher standards, the latter itself linked to publishable academic successes and behavioural complicity (Warnock 1978, DfEE 1997a, Gillborn and Youdell 2000, DfES 2005b, Parliament 1981; 1998; 2006; 2010, DfE 2012d; 2016b), policed through an ever encroaching system of school inspection. Indeed the aspiration of ever improving standards is found to be fundamental to the

current global Neoliberal culture that may be seen to drive educational vision (DfE 2016ab). Within a culture of Neoliberal individualism, improving performance is viewed as not only essential, but an individual obligation. Equally so, pupil ability and parental buy-in is fundamental to schools ability to successfully engage with the competitive organisational standards and examination successes demanded at government level and most notably evaluated through Ofsted inspections.

These tensions in working practice appear to problematize school response to pupils not easily retained or controlled, generating an incongruence between the protections accorded to pupils under the policy of inclusion and equality legislation and the responsibilities conjured through the vision of improving standards. Thus distorting the implications of disability as mitigation. Similar tensions are identified by O'Connell (2016) in relation to the Australian legal system, noting a divergence between the protective responsibilities of anti-discrimination laws and the regulatory functions of criminal law. O'Connell suggest that 'the inclusionary agenda of the one area of law is perversely inverted in the restrictions on public life and the exclusionary agenda of the other' (pp 10). It is further suggested that 'in disability discrimination law, the fear of the criminal haunts behaviour cases, with judges concerned about what behaviour might be sanctioned through the protections of discrimination law' (pp 10). These sentiments resonate within the UK education system and are particularly visible amidst discourses concerning behaviour and discipline (Blum 2007, DfE 2012d, Ofsted 2012d). They may thus be seen to disincline towards a therapeutic or restorative response, rather predisposing to separation on the basis of individualised accountability.

Looking more closely at theories of disability, I determined that the current established models of disability were insufficient to explain accountability in education. The Culpability Model therefore seeks to explain disability accountability through the charting of an identified division of disability attribution. Two pathways of attribution are cited, found to diverge between disabilities of a physical nature and those psychological in origin. Furthermore the Culpability Model asserts that accountability derives out of the reconciliation of the aforementioned school tensions. In essence the individualising of blame is found to serve institutional purposes, acting to preserve an institutions identity as both inclusive and disciplined. Nevertheless from the perspective of the working definition of disability and its status as a

protected characteristic under the 2010 Equality Act, such accountability is both illogical and incompatible, thus essentially discriminative.

Introducing a Culpability Model of Disability

Figure 1 illustrates competing demands in schools, demands that found conditions conducive to a culpability culture. Identified demands which require reconciliation, delivered through the accordance of accountability, which itself requires rationalisation.

Figure 2 demonstrates that such culture of culpability is not explained in the core tenets of the main two models of disability.

Figure 3 introduces a culpability model that suggests disability incurs twin attributions divided between physical and psychological disability presentations. The latter disproportionately vulnerable to apportioning of accountability due to a reconciliation of competing demands as outlined in diagram 1.

****Although culpability exists in both pathways, qualifications to disability entitlements are predicated upon impact on the collective, rendering psychological and behavioural disabilities most vulnerable, thus suggesting a differential conceptualisation of such disability**

Figure 4 expands on the twin pathways of attribution.

Competing Demands

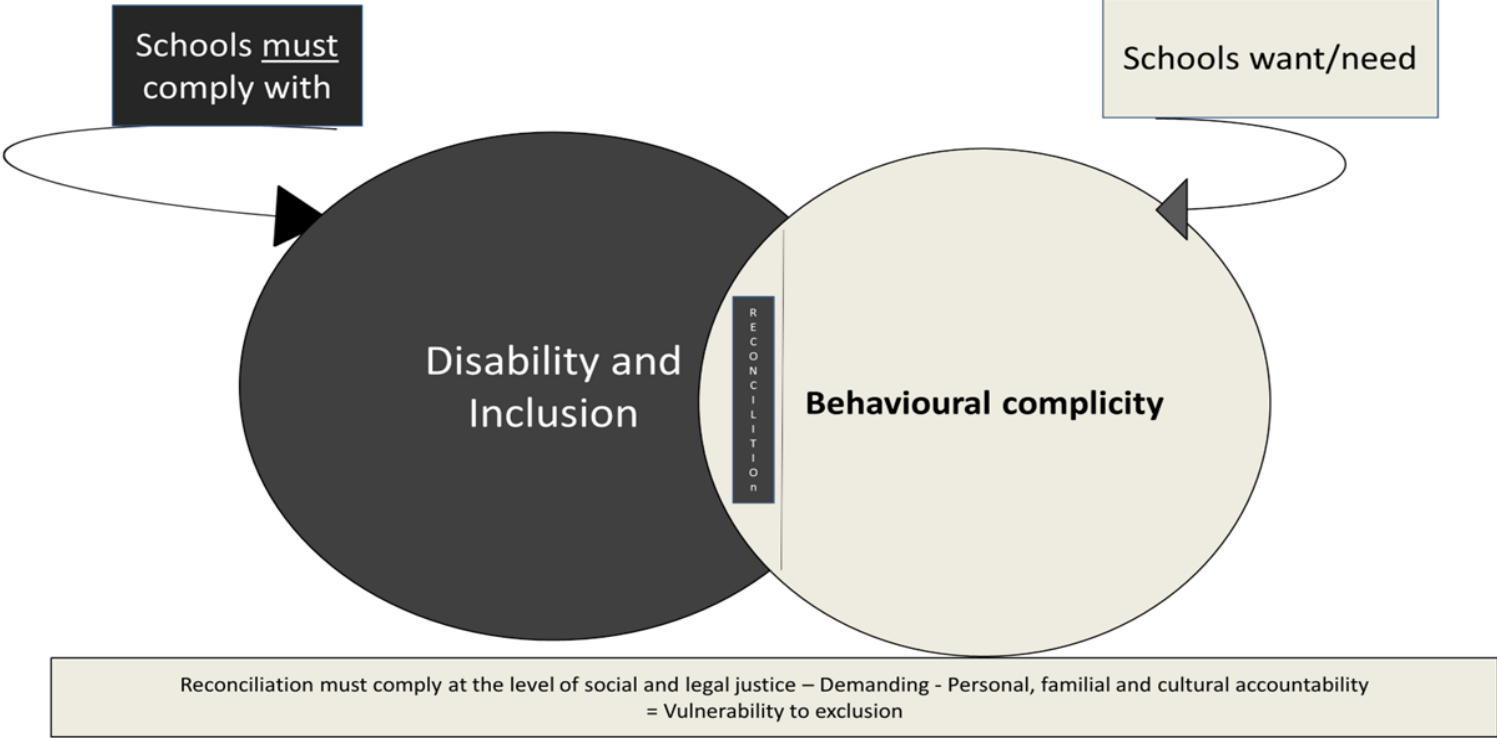
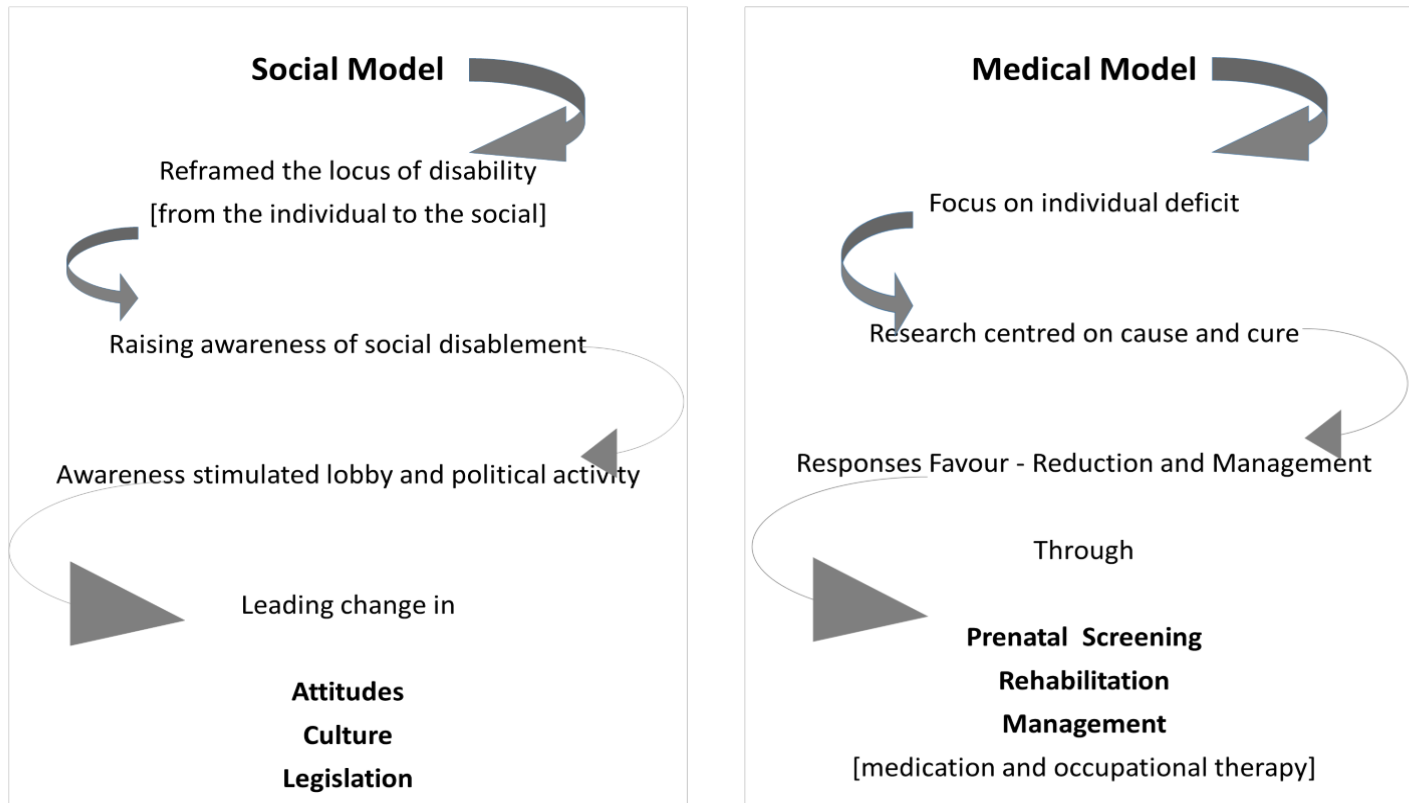


Figure 1: Competing demands

Conceptual Representations of Disability



Culpability for disability effects is not logically explained by either model

Figure 2: Conceptual Representations of Disability

Culpability Model of Disability in Education

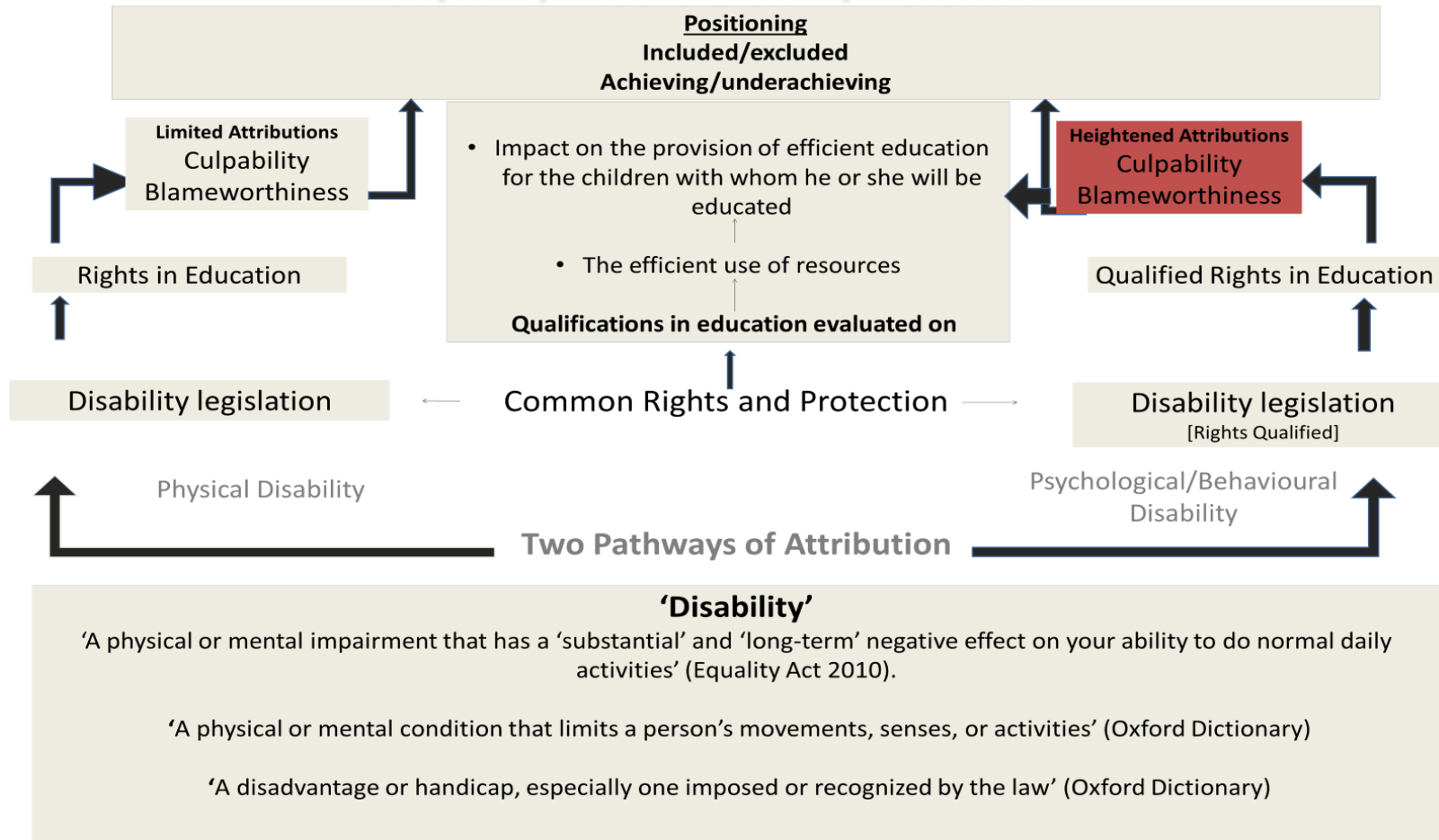


Figure 3: The Culpability Model of Disability in Education

Culpability and the Twin Pathways of Attribution

Culpability was found to impact most consistently on understandings toward psychological/behavioural disabilities

It was thus considered central to how disability understandings were formed within this arena

Impacting on rights, identity and social/educational positioning

And thus legitimating exclusionary responses that were compatible with both disability discrimination legislation and the core principles of Inclusion

Figure 4: Culpability and the Twin Pathways of Attribution

1.6.2 Ambition for the research output

The Culpability Model seeks to raise awareness of the injustices levelled toward disabilities which impact on behaviour. A particular ambition is to highlight that there is a current lack of disability parity, particularly in the school system. This lack has been experienced personally to be generative of barriers to social and educative participation amongst children with behavioural disabilities, in a manner similar to those previously observed by Oliver (1990) in respect of physical disabilities.

Although Oliver's observations were a precursor to the development of a Social Model of Disability and fundamental to many disability accommodations now considered standard practice, it has not responded to the expansion of disability types now commonly diagnosed.

Thus although the Social Model of Disability informs on the tendency of social systems to erect barriers to equal social participation, it lacks detailed scope, and fails to acknowledge that disability per se is not a homogenous state of being. The heterogeneity common to disability presentations, demand a nuanced appreciation of barriers which are specific to particular types of disability. Equally in its contemporary form the Social Model is considered to lack an adequate address of the embodied realities of disabled living, further distancing the practical effects from the political rhetoric (Shakespeare 2008; 2014, Hughes 2009, Allan 2010). Such disconnection is particularly significant given the known effects of disability disadvantage in schools. Not least upon academic achievements and emotional well-being, but also that disengagement from school is known to predispose to wider societal disadvantages, impacting on employability, socio-economic well-being and risk of offending (Loucks 2007, Henry 2012, Hughes 2012, Allardyce 2013). I suggest that these effects alone challenge the logic of exclusionary response in education.

1.7 Thesis outline

Chapter one has detailed the scope of the research, its design and findings, explaining why the thesis was guided in the first instance by a combination of personal experience and secondary data. This input is indicated to be foundational of the research foci and details experiences of accountability for the effects of neurodevelopmental disability. These experiences are shown to indicate an institutional intolerance toward the effects of behavioural disabilities. Further legitimating of disadvantaging practices which would be considered indefensible if directed toward the manifestations of a physical disability. The presentation of some

classifications of disability (medical labels) are described as 'difficult difference', a term borrowed from the sociologist Chrissie Rogers (2013, pp 132) and it is suggested that 'challenging childhoods' represent the epitome of difficult difference. Nevertheless it is also noted from personal experience that 'challenging' (behavioural difficulties) do not axiomatically generate association with disability.

Toward an understanding of the rationalisation of disability accountability, the study references respondent responses against 'the models of disability', to determine which, if any, conceptual referents are employed to make sense of difference. The models of disability represent conceptual concepts, which have been developed to make sense of disabled presence in the social domain. These concepts are found to have had a pivotal impact not only on societal understandings and responses to disability, but on the rights of disabled persons (Oliver 1990, Thomas 2004, 2007, Smart 2009, Allen 2011, Goodley and Runswick-Cole 2012, Florian 2013, Hughes 2015, O'Connell 2016, Rogers 2016). It is further noted that at times they are presented as existing in a dichotomous opposition. This is considered an erroneous impression, and it is suggested that in education, specific agendas appear to result in an eclectic adoption of these models, leading to erratic disability expectations and response.

Overall no single model or combination of disability models were able to account for the accountabilities found levelled toward pupils with behavioural disabilities. To the contrary, disability response was found to be responsive to role and position, factors which were heavily impacted on by tensions identified as inherent to the educational domain. The tensions identified are stated as professional and legal requirement to deliver both inclusion and continuously improving (publishable standards). Demands which themselves necessitate the maintenance of pupil complicity and competitive pupil attainment (DfES 2005b, Ofsted 2012, 2014b). In conclusion I argue for the necessity of a new conceptual model able to expose the locus of culpability in the school context, this is introduced as the Culpability Model of Disability.

Chapters two and three explore the research focus within the context of existing literature and theory. Chapter two is comprised of four subsections, sub section one looks at the nature of disability and how it has and can be known. Subsection two considers the nature of and response to 'challenging' behaviours, not least because although disability is stated to incur challenging behaviours by the medical profession, there appears little evidence of an axiomatic association outside of this

field. Notably 'challenging' behaviours are also associated with social and cultural explanations, serving to generate uncertainties in relation to cause. Subsection three considers the explanatory efficacy of the models of disability, whilst subsection four focuses upon the sites of challenge that emerge within the literature and which may signpost toward explanation for challenges and disadvantages experienced.

Chapter three directs attention to four discrete arenas considered to embody the primary social and legislative contexts pertinent to childhood disability. The four arenas identified are comprised of the school, the family and the legislative frameworks of Inclusion and Equality law. The contexts of school and the family emerge as primary sites of childhood disability identification, holding guardianship responsibility for disability identification and its management. Nonetheless despite a common purpose and function, they are found to differ in terms of role, agenda and priorities. Attention is then directed toward the practical enactment of the policies of Inclusion and Equality legislation. This legislation is considered definitional toward both disability status and subsequent response in education, although it is found to be impotent in relation to disabilities which result in presentations as 'challenging'. Overall focus is upon legislative interpretation, its implementation and practical efficacy.

Chapter four presents the study methodology, outlining its philosophical underpinnings, ethical implications, methods of data collection, analysis, and practical challenges faced. In particular this chapter addresses the ethical implications of conducting what is termed insider research. Insider research hosts varying challenges, not least in relation to the merging of roles that may extend incompatible priorities. Of particular significance were the tensions identified around informed consent and capacity to give that consent, where the respondents concerned are your own children. This issue more than any other highlighted the complexity of undertaking a duality of roles (that of mother and researcher). Not least I found there to be a disjuncture between a maternal responsibility to mediate decisions in the child or young person's best interest, juxtaposed against decisions that were led by the vested interests of the research undertaken.

Chapters five to seven are framed around ways of knowing in the different contexts this research has engaged with. In particular it addresses 'familial knowing', 'formal knowing in the mainstream school context and 'formal knowing in the special sector. These chapters present the findings and discuss the implications of the study,

thematically, mirrored against the identified meta-themes as outlined in section 1.5.10 and which are detailed more fully in the following section. Chapter eight concludes this thesis and reconnects with the impetus to my research and the research foci adopted. Overall this chapter is focused upon both the experience of blame and accountability and the theory of blame and accountability. It specifically considers the effects of blame and accountability on the childhoods such accordances produce. This chapter also returns to the notions of the functions served by blame and accountability, particularly in the school context. Toward this there is a further address of the functions which may be seen to be served, functions which are found linked to wider educational priorities and tensions. In so doing, this thesis contributes to both the identification of disability accountability and explanation for its presence despite the protections accorded by the legislative protections of equality legislation and in the educational context that of Inclusion. Chapter eight concludes with an expansion of detail of the Culpability Model and the aspirations held for the model's use, alongside the recommendations proposed and the identified contribution to knowledge the model makes.

1.7.1 Background to the determination of forms of 'knowing'.

Background: this research developed from personal experience of neurodevelopmental childhood disability, which itself was productive of many medical labels and resulted in for my children several (different) challenging childhoods. Common to each childhood, however, were the disadvantages and acts of discrimination I witnessed as common practice within and without the school system. In particular, sanction-led responses that implied and metered accountability irrespective of the medical explanations that had offered a core rationalisation for the difficulties my children posed. Hence although medicalised explanations conferred both school and equality rights, when called upon, they were found to be ineffective and often overruled by qualifications to their jurisdiction. This led me to conclude that all disabilities were not equal and that the Equality Act and Inclusion as an educational charter were qualified and essentially contradictory pieces of legislation.

A central research foci was to explore whether disadvantage was local only to me, or part of a wider pattern of disadvantage and discrimination. The research design reflected the areas of challenge experienced. These were found to extend on three discrete levels. Firstly challenge was made toward the legitimacy of the disability label (diagnostic classification), secondly there were challenges experienced toward

the actual diagnostic application (was it appropriate or accurate) and finally there was accountability for the behaviours and dispositions which had been viewed medically to be symptomatic of the eventual diagnosis made.

Toward explication, data was gathered from several sources: in combination these sources suggested that the same phenomenon (disability effect) was being viewed through differing lenses. It was further evident that these lenses were directly affected not only by context and the relationship held toward the child, but also individual opinions held toward specific disability types. Looking across the data sets it was possible to sketch broad differences and similarities in how disability effects were being viewed. Despite the identification of multiple themes across the data sets, there were found to hold a common purpose, this being as an aid to 'seeing and knowing', activity which was categorised under two broad descriptors 'familial and formal' knowing. Secondly ways of 'seeing and knowing' were found to be fundamental to the rationalisation of blame, a tendency also found to be consistent across the data sets.

Differentiation of ways of seeing is not a new term and is applied most specifically in the field of art, extending a commentary toward how the same phenomenon can hold multiple meanings and be 'seen' differently (Berger 2008). This approach is also effectively applied within Museum studies and the field of historicity. Similarly so feminist writing and disability studies, generating a greater appreciation of the construction of identities and stereotype (Garland–Thompson 2001, Southgate 2005, Sandell 2010).

Despite its contemporary popularity, the impact of different ways of seeing and knowing in education has been previously illustrated by Shulman (1991), challenging the potential of social research to record accurately any phenomena and suggesting that records indicate only one of many interpretations. These concerns have been most fully considered in relation to the use of visual material in the social sciences, pitted against the sentiment that the photograph never lies. Nevertheless, the practice of 'seeing' and 'knowing' are found to be a subjective practice, responsive to wider variables, as such are found to conjure the same truth claim concerns as those levelled toward textual record (Prosser 1998). The decision to use multiple data sources in a layered format acknowledges the multiplicity of 'seeing' and 'knowing'. This approach facilitated practically the collection of a broad spectrum of opinion, which upon analysis generated two umbrella descriptors that depicted how a child's

presentation was understood. These descriptors were termed 'formal' and 'familial knowing' and were found primary to the ways a child's disability was received and managed.

1.7.2 Chapters five to seven - 'ways of knowing'

Chapters five, six and seven explore differing ways of 'knowing' and draw upon the studies unique layered data base to support such division. These differing conceptualisations are found to be primary towards a tendency to accord blame and hold implication across the child's life span beyond the school years. Chapter five focuses upon 'familial knowing' and extends from personal and familial narrative. Chapter five concentrates on what is termed 'formal 'knowing' led by data gathered from teachers and SENCOs in the mainstream context, whilst in contrast Chapter six draws upon data gathered from two longitudinal volunteer placements in the special sector, an independent special school and a pupil referral unit.

'Formal knowing' in the school context was found divided between 'medical' and 'pedagogical knowing', a differentiation which was at times contradictory and generative of incongruent understandings. Furthermore the scope of formal knowledges were found to be responsive to personal experience and appeared to act as a bridge between formal and familial ways of knowing.

In combination these varying conceptualisations were both confirmatory of the challenges personally faced and offered elucidation for the challenges and disadvantages which are also documented in wider academic literature. In analysis the triangulation of multiple ways of 'seeing' and 'knowing' not only highlighted propensity to accord blame and accountability, they were suggestive of the tensions and wider discourses that contributed to such disposition. As a result they caution against partiality and hint at the potential of more rounded holistic forms of 'knowing', which can guard against discriminatory response and tendency.

1.7.3 Chapter eight: Observing, experiencing and theorising disability accountability

Chapter eight draws together the forms knowing, blame and accountability expressed across the data sets, comparing not only its rational but its effect. The chapter concludes by theorising the nature and function of blame in contemporary school systems, drawing upon wider considerations of power and social control toward explicate its guise. This chapter seeks to emphasise both the connectedness and discreteness of 'knowing'; knowledge which is problematized further by the many

presentations of disability and medical labels that are common to contemporary mainstream classrooms. In conclusion it is suggested that to mount an effective challenge to disability inequity and to ward against discriminative accountability, it is necessary to found the 'knowing' of all parties through open and honest communication between not only parents and teachers in the mainstream, but also between teaching professionals across the range of mainstream and specialist provision.

Chapter eight concludes with the study conclusions, emergent recommendations and identified limitations. It outlines the need for a Culpability Model of Disability, able to expose both tendency toward disadvantage and the tensions from which they derive. The study finds variation of opinion in respect of medical labels, similarly so parental experiences. Nevertheless, implicit throughout are accordances of accountability for the manifestations of behavioural disabilities, colloquially described as 'challenging childhoods'. Propensity to accountability is considered to deflect association of behaviour as symptomatic of disability, thus inhibiting of timely or pertinent support. Neurodevelopmental disabilities are stated to be the only disability genre that is openly and legitimately sanctioned for its effect, albeit this tendency is followed closely by disposition to hold individuals accountable for lifestyle induced poor health (Maclean 2009, Heeney 2015, Hughes 2015). In relation to disability induced behavioural infractions, accountability is considered discriminatory, yet is found to be immersed within a culture of silence. Toward understanding of such silence, this conclusion draws upon the personal narratives shared by families and the author's personal experience. Particular note is made of the effects of stigma and indeed circumstance toward the continuation of familial silence and acceptances of blame. In conclusion this study calls for address of disability accountability and seeks that such disabilities are responded to in parity with other disabilities of both physical and organic origin. Toward such goal, this research calls for an end to the silence and shame behind which many families are shrouded, viewing it as a preliminary step toward disability equity.

Chapter Two. Literature Review - Knowing Disability – Seeking Disability Challenge

2.1 Scope

This review is directed to issues of accountability directed toward children with behavioural disabilities, primarily but not exclusively in the school context. It begins by considering the nature of disability and the complexity of its knowing. In so doing it finds what is, or is not considered a disability to be inconsistent; responsive to context, familial framing and individual perspective. The review also finds that the disabled population is far from homogenous and that the term 'disabled' is an inadequate descriptor of the range of human variation that is contained within its title.

In substance it would appear that disability holds as its constituent parts, its embodied physical or psychological effects, the sum of its presentation to the social world and its subsequent response, mediated through what is (or considered) seen and known (Macleod 2006, McLaughlin 2006, Mallett and Runswick-Cole 2011, Ronson 2011). Furthermore it is found that the medical labels which define disability, confer an unequal status on those identified. In particular a disjuncture is found between disabilities of a physical nature and those extending from psychological differences (BIBIC 2005, Thane 2005), both in law and education (Parsons 2005, Jull 2008, O'Connell 2016). 'Behaviour' as a symptom of disability emerges as being particularly contentious and difficult to reconcile with the classic image of disabled childhood (Prins 2015), fostering an incongruence which opens spaces for blame and accountability (Rogers 2007, Youdell 2011, Slee 2013a).

Personal experience had led me to question why when challenging behaviour is considered symptomatic of disability and indeed forms part of the criteria for diagnosis) it is also rationalised as blameworthy, both in the school and wider social context. Accountability is found to render the child vulnerable to school exclusion and lifelong wider social disadvantage (McCrystal 2007, Allardyce 2013), hence this review seeks to explicate the logic of disability accountability and disability challenge in the school context. The focus of this study necessitates problematizing disability as a consistent (and diagnosable) state of being, by probing the logic upon which it is identified, colloquially understood and responded to. 'Challenging behaviours' are found to pose a particular dilemma in both reception and response, summoning

judgement as to whether the presenting challenges are representative of the child's nature, or the embodiment of a medical condition (Cross 2011, Pfeiffer 2015), for which the child is unaccountable (Glackin 2010, Titchkosky 2012).

The means of understanding difference are found to coalesce around discrete conceptual representations, known colloquially as the models of disability, although found rarely stated in such terms in schools. The models, may be most usefully defined as conceptual frames of reference, responsive to both the embodied and social situation of disability (Oliver 1990; 2013, Crow 2010, Shakespeare 2014). They are found swayed by influence and advantage (Anastasiou 2013, Haegele and Hodge 2016), although frequently presented as opposing concepts. This review finds nevertheless that in usage they are employed eclectically, directed to given purposes (Gabel 2004, Anastasiou and Kaufman 2013).

Looking toward the origins of what I will term disability scepticism, particular arenas of challenge are evident, aligned to issues of causation and intent (Glackin 2010). The reliability and rationale for the expansion of medical labels commonly applied in childhood are particularly contentious. Fierce debates are found within and without the medical profession, these envelop medical, social and relational concerns and speak not only to specific labels, but to the very constitution of disability (Conrad 1989, 2000, 2007, (Amaral 2007, Rafalovich 2001 a; b, Rose 2006, Lewis 2009, Wedge 2015). Finally attention is directed to the primary social and legislative contexts a child inhabits. These contexts are considered fundamental to identifications of disability, disability response, legal protections and also problematically accordances of accountability (Jull 2008, O'Regan 2009; 2010, Robinson 2011; 2015). Overall the contexts identified are found to be primary to not only how disability is known, but to how it is received.

In summation delineations of disability and 'challenging' emerge as fluid; responsive to wider social variables, context and academic opinion (Oliver 1990, Croll 2002, Hutchings 2007, Holt 2008, 2010, Riddell 2011, McCoy 2012). As such they are punctuated by 'grey areas' generative of spaces for challenge and by extension accountability. In the school context disability accountability appears influenced by the level of disruption to teaching the disability effects. Two core dilemmas emerge; firstly in respect of appropriate response, where conducts at face value are warranting of accountability, but derived from a disability, thus logically situated outside of an accountability frame. Secondly the priorities of schools, led by external

pressures mitigate against leniency, thus as there appears no axiomatic association of disability with challenging behaviour, pupils are found to be vulnerable to being embroiled in discourses of blame which acts as a legitimisation for their exclusion.

2.1.1 Format

This chapter comprises four subsections; subsection one focuses on the nature of disability and disability accountability, seeking clarification about how disability is known. Toward such understanding an historical perspective is drawn upon (Atkinson 1997, Stiker 1997, Armstrong 2003, Borsay 2005) revealing three main paradigms of explanation (medical, social and relational). These paradigms are found to be primary to processes of knowing, particularly its consolidation into medical or social explanations for difference (Oliver 1990, Conrad 2000, 2007, 2010, 2014, Rafalovich 2001a, b, Timimi 2010, Ronson 2011).

Processes of knowing are found at core to be relational, responsive to wider political and economic priorities as well as contextual exigencies. Notably, formal identification of disability in education underpins the allocation of support and service provisions (Parsons 2005, Florian 2008a, Dumit 2006, Slee 2013a) as well as educational rights (Rogers 2007b; c, 2012, Allan 2010). Consequently the processes underpinning recognition cannot be assumed neutral, despite the medical labels and logic they embody being found bounded by a medical paradigm, which has itself been likened to the concept of the lifeworld (Husserl 1970, Schutz 1973, Habermas 1987, Lupton 2012).

Subsection two looks to challenging behaviour and interrogates the objectivity of its delineation. It focuses on the understandings stimulated by behavioural challenge and the factors that are directive of the attributions made toward its causation. Specifically I consider the contingencies which link or deflect association of challenging behaviours with disability. This subsection continues the theme of knowing and explores how knowing is forged in relation to challenging behaviours and in particular how this knowing legitimates or deflects accountability and disability challenge. The subsection concludes with a consideration of how the challenging child is constructed as a latter day other and its implication for disability equity.

Subsection three directs attention to the models of disability, looking toward their contribution in respect of how disability is visualised in society. This subsection explores the impetus to the development of conceptual models of disability and their

impact on the address of discrimination and disability equity. Three main models are discussed, the Medical, Social and Embodiment models of disability. Overall disability is found to extend the body and is defined as such in the medical and social domains. Disability is thus considered to encompass these three arenas, just as each holds implications in relation to tendency toward accordances of accountability and deficit. The models are found to reflect differing aspect of the physical and social realities of disability and are pivotal to the knowing that forms around difference which is defined as disability. Notably although the Social Model of Disability has led to an awareness of disability discrimination, whilst the Embodiment Model serves to remind us of the reality of physical/psychological impairment; this review finds no dedicated model to explain the issue of selective disability accountability, particularly that which accrues around impairments of impact on behaviour. This subsection concludes by justifying the urgent need for a multi-faceted model able to address the specific disadvantages found to impact on this discrete population in society generally and more specifically in the school context.

Chapter two concludes with subsection four and looks specifically at the sites of challenge. In particular it explores in detail the uncertainties within and without the medical profession which serve to undermine behavioural disabilities and individual diagnosis. It also considers how accountability can be resisted and the potential for agency within what at times appears an impenetrable system. Although sites of challenge are found to extend across the medical, social and relational contexts, it is the debates ongoing within the medical profession which appear to act as the impetus to disability challenges in the wider domains and in combination undermine the status of behavioural disabilities and the association of behaviour with disability (Araujo 2005, Areheart 2008, Campbell 2009, Boyd 2012, Levy 2014, Cologon 2016). Consideration is given to the employment of accountability as a means of social control, alongside a wider address of unequal social relations, predicated upon the social variables of social class, gender and ethnicity, factors found to impact on vulnerabilities to disability challenge.

2. 2 Subsection 1: What is this thing called disability?

Expanding on the outline offered in Chapter one, this section explores the nature of disability; finding the residue of its historical roots explanatory toward both its contemporary form and also response (Foucault 1967; 1973; 2006, Szasz 1987; 2007; 2012; Stiker 1997, Armstrong 2003, Borsay 2005). The influences on 'knowing' are explored towards an understanding of the various explanations for difference. The dominance of medical explanations are explored and it is noted that despite alternative explanations for human difference, the default explanatory frame is medical. This frame is found to extend across disciplines and rarely compromised by internal or external challenges, supporting contention that medical explanations retain a paradigmatic dominance (Lupton 2012).

Relational factors are heavily implicated in the sense made of difference (Barr 2015, Beckett 2015) and central to subsequent response, not least in regards to wider attributions around familial accountability and competency (Holt 2008; 2010, Nind 2008). Overall what constitutes disability is found to be fluid and responsive to both professional and layperson assumption (Thomas 2007, Grant 2010, Hardwood and Allen 2014, Wedge 2015).

It is also found that medical labels and the state of disability are contested, charged with representing a social construction, rather than discrete organic disorder (Gergen 1990, Conrad 2007, Timimi and McCabe 2010, Conrad and Bergey 2014). Such claim has important implications as the identification of difference is also found to be implicated in a more general social propensity to categorise. Schooling emerges as a key agent of sorting (Hacking 2007), whereupon teachers are directed in a secondary professional capacity to be alert to the early identification of disability (Rafalovich 2001a; b; 2004, Rothi 2008), although the objectivity of identification is questioned (Croll 2002, Florian 2006, Dyson 2008, Begeer 2009, Gould 2011, Heilker 2012, Miller 2014).

This review thus finds that there are many ways of knowing difference and the means by which persons process and decode information is considered important (Kelly 1963, Moscovici 2000) to an understanding of the sense made of difference. Notably not all difference stimulates association with disability, particularly where behaviour is implicated (Waterhouse 2004, Macleod 2006, Bailey 2010, McCoy, Banks and Shevlin 2012, Heeney 2015). The social representations of medical labels are found

primary to laypersons and secondary professionals ability to 'know' a disability, although the stereotypes which accrue around medical labels, are found to bear little resemblance to the reality or diversity of a condition (Murray 2006; 2008, Berg-Dallara 2014,).

Notably, disabilities which impact on behaviour are found inconsistently represented and trivialised through comic depictions which obscure any accurate impression of the challenges they pose (Kirkland 1999), or their impact within the family (Rogers 2007, Carpenter and Emerald 2008, Vargas 2013). Equally where challenging behaviours are a key manifestation of disability, inaccurate representation is found to distort the controls able to be imposed by parents and schools, fuelling suggestion that pupils are out of control and that families are complicit (Walters 2007, Holt 2008; 2010; Jull 2008, Doubet and Ostrosky 2015).

Medical labels may be considered the consolidation of medical claims to truth; yet are contested from within (Lochman 2015, Meyers 2016) and without (Bursztyn 2011, Conrad and Bergey 2014, Graham 2015), as a result are found to destabilise the confidence held toward their claims. Disability identification is also found to differ from other types of illness, as many of the labels used, and indeed even the status as disabled are constitutive of an identity (Christian 2004, Matthews 2006; 2008). These labels are found to generate both expectation and confer social responsibilities, not least the responsibility to minimise disability effects where reasonable, or to submit to the social role of a disabled person (Parsons 1952, Singh 2004, Blum 2007, Thomas 2007). This review finds that it is a combination of expectation, presumption and accordances of responsibility which fosters social intolerance and by extension accountability (Parsons 2005, O'Regan 2009; 2010, Paivi 2008, Rogers 2013, O'Connell 2016).

It is also noted that medicalisation, particularly formal identification, is heavily implicated in wider resource entitlements (Florian 2008a) and it is at this juncture that challenges to entitlement are most evident, linked to wider considerations of deserving and undeserving (Parsons 2005, Berube 2006, Dumit 2006, Florian 2008a, Slee 2013a). It is therefore concluded that 'knowing' disability is far from an objective endeavour. As a result it is necessary to engage with how disability has been known, mindful of the underpinning relations upon which it is founded (Francis 2013)

2.2.1 Medical dominance – (internally challenged, yet limiting of challenge from without)

Disability identification remains the preserve of the medical profession, despite such dominance being questioned by alternative conceptualisations of what disability and indeed psychological labels represent (Szasz 1973; 1987, Laing 1985, Oliver 1990; 2013, Baker 2002, Rose 2007b, Shakespeare 2008; 2014, Ronson 2011). It is therefore important to explore why medical explanations of difference retain not only dominance, but emerge as the only reasonable explanation for physical and psychological difference. The expansion of medical labels denoting difference is found to attract consistent controversy (Gergen 1990, Conrad 2000; 2005; 2007, Sax 2007, Bursztyn 2011). Nevertheless the expansion of medical labels may be alternatively summed as the output of a process of trial and error, an iterative process of confirmation and refutation. Indeed it is notable that debates concerning the credibility and constitution of medical judgement have failed to impact on the monopoly of the medical profession to define difference (Barkley 2002; 2011; 2012, Sorenson and Thomsen 2005, Frances 2012, Smith, Reichow, and Volkmar 2015). Lupton (2012) suggests this is because 'medicine' as a body of knowledge in the broader sense exists as a discrete 'culture'; defining of its scope, focus and intent. This perspective stands in contrast to those proffering theories of power (Foucault 1967, 1973, Szasz 1973; 2007; 2012) and professional self-interest (Kutchins 1997, Conrad 2007, Southall 2007, Ronson 2011, Tomlinson 2012). Such influence however holds the potential for abuse as Lupton cautions: 'Within the current obsession for locating the genetic precursor of illness, diseases and behaviours, the knowledge base of working medicine has encroached even further into defining the limits of normality and the proper functioning and deportment of the human body' (pp. vii). The licence to define may therefore be alternatively described as the right to delineate acceptable and unacceptable being.

Culture is defined as a 'conglomerate of meanings, discourses, technologies and practices that accumulate' (Lupton pp. viii). This definition mirrors what Kuhn (1962) states to be the essence of a paradigm. The pervasiveness of such knowledge base is illustrated in working practice by Rafalovich (2001a, b, 2004). Charting the demise of psychoanalysis, it is noted that this demise did not destabilise the credentials of the medical profession, rather resulted in the forging of a new alliance between neurology and psychology, as an explanatory framework for explaining difference.

Professional monopoly does not equate to objectivity as Thane (2010) finds, stating that 'some disabilities – generally, physical disabilities such as being blind, deaf or dumb have always been more sympathetically treated than others, such as mental disabilities (pp. 3). Similarly Angermeyer (2006) finds lay public ability to differentiate between discrete categorisations of mental illness limited, furthering the potential for decisions reached to be based on assumption not medical judgement. Teachers acting in a secondary professional capacity, may also be seen to be similarly limited in their ability to discriminate. As a result, judgements may reflect personal opinions and pedagogical pressures as well as latest medical opinion.

The enmeshing of professional practice within a medial paradigm has been likened by Lupton to the sociological concept of the 'lifeworld' (Husserl 1970, Schutz 1973, Habermas 1987) extending possible explanation for the resilience of medical explanations for difference. The concept of 'lifeworld' is foundational to the development of phenomenology and represents the conceptual frame from which collective social understanding is drawn. It is therefore a useful concept to elucidate the esteemed position medicine enjoys within Western societies. Habermas (1987) expands, stating that 'the cultural reproduction of the lifeworld ensures that newly arising situations are connected up with existing conditions in the world ... it secures a continuity of tradition and coherence of knowledge sufficient for daily practice' (pp 140). It may be reasonably suggested that the 'lifeworld' in Western societies serves to bind means of understanding and responding to physical and psychological difference within a medical frame.

2.2.2 The relational and functional aspects of 'knowing'.

Identifying and 'knowing' disability has been viewed as a communal activity, extending from an overarching paradigm, through to the various professions and the social collective. The concept of the lifeworld may be taken to imply a static and unresponsive environment, yet Habermas (1987) denies such identity, suggesting it to exist in a state of perpetual motion, generative of and responsive to societal shift as such it is in essence relational. It is also notable that the three key arenas of societal existence Habermas cites (the objective, the social and the subjective), can be likened not only to the pervasive layers medicine as a culture pervades, but to the levels of human cognition implicated in psychological theories which privilege layers of consciousness (Rogers 1957, Freud 1964, Jung 2014).

Disability identities and accountabilities may be seen therefore to extend not only from their physical and psychological manifestations, but from the meanings negotiated during the relational engagements within which they are embroiled. For example, Rose's (2006) contention that 'neuroscience emerges at 'multiple interfaces between medicine, biology, psychology and philosophy' (pp 191), challenges the idea of objective theory progression. To the contrary it implicates a relational model punctuated by alliances both within and without the medical profession, through which the nature of difference is negotiated.

Rafalovich (2001a; b) illustrates how professional practice is relational in its implementation and thus holds implication for aligned professional practice. Rafalovich charts how the field of neurology has through historic circumstance, developed a symbiotic relationship with the field of psychology and by extension that of education. Such relationship is stated to have enabled the rationalisation of psychological phenomena within a medical frame, despite lack of organic markers, as is the case with many neurodevelopmental disabilities, particularly ASD and ADHD. As the manifestations of psychological disorders are chiefly behavioural, joint intervention has incurred both medical and behavioural interventions, supported outside of the clinical setting by aligned professionals such as teachers. Problematically this duality of approach also signifies a juncture which fosters individualised accountability. Thus whilst personal accountability for organic abnormalities may be uncharitable, accountability for failing to respond to behavioural interventions, deemed 'scientific' is not, enabling individualised and familial blame to coexist within a medical frame.

Barr (2015) seeking explanations for disability accountability and prejudice also privileges the relational from the perspective of the social collective, through the employment of the Integrated Threat Theory of Prejudice (ITTP). The ITTP posits that relational dynamics of in-group members predisposes them to infer that out-group members will act in ways that compromise the security of the group. Noting that disability research infrequently compares different presentations of disability, Barr's research compared the relational dynamics between persons with physical and behavioural disabilities (pp 224). Initial results indicated that behavioural disabilities attracted the most negative responses, although increased exposure fostered greater understanding and more favourable opinion. Barr (2015) also observed that positive attitudes to persons with disability tended toward a developmental path; beginning

positively in childhood and declining in late adolescence and early adulthood, whereupon a turn to more favourable opinions through to late adulthood was found. These are significant findings in relation to disability intolerance, particularly when considered in relation to the educational policy of inclusion, which attracts continuing critique (Warnock 2005, Cigman 2007, Rogers 2007 b, c, Party 2010), not least for its negative social effects.

Despite the implication of fluidity, the relations underpinning 'knowing' can also resist change. Looking at the continuance of disability oppression in UK schools, Beckett (2015) found that the current governmental climate, particularly an inactive approach at a pedagogical level were chief factors inhibiting disability equity in schools. Indeed Beckett observed that 'nondisabled children were found to enact cultural schemas that sustain their privileged position and subordinate disabled people' (pp 76), signalling relationships which were considered to mirror observed pedagogical practices, particularly the relations they normalise.

These relations are constitutive toward how disability is 'known', yet the dynamics are the antithesis of what Barr indicated to be essential to reduce in-group out-group distance. It is thus troubling that Beckett (2014) finds that 'negative attitudes towards disabled people permeate UK society' (pp 856), yet non-disabled childrens attitudes towards disabled people remain under-researched (ibid). Such research is essential to uncover and challenge the explanations disability identification currently resides upon. This is important because school level ethnographic studies suggest emotive referents act as a motivational impetus, not only for the disability identities conferred, but for those adopted (Benjamin 2002, 2003, Black-Hawkins 2008, Youdell 2010).

It is pertinent to consider whether difference determines its meaning or whether pre-existing meanings direct how difference is received. It is also worthwhile to note that the labels available are themselves the output of collaboration. Hobbs notably both champions and cautions about the utility of medical labels:

'Classification can profoundly affect what happens to a child. It can open doors to services and experiences the child needs to grow in competence, to become a person sure of his worth and appreciative of the worth of others, to live with zest and to know joy. On the other hand, classification or inappropriate classification, or failure to get needed classification – and the consequences that can ensue – can blight the life of a child, reducing opportunity, diminishing his competence and self-esteem, alienating him from others, nurturing a meanness of spirit and making him less of a person than he could become'(Hobbs 1975 pp. 1).

The above sentiment also retains a contemporary significance in education (Florian 2008a). Particularly as discrete categorisations of disability (medical labels) stimulate

controversial debate, many rejecting of medicalised claims and supportive of a constructivist stance (Gergen 1990, Molloy 2002, Rapley 2004, Bailey 2006, 2009, 2010, Amaral 2007, Southall 2007, Dudley-Marling and Paugh 2011, Timimi 2009, 2010).

Equally controversial is the fluidity of medical labels, witnessed through the reconfiguring and expansion of medical labels in the name of medical progress. Yet the reach of engagement may be generative of diagnostic insecurities as the following excerpt indicates:

'While DSM has been the cornerstone of substantial progress in reliability, it has been well recognised by both the American Psychiatric Association (APA) and the broad scientific community working on mental disorders that past science was not mature enough to yield fully validated diagnosis - that is to provide consistent, strong and objective scientific validators of individual DSM disorders' (Association 2013 pp. 5).

These concerns, although openly debated within the medical profession, are rarely accessible or publicised in the school context, hence they exist outside of the relational existence of the teaching profession. They may hence destabilise the confidence secondary professions, and similarly those outside of the professional field, have toward the certainty of medical labels.

Equally the meanings coalescing around disability as a state of being may vary in response to the underpinning assumptions individuals and social groups hold. For example Curran and Runswick – Cole (2013) call for a more critical exploration of the nature of disabled childhoods, illustrating that by moving emphasis from medicalised understandings, it is possible to produce a deeper and interconnected appreciation of how disabled childhoods are produced and experienced. Such approach is considered particularly useful toward appreciation of how some disabled childhoods develop as blameworthy, whilst others do not.

A relational perspective is also useful for explicating how individual accountabilities become intertwined within wider political and moral notions of what 'challenging (troubling) behaviour' is, equally so its relationship to disability (Wasik 2015). For example the contributions contained within Wasik's edited book, combine to highlight the subjective and political nature of not only what is considered 'troubling'; but also the scope of appropriate response to 'trouble'.

Responses to trouble are found embroiled within the criminal justice system and reflect the stance of government and wider social and international issues. Hence although the manifestations of disability do not axiomatically link to the criminal

justice system, such linkage emerges where disability effects are found to impact on social conduct. Indeed it is in this context that the most obvious parameters of blameworthiness are founded, based upon political and legal determinations of the scope of dismissible 'trouble' and sanction worthy 'trouble' (O'Connell 2016). In the case of 'sanction worthy trouble', there appears little acceptance of disability as a mitigating factor driving conduct (Loucks 2006, Talbot 2010, 2011, Hughes 2012), thus serving to disassociate 'behaviour' as a valid symptomatic indicator of disability.

The explanations proffered to explain the origins of disability reveal sites of potential challenge and also seats of accountability, reflecting not fact, but collaborative output. Thus as understandings change, so do the guises of challenge and accountability. Kudlick (2003) indicates that 'disability history teaches us how previous generations have marked what it means to be human; in particular, 'reverence to the perfect human body and mind' (pp 764) is said to perpetuate an illusion that physical and psychological equilibrium is the human norm.

It may be argued nonetheless that differentiation between difference as human variation, and difference as physical or psychological deficit is warranted in terms of support and levelling disadvantage. Observances of difference do not automatically equate to disability, rather it is the evaluative attributions attached to difference which emerge as problematic. Typically the parameters of difference are found measured against the concept of the norm (Winance 2007), a standard charged as being derivative from subjective opinion, not fact (Bakker 2002, Waterhouse 2004). Armstrong (2010) concurs with this sentiment, suggesting that difference does not imply deficit through its embodied integrity, rather emerges through a societal unwillingness to consider the positive benefits of difference. Looking across the spectrum of medical labels that define disability one can see that it is not all labels that attract deficit attributions, indeed whilst conditions such as ADHD are vulnerable to deficit ascription (Bailey 2010), autism has entered into folklore as synonymous with giftedness (Murray 2006, 2008).

The defining of selective human difference as abnormality has been suggested to deflect inherent human frailty, likewise that adherence to the concept of sameness confers an ontological security and predictability to the human condition, which unregulated difference denies (Stiker 1995, Armstrong 2003). This view suggests that the communal ordering, rationalising and othering of difference is foundational to the appearance of a knowable and predictable social context (Hacking 2007).

Nonetheless such a tendency also opens spaces for the vilification of difference, which has been considered to compromise the social equilibrium (Young 1999, Youdell 2006, Rogers 2012, 2013), and by extension rationalise its control. Jasanoff (2004) states 'science and technology account for many of the signature characteristics of modern society... the reduction of individuals to standard categorisations that demarcate the normal from the deviant and authorise varieties of social control' (pp 13). This theme of control is implicated by Turner (2006), who suggests that 'how a society defines disability and whom it identifies as deformed or disabled may reveal much about that societies attitudes and values concerning the body' (pp 2), and one suggests contemporarily the mind.

Drawing upon a critical disability studies perspective (CDS), Goodley and Runswick-Cole (2016) extend Kuddlick's (2003) assertion that disability marks what it means to be human, rather suggest its form is shaped by the nature of the institutional imperatives which constitute the foundations of a society. 'Proponents of CDS emphasise the complex social, cultural, material and economic conditions that undergird the exclusion of disabled people' (pp 2). Indeed Goodley and Runswick – Cole find that manifestations of disability have served to distance disabled children from the mainstay of humanity, due to a perceived inverse relationship between ability and disability. Notably the continuation of segregated special schools in the UK would appear to support this contention.

Opposing this dichotomy, Goodley and Runswick-Cole (2016) argue that the dignity, determination and creativity demanded to meet the challenges of childhood disability is defining in its own right of humanness, albeit disavowed in a society which privileges ability above everything else. In challenge to the privileging of ability, Goodley and Runswick – Cole (2016) adopt the term 'dis', seeking 'simultaneously to contest and to claim the (normative) human in the lives of disabled people (pp 3). They also call for a deeper consideration of 'how we value the human' (ibid), although this has not been extended to the realm of what might be termed 'challenging difference'.

Developing this theme Goodley, Runswick–Cole and Lilliard (2016) suggest that intellectual disabilities hold capacity to extend the boundaries of not only what it means to be 'human' but also of what 'human' could be. However in relation to the less salubrious effects of disability (Carpenter and Emerald 2009, Vargas 2013, Berg-Dallara 2014) it is hard to envisage what definition of humanity it might propose

and in this sense it is felt that once again the spectrum of disability is only partially addressed. Goodley and Runswick-Cole (2016) do however usefully delineate the multiple contexts where dis [ability] disavows the human. Inverting the traditional direction of influence, it is asked 'what disability does to the typical, common-sense normative human categories of adult, youth and family' (pp 5). In doing so, dis/ability is positioned as an influencing variable on 'able', which acknowledges the theoretical, practical and political work that takes place either side of the ability/disability binary' (pp 3). The idea that difference can actively define what is considered typical is also addressed by Pinchevski (2005) in relation to the boundaries of communicability.

Rogers (2016) asserts that processes of devaluation are embedded within the services which are entrusted to support and care. Rogers (2016) points to the domains implicated in the act of caring (emotional, practical and socio-political) and finds them to be punctuated by careless, rather than caring relations. Notably it is these acts of carelessness which serve to dehumanise and devalue. Within the accounts provided by Rogers, one can identify sentiment which resonates with my own personal experience. Not only in respect of not being listened to, or being cared for. But in relation to the positioning of some young people outside of the mainstay of humanity; position which denies their uniqueness, qualities and common humanity.

2.2.3 'Seeing', 'knowing' and 'evaluating'

'Seeing' involves not only immediate stimuli, but evokes prior knowledge. In essence 'seeing' is processed through what is already 'known'. Such 'knowing' may be likened to Kelly's (1963) theory of personal constructs and Moscovici's (2000) Social Representations Theory. This suggests the component parts of knowing are pre-formed by existing social representations and framed around conceptual opposites, an information processing tendency Kelly refers to as Constructive Alternativism (CA). The idea of CA is important as it informs us of how meaning is generated through reference to its opposite. Thus in the case of disability, its implications are laid evident through an understanding of ability. Similarly, 'challenging' behaviour is rendered sense worthy only through a prior notion of what complicity is.

Reference to the ongoing impact of prior knowledge at the level of the collective enables one to visualise how a culture becomes pervasive within a community. This is the case in respect of physical and cognitive difference, whereupon it is common

practice for it to be referenced through a medical lens and understood as primarily physical or psychological deficit (Foucault 1967; 1973; 1997; 2006, Borsay 2005).

This stance is however not absolute as other knowledge perspectives are evident, in particular explanations for difference from a social constructivist or relational lens indicate the locus of deficit to lead from relational and structural inequalities (Oliver 1990; 2013, Foucault 1997, Shakespeare 2006; 2014, Conrad 2005; 2007, Goodley and Runswick – Cole 2015; 2016). Social science data would indeed favour the latter stance, as disability is heavily associated with social and economic disadvantages (Blackburn, Spencer and Read 2010, PT 2016). It is therefore pertinent to question the origin of inequalities, to determine whether they originate from systemic barriers, or are a consequence of the physical and psychological effects of disability. Equally it is of interest as to what extent these determinations can elucidate the accountability found metered toward those whose disability impacts on social conduct (Hughes et al 2012, O'Connell 2016), a presentation Barnes (2014) determines 'bad difference'. It is nevertheless telling that the term 'disability' is found to place value on the state of difference and imply a lack (Goodley, Runswick-Cole and Liddiard 2015, Goodley and Runswick-Cole 2016, Rogers 2016).

Childhood disability holds association with maternal and familial disadvantage (Kingston 2007, McLaughlin 2008b, Jull 2008, Landsman 2009, Gallagher 2010b) and alludes to a secondary lack which can be likened to courtesy stigma (Goffman 1968b). The impact of childhood disability and indeed its identification is nevertheless mediated by the characteristics of the child's family and is discussed more fully in section four (Carpenter 1999, Carpenter and Austin 2007, Rogers 2007; 2007a; 2013, Carpenter and Emerald 2009, Blum 2006; 2016, Nind 2008, Holt 2008; 2010: 2012).

McLaughlin and Goodly (2008b, McLaughlin 2016) find there to be a complex interaction between professional services and the families of children with disabilities, resulting in the exercise of agency in all domains, disability is therefore most accurately described as collaborate. It would however be distortive to suggest that there is no dependency of either the young person or the family on the medical profession to remediate the physical and psychological effects of disability. However it is fair to suggest that in the case of behavioural disabilities, the relationship is distorted by the competency evaluations which accompany professional input (Tardy 2000, King 2006, Rogers 2007) based on the subtext of regulation to the norm,

whereupon 'normative expectations of child behaviour help to facilitate the production of 'self- regulating subjects' (McLaughlin 2016, pp 58).

The ethics of disability identification is also problematized and alongside this there are implications for how difference can and should be known. Barnes (2014) argues that disability as it is understood from the logic of a medical model cannot be dismissed as simple difference, as disability difference conjures ethical questions around the merits or non-merits of clinical interference and non-interference. In particular ethical issues arise in relation to the extent to which there is medical and social responsibility to intercede in the effects of disability, counterbalanced by consideration of the moral implications of not assisting a disability. Disability thus emerges an inconsistent state (Szasz 1974; 1987, Foucault 1997; 2006; Stiker 1997, Borsay 2005), which implies that its 'knowing' will be similarly inconsistent.

Nevertheless although delineations of difference are found to be an historic constant (Foucault 1967; 2006, Stiker 1997, Borsay 2005), it has not held an axiomatic association of disability remediation (Turner 2006). Instead association of disability has also been wedded to issues of social control (Foucault 1973; 1977). This has been found linked to not only a determination of an individual's worth in terms of social productivity and the perception of threat their presentation indicated (Armstrong 2003, Borsay 2005, McDonagh 2008), but also their burden on the family, which itself impeded familial economic productivity.

The challenges brought by the antipsychiatry movement were fundamental to an address of such 'knowing' (Foucault 1967, Szasz 1974; 1987;1988; 2012, Laing 1985, Rissmiller 2006), bringing into the public domain the scope of injustices metered in the name of medicine and social equilibrium. Goffman's classic study 'asylums' remains a classic text which details how a psychiatric diagnosis can become the de jure 'knowing'. Channelling of all subsequent observation and deduction, as a result, a psychiatric diagnosis was not only longstanding, but pervasive in a manner physical disabilities were not.

Thomas Szasz (1973; 1987; 1988; 2007; 2012) has been fundamental to the anti- psychiatry movement and is most famous for challenging the orthodoxy of mental health labels and exposing the practices sanctioned in the name of medical progress. Szasz (1988) also takes issue with the psychological approach known as psychotherapy, suggesting that just because something is defined from a medical

lens as evidence of a psychological disorder, does not mean it is. Szasz likens psychiatry and psychotherapy as a belief system similar in orientation to that of religion; and in this sense 'knowing' is an act of faith that cannot be substantiated outside of its own internal logic. Notably Szasz does not deny the phenomenon that is stated to signify psychological disorder, simply its interpretation, as he states; 'Of course they exist, only to the person who rejects the miracles of psychiatry, they are simply not diseases or treatments, but (only) the claims and conduct of persons identified as psychiatric patients and practitioners' (pp xii).

Szasz's claims resonate with those who maintain constructivist and relational stances, contesting the expansion of medicalisation (Timimi 2004, Timimi and Taylor 2004, Timimi and Leo 2009, Timimi and McCabe 2010, Conrad 2005; Conrad 2007; 2010, Conrad and Bergey 2014). It is interesting that Szasz refers to patients as well as practitioners in terms of a medical standpoint, not least because the identities that are adopted and defended by diagnosed patients may be seen to be equally fundamental to the perpetuation of 'knowing' (Wrongplanet.net 2012, NAS 2015; 2016, 'Young minds' 2016). McLaughlin (2016) refers to this as the process of becoming a self-regulating subject (pp 58), regulation which is also observed through historical account of patient experience. Taylor's (2014) biographical account of being an in-patient in an asylum during the latter stages of de-institutionalism is illustrative, yet far from being viewed in retrospect by Taylor as oppressive, she recalls her stay as a positive intervention that is not paralleled commonly.

Taylor challenges the controversial identity of subject-hood most commonly conjured by critics of the asylum movement, which one might suggest supports the notion of being self-regulating subject, or indeed it may as accurately represent an alternative perspective and speak in support of medical intervention. It is notable that Taylor observes the tensions within the mental health profession from a patient perspective, discussing freely the treatment implications of biomedical versus psychological approaches. Within this discussion it is clear that what is central from the patient perspective is the impact of the needs presenting and its implication for patient recovery. Taylor poses the question 'what would happen to me now if I were a young woman in the midst of a severe emotional breakdown?' (pp xx).

This question reminds us that outside of big debates and paradigm shifts which define 'knowing', the actual problems people experience in living (Conrad 2007) remain the same. It is therefore notable that the de-institutionalisation movement is

stated by Taylor (2014) to hold its own limitations and prompted the question posed by Taylor posed above. It is also fair to suggest that patient accounts serve to illustrate Szasz's contention, that the same phenomenon can conjure alternative meanings, yet represent the same phenomenon. 'Knowing' may thus be more accurately depicted as perspective, which by its partiality is vulnerable to being value laden and contextually responsive.

2.2.4 Claims to truth

The objectivity of scientific truth claims is challenged as wider social and relational factors are found implicated not only toward disability identification and the medical labels applied, but also to vulnerability to accountability (Nind 2008, Holt 2008; 2010; 2012, Heilker 2012, Heeney 2015 Kulz 2015). Indeed it is the inequity imputed to difference, not difference per se, which implies there to be a power imbalance, between the identified and those entrusted to be identifiers. Nevertheless identifications of difference are also found to be resisted (Erevelles 2000, Gabel 2005, Hughes 2005, Hacking 2007), which complicates the notion of absolute subjection.

Whilst acknowledging the potential for resistance, the complexity and inter-connectedness of signifiers to difference supports Foucault's (1980) assertion that power is not consolidated in any central point, rather draws strength from its diffusion across a range of claims to truth. Indeed in the educational domain particularly, the intentions driving identifications of difference are found linked to wider prejudices and priorities in the social and structural domains (Tomlinson 1982; 2012, Graham 2008, Youdell 2011, Graham and Macartney 2012, Caslin 2014). Equally the explanations for and control of difference appear to operate symbiotically, predicated upon wider concerns surrounding impact on others. This suggests that far from being able to remediate 'the political status of science' is appropriated for 'the functions it could serve' (Foucault 2000, pp 111). Thus although medical labels and wider accordances of deficit difference logically extend from the ownership of truth claims, in operation, content concedes to function, as the work of Giroux (2009) and McGregor (2015) suggest, finding truth claims to difference, harnessed toward the control of youth.

'Othering' can be usefully summed as the process of subjugation, founded upon attributions accorded to difference. A discernment which has been considered directly responsive to prevailing social, economic and political periods (Rose 1989,

2007, Stiker 1997, Young 1999, Armstrong 2003 and Bauman 2004), shaping of both who is 'othered' and in what guise. Economic relations are also implicated in the types of difference considered accountable, threatening or support worthy (Young 1999, Liasidou 2012). The mechanics of surveillance are developed by Foucault (1967, 1973) who drawing upon the concept of 'gaze' determined the school to embody in design what Bentham termed the panopticon.

Foucault's (1981) paper, 'the order of discourse' expands on the centrality of discourse as a regulative forces and suggests historically that discourse is implicated in three divisions of exclusion. These consist of the prohibition to speech, the division between madness and reason and the will to truth. These divisions Foucault describes as prohibitions, which may be seen to retain a contemporary significance in respect of power; control; identity and knowledge production. In operation Foucault visualises these to operate not concurrently or in parallel, but as a constantly changing interlocking grid.

Looking at each in turn it is possible to see such prohibitions operational in the contemporary domain, with a particular relevance to disability accountability and its defence. Firstly looking at the prohibition on speech, it is reasonable to suggest the current surveillance of the spoken and written word is at its highest. Not least as what is said and how, forms part of diagnostic criteria for medical labels such as Autism and ADHD. Secondly there is scrutiny of speech on social media and in the public domain, restrictions which are legislatively stated in respect of hate crime and equality (Parliament 2005; 2010), governing what can and cannot be said. Secondly the division between madness and reason is found primary to lead to a silencing of the mad, leaving their voice 'having neither truth, nor importance, worthless as an exercise in law' (pp 53). As Foucault states, 'the madman has been the one whose discourse cannot have the same currency as others' (pp 53).

The idea of currency has a contemporary relevance; it speaks to the weight given to what is said and the timing of the invitation to speak, not exclusively the principle of voice. Visser (2015) notes that for pupils with emotional and behavioural issues, their voices, although sought during the statutory school years, appear less sought post 16. Visser indicates concern that the dispositions observed which led to the label SEBD appear to lose significance post 16, leaving those past the age bar without any defined channel of communication. This is the limitation of contemporary claims to 'give voice', they are contextual, time referenced and in some cases imposed by

government. Pupil voice initiatives may therefore be accused of being chiefly functional to meeting official responsibilities, rather than genuine interest.

Goffman (1968) and Rosenhan (1973) both make reference to how medical labels can become self-confirmatory post identification, thus directive of subsequent explanations for human action and thought. The medical label may thus be seen as a dominant discourse, directive of other discourses and interpretations. As Foucault (1981) states 'discourse is not simply that which translates struggles or systems of domination, but is the thing by which there is struggle', essentially, 'discourse is the power, what is to be seized' (pp 53). Hence drawing upon Foucault to explain the impact and potency of medical labels, it is reasonable to suggest that they represent the successful outcome of the struggle to appropriate the discourses around physical and psychological difference. Such view exceeds the stating of the obvious as it impresses upon us that the same phenomenon can be rationalised in any manner of ways, but very few attain legitimacy.

Foucault (1981) claims that the space between truth and falsity represents the third division, termed 'the will to truth', this juncture is stated to be where claims to truth reveal their local (and varied) sources of power as Foucault explains:

'This will to truth, like other systems of exclusion, rests on an institutions support: it is both reinforced and renewed by whole strata of practices, such as pedagogy of course; and the system of books, publishing, libraries; learned societies in the past and laboratories now' (pp 55).

From this excerpt one can begin to appreciate the tapestry of knowledge that scaffolds 'knowing', and how it is built upon claims to truth. One can also see how these claims become embedded within the very fabric of social life, presenting both impression of reason and of truth. They may be thus viewed as directive of what can be 'known'. Notably, within such tapestry, challenges to 'knowing', suggest unreason, an identification which serves to protect and perpetuate the dominant discourse.

The notion of surveillance resonates in the field of education, as by the nature of its function it is 'legitimately' directed to the testing and monitoring of pupils.

Nevertheless the markers of educational success are themselves linked to the priorities of wider institutions, not least a global skills economy (Tomlinson 2008). The configuration of education is thus illustrative of how a dominant set of ideas can be assimilated and delivered in prescriptive format, maintaining illusion of choice and merit, whilst simultaneously defining failure and difference. As Bourdieu (1977) states, 'pedagogical action is, objectively symbolic violence, insofar as it is the

imposition of a cultural arbitrary, by an arbitrary power' (Bourdieu 1977, pp 5). Schools through their evaluative tasks may be seen as prescriptive toward simple 'being', in relation to not only ability, but conduct, disposition, development and appearance. These latter determinations exceed simple difference and open up spaces for accountability.

The truths which are objectified through the ownership of claims to truth conjure notions of deserving and underserving and are cited by Armstrong (2003) to underpin medicalised accountabilities through the 'notion of treatment', which acts to confer responsibility for the management of self (pp. 10). Such management is heavily implicated in education and the parenting role. Patient responsibilities were initially documented by Parsons (1952) and termed 'the sick role' and in brief comprised the legitimisation and necessitation of medical intervention and acceptance of personal duties toward health remediation in exchange for an exoneration from societal responsibilities. The threads of such responsibility and the spaces open to accountability are contemporarily evident in education as has been suggested in relation to ADHD (Singh 2004, Greydanus 2005, Blum 2006, 2016), where despite the notion of equal partnership, parents are expected to follow professional advice to remediate the effects of a disability (Armstrong 1995, Todd 2003, Lamb 2009, Rogers 2011).

Perceptions of dangerousness speak of the need of containment (Foucault 1967, Stiker 1997, Armstrong 2003, Borsay 2005, Dale 2006) and have been central to the surveillance for and control of difference. This may be seen to be paralleled in education systems, whereupon despite a general association of disability and SEN with exclusion, closer inspection reveals that it is effects of a behavioural nature which render a pupil vulnerable to exclusion (DfE 2015b; 2016). Identifications of difference may be said therefore to be linked as much to control as they are to the distribution of resources.

2.2.5 Expanding the profession – creating non-negotiable deficit

The expansion of medical labels to explain difference has been historically attributed to the growth of professionalism (Freidson 1970), such sentiment retains a contemporary significance as Grant (2010) asserts: 'the official label at any one point in time has harnessed and supported the development and growth, at least since industrialisation, of an industry of professionals whose work has been based upon

these varying definitions' (pp 3). In education this is most evident through the expansion of 'special' educational provisions, which is dogged by its medical and inegalitarian legacy (Armstrong 2003, Benjamin 2002, Slee 1993, 2001, Tomlinson, 1982, 1985, 2005, 2012). Not least that it has disseminated illusory claims in respect of redistributive and social justice during both the integrationist movement (Slee 1993) and of more recent history the inclusion agenda (Acedo 2009, Cigman 2007, Dunne 2008, Hodkinson 2011, 2012, Rogers 2007b, 2012).

The 1944 Education Act offers clear example of not only how medicalisation of disability led evaluations of differential worth (Parliament 1944), but also how such understandings supported the expansion of a profession tailored to their needs, through the detailing of how children were to be sorted based upon medical categorisations of ability and need. This period in educational history also offers example of how discriminative practices can become embedded within institutional structures and take on the guise of reasoned action. One of the criteria contained within the 1944 Act introduced the classification of 'ineducability' and of itself offers a clear example of how invocations of worth can delineate both entitlement to and level of resources in education. Indeed the category of 'ineducable' was founded upon belief that the child was unsuited for education, serving to sanction a transference of care from the educational domain into the medical arena. Such move is not only known retrospectively to have been foundational toward expectations both self and ascribed into adulthood (Atkinson 1997, Armstrong 2003), it also illustrates how a licence to define can be all encompassing and at this period in history was non-negotiable as the following life history excerpt shows:

'In them days if you had learning difficulties or anything that's where they used to put you. They didn't say, 'Oh you could go into a big house and someone would look after you.' They would just say 'you gotta go into a big hospital', and that's it (Atkinson 1997 pp 29).

Controversially although the category of 'ineducability' was revoked by the 1970 Education Act, transferring all childrens educative needs into the care of their Local Authority (Parliament 1970), contemporary practice suggests that in reality little has changed. The legacy of medical involvement in education persists, punctuated by the reliance of the education profession on medical labels and medical input into pupil management (Hobbs 1975, Florian 2008a). Similarly despite universal access to education, there remains a body of pupils who are subject to permanent and serial fixed term exclusions (DfE 2013b) and it is suggested that permanent exclusion resonates with the aforementioned category of 'ineducability'. Hence despite an

expansion of medical labels there is still an intolerance toward certain types of difference (Dumit 2006), which speaks of educational worth and entitlement.

The significance and effect of disability identification in the contemporary educational context is expanded upon by Christensen (2004), stating it to have an impact on three levels. Firstly serving to create impression of a natural dualism, those able and those not, the latter frequently conjuring of pity, sympathy or intolerance. The concept of ability in education has been referenced against what is termed 'ableism', found in education to be calculated upon the premise that there is a standard of typical development (Gabel 2005, Heir 2002, 2005, Goodley 2011). Secondly Christensen (2004) suggests medical labels can become definitional of the person, rather than representing a difficulty the person may hold. A consideration which has been fundamental to the development of 'labelling theory' within the field of mental health and learning disability (Hatton 2009). Finally within deficit conceptualisations are found to deflect any wider organisational scrutiny toward the appearance of difficulty, hence operate in a confirmatory manner, supporting medicalised explanations for difference. Schools have been charged with being constitutive of the differences they purport to identify which further challenges the ideal that the educational context operates a site of objective surveillance (Araujo 2005, Cremin 2005, Bailey 2009, Graham 2007b, 2008, Paivi 2008). To the contrary, schools are considered a productive force (Foucault 1982, 2000), serving to perpetuate existing inequalities (Bourdieu 1977) and deflect critique through the individualising of failure (Allen 2006, Youdell 2006, 2011).

Classifying impairment has been identified as a core educative function, 'schooling remains a critical agent in defining, labelling and treating disability' (Slee 1993, pp 353). Indeed educative input is frequently introduced into the medical domain as 'supporting medical information', mandatory information inputted into 'statementing'/EHC assessment. Referring to C. Wright Mills distinction between public issues and private troubles, Tomlinson (1982), suggests 'those in charge of special education have a vested interest in defining problems as purely private troubles for individual families' (pp 24). Hence although educative needs were posited to move from a medical frame (Warnock 1978) and do not specifically imply individual impairment, the evidence supporting need does. Rendering categories of childhood disability and disorder, a clearly private trouble.

Allan (1996) drawing upon the work of Foucault emphasises not only the constitutive effects of identification, but their longevity. 'Following assessment the child with special needs is marked out for perpetual surveillance for the remainder of his or her school career and beyond'. This is evident in school practices, supporting Foucault's (1977a) claim that schools are sites of surveillance.

Nevertheless although currently medicine/psychology and education are found to engage in a working relationship, the nomenclatures employed are at times misaligned. For example educationally terms such as handicap were discontinued upon advice (Warnock 1978), yet within diagnostic texts (Association 1987, 2000), such terminology is more recent and internationally current (Wedge 2015). The term 'mental retardation' until the recent revision of the DSM (DSM-5) remained a working classification. This suggests that cultures within cultures exist, rendering more complex any definitive mapping of the contexts and structures within which disability and challenging emerge.

2.2.6 The psychiatric profession – controversy and concerns

Although the activity of 'knowing' has been described as linked to the stock of existing knowledge, the existence of different periods of truths is destabilising of the notion of any de jure truth (Foucault 1967, Foucault 2006, Stiker 1997, Borsay 2005, Turner 2006). Consequently 'knowing' is rarely a linear process, it is more accurate to suggest that discrete claims to truth have rationalised different categorisations and understandings of difference, latterly supporting the defining of disability as both medical/scientific advance and the product of social construction (Conrad 1989, 2000, 2007, Rafalovich 2001 a; b, Rose 2006, Lewis 2009, Wedge 2015).

These claims are also challenged as disability history also alludes to the impact of differential relations of power on both the appearance, identification and response to disability (Stiker 1997, Rose 1989, 2007b). Identifications which are also heavily implicated in resource allocation (Borsay 2005) evaluations of human worth and accountability (Armstrong 2003, Atkinson 1997, Dale 2006).

Grant (2010) sums the process of diagnosis as 'warranted ascription', and suggests that the labels themselves are less important than the processes involved in their conferment. Indeed the diagnostic process is described by Grant as the 'labels applied by interests who hold the power to define others and who through their power, claim the label to be warranted' (pp3). This delineation of the diagnostic

process exposes inherent inequalities in the diagnostic relationship, which is marked in the case of adults, but doubly so in the case of children who have no capacity to resist or seek diagnosis. It is unsurprising therefore that the authority of the psychiatric profession has encountered consistent challenge, not least during the period defined as the 'anti-psychiatry movement (Foucault 1967, Szasz 1974; 1987; 1988; 2007; 2012, Laing 1985, Szasz 1974; 1987, Rissmiller 2006), but also in relation to the expansion of childhood medical labels, particularly the expansion of autism spectrum disorders (ASDs) and attention deficit hyperactivity disorders (ADHDs) (Kutchins 1999, Conrad and Potter 2000, Conrad 2005; 2007; 2010, Sax 2003; 2007, Southall 2007, Timimi and McCabe 2010, Ronson 2011, Smith 2012, Conrad and Bergey 2014, Whitely 2014).

Dumit (2006) alludes to the practical need of holding a formal medical label stating that in the United States, lesser known, or indeed conditions without dedicated diagnostic criteria exist as contested terrain, resulting in a denial of access to needed medical insurance or social supports. Although Dumit's observations are not relevant in the UK which benefits from a free at the point of delivery health service, they are highly relevant in respect of legal protections and educational entitlements. Indeed it is important to be mindful that an official medical label is not only an explanation for difference, but serves to legitimate entitlements to needed supports and medication. Thus Dumit's observation skilfully shows how there is an interconnectedness (formed out of necessity), between medicine as a profession and a truth system and other key social institutions, as such serves to privilege such knowing above other ways of explaining difference.

It is equally of concern that the process of 'knowing' is founded upon unequal relationships, notably the identifier and the identified. It may be argued that disability identification is founded on the licence to define, rather than its inherent visibility, as only particular professionals hold such licence. Disability identification is also found to be selective of who and what is diagnosed particularly in relation to children in the school context (Croll 2002, Riddell 2011, McCoy 2012). Such selectivity has been viewed as functioning to perpetuate social stratification, legitimate social control and rationalise an unequal distribution of resources and opportunity (Butler 1997, Dumit 2006, Rose 1989; 2007). Looked at from this perspective, disability accountability may simply reflect unequal power relations and a desire to control, which through the logic of the doctor patient role presents the epitome of reason.

The anti-psychiatry movement not only challenged the orthodoxy of psychiatric practice, they challenged the credulity of many established medical labels. Equally significant were other social studies which highlighted aligned effects from the professions dominance. Of particular significance are studies that have highlighted how the expectations generated through a diagnosis, set in motion a self-confirmatory effect, colouring interpretation of all subsequent behaviours (Rosenhan 1974, Goffman 1990).

These processes are seen to not only confer identity from without, they are also found implicated in the development of a person's sense of self, process which has been termed the 'looking glass effect' (Cooley 2010). The Looking Glass effect may be summed as the superimposition of identity reflected from the impression of others. Impression which in this example extends from established disability identities and which are central to the internalisation of the types of knowing reflected. Graham (2015) cautions further about the dangers of pathologising young people, not least in respect of the limitations such identity confers, 'young people may come to know themselves as "disordered", which can rob them of both the voice and agency they need to overcome their circumstances' (pp 30), but also because such pathologisation, can deflect attention from the social circumstances which may equally trigger the appearance of a disability. Dunlop and Newman (2016) add to these concerns by suggesting that the condition ADHD is more complex than its image and frequency suggest, thus what may present as ADHD may indeed be equally indicative of other disorders and the authors thus call for diagnostic caution and increased scrutiny.

Despite the anti-psychiatry movement serving to politicise mental illness and medical agenda, contemporary concerns about the conduct of the profession persist. Most recently Lewis (2009) has cautioned that psychiatry as both a scientific field and service profession, positions itself as a/theoretical), obscuring the functions served through its services. In relation to childhood disability and notably disabilities of a behavioural nature these claims have been most strongly voiced in relation to the medicating of children. Particularly the use of stimulant drugs such as Ritalin to affect school conduct and performance Central to this issue has been the contention that the pharmaceutical companies have promoted medication out of self-interest (Efron 2015, Graham 2015, Mayes 2015b).

The use of medication thus becomes synonymous with responsible parenting, Blum (2016) describes this as the process whereby 'a public responsibility for child health [which is] ...pushed back onto mothers through Neoliberal discourses of personal responsibility' (pp 99-100). Such discourses accord accountability for the identified conditions remediation, hence any familial inability or rejection of conventional medical advice is found to heighten vulnerability to assertions of recklessness and allegations of complicity toward their child's disorder. (Singh 2004, Greydanus 2005, Blum 2006, 2016).

Middleton (2016) revisits the issues raised by both Goffman (1968) and Rosenhan (1973), finding that despite the movement away from institutionalisation and psychological practices based on collaboration (Rogers 1959), for those patients who are deemed a risk to self or others, there is still a perception of coercion, even if it is not physical in nature. Toward an explication of these findings, Middleton draws upon the relationship of psychiatry with the legal framework, noting how treatment can be court appointed even in the absence of a crime. Middleton concludes by stating:

'The need to lawfully contain and coerce someone who is not formally criminal is a challenge to conceptualisations of the human being as one governed by individualised reason. As a result, the practice is shrouded, inconsistently applied and controversial, and it is likely to remain so until or unless there are significant shifts in public discourse concerning psychiatry as a whole' (pp 66).

The professional knowing of childhood disability offers an astute example of how the same phenomena can be rationalised differently, altering not only understanding of its causation, but the logic of response. Wedge (2015), charts how interpretations of difference and disorder by the French psychiatric profession have deliberately deviated from sole reliance on medical criteria as contained in DSM. Finding that as a profession the decision was made to privilege social explanatory factors, most particularly parenting and culture. Such approach has served to de-medicalise some presentations of childhood difference, particularly ADHD, with a significant impact on both indigenous prevalence rates and wider claims of global prevalence consistency. Professional debates centred on diagnostic criteria differences offer further example of how knowing (and recognising disability) extends from negotiation and collaboration. Such process is particularly marked in the absence of any organic diagnostic test, at which point diagnosis defaults to clinical subjectivity, bounded by the culture in which it is embedded (Tripp 1999, Polanczyk 2007, Bauermeister 2010). Notably this culture also bounds the parameters of accountability and conduct protocols generally.

Knowing is professionally controversial; within the medical profession fierce debates surround explanations for behavioural and psychological difference, these are most clearly exemplified by reference to the condition ADHD and contemporarily through the ongoing concerns toward the new medical label added within DSM 5 (Association 2013a) Disruptive Mood Dysregulation Disorder (DMDD) (Mayes, Waxmonsky, Calhoun, Kokotovich, Mathiowetz, and Baweja 2015a). In relation to ADHD, debates regarding both prevalence and indeed existence coalesce around organic, cultural and organisational factors and are underpinned by a questioning of the role of culture and context toward its appearance (Danforth 2001, Timimi, 2004, 2009, Polanczyk 2007, Polanczyk 2007, Rohde 2005, Graham 2007a, b, 2008, Horton–Salway 2015).

The dialogue around ADHD has been actively constitutive, impacting on the very core of the classification itself, as Horton–Salway (2015) observes, finding ADHD to be ‘produced in discourse and associated with moral evaluations produced in media stories and drawn on by parents who have a child with a diagnosis of ADHD’(pp 158). Interestingly these moral evaluations are found by Jimenez (2015) to be enshrined legislatively through the concept of ‘sound mind’ as the determination of societal competency. Indeed this state is considered to be definitional toward the parameters of psychological difference that is acceptable and warranting of liberty.

Equally it would appear that the inclusion of the new medical label DMDD in the DSM 5 has conjured controversy, as Lochman, Evans, Burke, Roberts, Fite, Reed, De La Peña, Matthys, Ezpeleta, Siddiqui and Garralda’s (2015) recent paper indicates.

Most specifically the clinical precision of DMDD as a discrete condition is questioned, as such its inclusion in the planned revision of the ICD, ICD -11 is in question. Mayes et al (2015a) equally challenge the discrete nature of DMDD, finding in trials that it cannot be differentiated in terms of symptomology from other conditions of a similar nature, in particular the syndrome known as Oppositional Defiance Disorder (ODD).

As a result it is recommended that DMDD be subsumed under the classification ODD in the new ICD. Hence although human difference may be a constant (Scheer and Groce 1988), the newly configured medical label DMDD illustrates that it is the knowing of such label that defines its meaning, or indeed rejects its meaning. Indeed it may be said that the dynamics that are evident in relation to both ADHD and DMDD illustrate in working practice Scheer and Groce’s (1988) claim that the persistence of disability in society has acted as stimuli for the emergence of ‘traditional bodies of knowledge ... to accommodate the presence of disabled members’ (pp 26). Not

least because there is a growing determination to define medically 'challenging' behaviours (Cross 2011).

Of note in relation to the increasing medicalisation of behaviour, is the continued practice of spectacle, shame and stigma, albeit in a contemporary fashion, levelled through accordances of selective accountability (Parsons 2005, Perlin 2000; 2008; Jull 2008, Boyd 2012, Lockwood 2012, Caslin 2014, Jimenez 2015). The scope of challenge is frequently expressed through popular media (Briant, Watson and Philo 2011), reflecting economic and political issues (Garthwaite 2011, Heeney 2015, Roulstone 2015). Banner headlines in popular newspapers illustrate latter day shaming and operate to not only challenge the integrity of both parents and disabled children, but also to position them as blameworthy, through a subtext that intimates, burden, financial exploitation and blame.

Such commentary also disseminates a form of knowing, which although colloquial in nature has real ramifications and serves to position parents and disabled children negatively. It also denies the reality and responsibilities of disability difference, not least the financial and emotional disadvantages that are known to accrue (Carpenter 1999, Jackson 2004, Carpenter and Austin 2007, Kingston 2007, Rogers 2007; 2011; 2012, 2013; Carpenter and Emerald 2009, Gallagher 2010b, Gill, & Liamputtong 2011). It is also paradoxical that much popular news coverage embellishes the financial benefits of a disability diagnosis, when current and historic statistics show families who have a disabled family member suffer greater financial hardship than those without (PT 2012; 2014; 2016). The following two examples offer illustration. 'Parent of a child with ADHD? Have a free car under a £1.5bn taxpayer-funded scheme' (Walker 2011) and 'Unscrupulous parents seek ADHD diagnosis for benefits' (Goldberg 2011). Both comments hold implication of deliberate abuse of a system that is designed to support disabled children and their families and the tone of such commentary reinforces a division of deserving and undeserving claimants. Equally such commentary echoes historic responses to disability (Stiker 1997, Armstrong 2003, Foucault 2006), reinforcing not only accountability but unequal position and opportunity.

2.2.7 Identification of difference as an aid to resource allocation in schools

The act of knowing is found to be heavily implicated in issues of economics and social fairness, as such, found to be value laden and politically motivated. Hacking

(2007) suggests the sorting of persons is intrinsic to societal organisation and places emphasis on the functions of sorting, as much as the premises upon which sorting occurs (Bauman 2004). Borsay (2005) and Florian (2008a) emphasise that formal disability identification is central to the distribution of resources, generating a dependency which serves to legitimate intrusive evaluations of private and familial life (Laing 2001). The medical profession emerge as custodians of bodily and psychological truths, not least through their alignment with wider support agencies, who are entrusted with the responsibility of metering public resources. Fulcher (2015) defines policy as the struggle of competing objectives (pp7) and this is considered a useful visualisation to describe the relationship dynamics between the home, school, medical profession and government.

Disability may therefore be determined 'knowable' through the detailed knowledge held by the medical profession. Knowledge which claims scientific objectivity. Such claims have however been challenged, most notably by the anti-psychiatry movement (Foucault 1967, Szasz 1974; 198; 1988; 2012, Laing 1985, Rissmiller 2006), as well as through critiques of professional monopoly and assertions of professional manipulation (Freidson 1970, Kutchins 1999, Rose 2006, Bursztytyn 2011). It is relevant therefore that disability identification is also found to be responsive to financial and political imperatives, which of themselves negate claims to objectivity (Stone 1984, Erevelles 2000, Roulstone 2015).

Schools are cited to be a crucial agents of sorting (Hacking 2007), operating in alignment with wider legitimating discourses (Nunakoosing 2012) which underpin the rationalisation for such sorting (Tremain 2005). Sorting can also be alternatively viewed as the means schools employ to perpetuate inequalities and privilege (Bourdieu 1977). Indeed schools are stated to be 'located at the heart of the social division of labour, that marks distinctions between mental and manual labour' (Erevelles 2000, pp 45). Schools through their educative role are also key to the channelling of abilities. The notion of ability is however problematic, based upon the assumption of a fixed measure of ability (Hehir 2002; 2005, Campbell 2009, Goodley 2014). School practices Erevelles suggests are founded upon the configuration and employment of a prescribed curriculum, which itself manipulates and moulds not only the norm, but also modes of conduct and being (Nunakoosing 2012). Such view supports the contention that learning and behavioural differences are socially

constructed and collectively affirmed, thus challenging medical claims of default (normal) physiology and psychology.

Nunokoosing expands on this position and observes how 'power and knowledge produces the rationale for interventions into peoples lives and defines how we are to relate to them and how we should act on their conduct' (pp, 202). Schools emerge therefore as holders of power through their claims to and control of knowledge. Such knowledge is not however purely academic, schools also are entrusted to make claims about pupils psychological status, claims which are increasingly rationalised within a medicalised and psychological frame and illustrative of what Foucault (1997b) refers to as biopolitics.

Tremain (2005) cautions that 'practices of division, classification and ordering around a norm have become the primary means by which to individualise people, who come to be understood scientifically, and who even come to understand themselves in this way' (pp, 6). This is an important point, one which may explain why there is limited resistance to the medical and social labels so readily applied both in school and the community. Notably surveillance in the educational domain, is enacted through referral practices which illustrates the interconnectedness of professions within a single paradigm. It is also considered to offer the impression of objectivity to parents and their children, which Nunokoosing (2012) states to be central to an acceptance and internalisation of the labels accorded following observation.

Although sorting practices operate in education under the guise of (educational need), they are heavily implicated with the allocation of resources and conferment of educative rights (Florian 2008a). Notably educational needs which exceed the norm are rationed through the now obsolete statement of special educational needs and more recently the Education and Health Care Plan (EHC) (Galloway 2013). The distribution of resources demands evaluation around entitlement, and although found to be both an historic and contemporary constant is also found to be inconsistent in its constitution (Stone 1984, Barnes 1991b, Borsay 2005, Roulstone 2015).

The metering of resources is stated to be a prime cause of disability inequality, as entitlement is counterbalanced by the presenting disabilities impact on the majority (Roulstone 2000, 2015, Garthwaite 2011), which serves to negate disability protections (Jull 2008, O'Connell 2016). Hirschman's (2016) observation of disability disadvantage in the United States, is found to be internationally relevant. 'In a country that claims to provide among the strongest disability rights in the world, we

find a reality that disabled persons are still often treated as second-class citizens, perhaps even second-class humans, to whom the state may make charitable concessions, but who are not properly the subject of true human rights' (pp. 43-44). Such contention signifies that differences which are identified as disability confers onto those identified, a status which is less than. Notably however, Hirschman does not adjust these contentions to reflect either the stratifications within disability, or the other social variables which may lend to or mitigate against such negativity. Hirschman thus presents a deterministic view, which is distortive and denying of personal (Blackmore 2012) and indeed familial agency (McLaughlin 2011).

Stone (1984) proclaimed that 'the concept of disability is fundamentally the result of political conflict about distributive criteria and the appropriate recipients of social aid'. (pp 1). Such position whilst overtly disregarding of the embodied reality of disability (Shakespeare 2006; 2014, Ramanathan 2010), implicates that 'medical certification of disability' to be 'one of the major paths to public aid in the modern welfare state' (pp3). Nevertheless shifting disability entitlements, responsive to economic exigencies reveals how wider tensions mediate not only who is identified as disabled (Read 2005) but entitlement to resources (Garthwaite 2011, Roulstone 2015). It also highlights how disability status is negotiated, rather than simply diagnosed (Munyi 2012). Indeed it may be said that negotiations around entitlements, mark the juncture at which personal struggles, whether physical or psychological, are delivered into the public domain for scrutiny toward accordances of a formal disability status (Winance 2007).

The processes through which difference comes to be known as disability have been described by Winance (2007) as transactional. Drawing upon the work of Goffman, Winance suggests that the miniatures of social engagement reveal both subtly and explicitly, distance from predefined social norms. Such distance holds potential to be received positively or negatively, and in the case of the latter, leads to a conclusion of 'negative difference' (pp 628). Such negativity, although contemporarily rationalised in medical terms, has been historically is found to have been differently attributed at different points in history, aligned to the dominant belief systems of the time (Stiker 1997, Armstrong 2003, Munyi 2012). Historic rationalisations of disability (Atkinson 1997, Stiker 1997) are also found legitimated through a language of deficit, operating to delineate various permeations of difference, which are productive of deficit identities (Foucault 1967, 1973, Armstrong 2003, Borsay 2005).

It may be suggested therefore that the common classificatory systems operational at any given time are definitional toward what constitutes 'disability' and align with the dominant knowledge systems operative. A transactional visualisation demonstrates how human difference can never be uncontentious, because it is always referenced against those who claim the rights to truth (Foucault 1972; 1980), hence it is simultaneously private and personal. Thus 'difference' in an era punctuated by human rights and restraints (Munyi 2012) confers simultaneous access to social, medical and legal protection, a shift in climate and it results in a sharp denial of such rights for some (Heeney 2015).

The processes through which entitlements are accorded or denied may be seen to be complex and aligned to wider structural imperatives. Nevertheless Winance's reference to 'negative difference' resonates with Rogers (2013) identification of 'difficult difference' (pp 132) and suggests that indeed the marking of 'difficult difference' and the negation of rights, may hold economic functions when social resources are limited, but a climate of social equity prevents overt discriminations.

Hirschman's (2016) asserts the perpetuation of disability inequalities is fostered through undue emphasis on social rights, which in constitution are fluid and determined on the basis of political will, dominant knowledge systems and social sentiment. As such are found by Hirschman to be vulnerable to shifts in political direction, yet diminished through the wider priority accorded to utilitarian principles, not least the sustainment of the status quo. Certainly governmental initiative to reduce the economic deficit, by amongst other cuts, lowering the welfare bill can be seen to have generated a deserving and undeserving divide (Garthwaite 2011, Heeney 2015, Roulstone 2015). Against this Hirschmann (2016) argues for equality to be founded in first instance on the notion of personal freedom, permitting concepts of justice and rights to be metered through consideration of their impact on such freedoms. It can be no coincidence that the post war economic boom years witnessed an expansion of social supports, whilst the latter period, punctuated by the global economic crisis has overseen the receding of such entitlements.

Considerations of deserving and intent are found to hold an historic consistency, as Stiker (1997) acknowledges, citing association of uncleanness and sin to have been heavily implicated in explanations of difference when religion was a main marker of what it meant to be human. Although medical logic now channels such identification,

evaluations of entitlement are still apparent, particularly in education as the secondary data introduced in Chapter one indicates (pp 11-13).

In contrast, Heeney (2015) suggests accountabilities for social dependencies are more complex, determined upon former social position and cultural affinity, resonating with the notion of Social Capital as developed by Bourdieu (1986). It is notable that similar assertions are levelled toward the attributions made of a child's difference in education (Croll 2002, Florian 2006, Dyson 2008, Begeer 2009, Gould 2011, Heilker 2012, Miller 2014), which suggests that the appearance and sense made of difference may be mediated through congruence or incongruences between the individual and the wider social domains that individual intersects with. Hughes (2015) defines this process as 'cultural insularity', a term which is similar in its premises to Barr's (2015) ITTP. Irrespective of the means of sorting, the results are stratifications based on perceived deficit alongside selective accountability for such deficit.

Discourses of entitlement are also disseminated through contemporary media (Keith 2001, Dale 2006, ADHD.org.nz 2011b, Fernie-Clarke 2011) and social media, which acts to rationalise identities of deserving or undeserving as right and proper (Draaisma 2009, Institute 2010, Sarrett 2011, DisabilityPlanet.co.uk 2015). Such dissemination offers explanation for why some medical labels attract fascination (Murray 2006, 2008, Schreibman 2007, Sarrett 2011) and others condemnation (Schmitz 2003, Bailey 2010). Consequently although disability as a state of being holds most recently status as a medical/psychological anomaly, placing it outside of issues of accountability; political and social discourses introduce accountability through the sentiment of merit. This is a classic illustration of social positioning (Harre 1999) and resonates with Foucault's (1977) claim that the exercise of power inevitably results in the delineation of subject positions, which by definition are unequal. One could thus argue that the underpinning drivers of difference are harnessed not to guide distribution of resources, but to effect rationalisation for its denial (Stone 1984, Roulstone 2016).

Conspicuously the expansion of medical labels in respect of behavioural and psychological difference, may also be viewed as an attempt to create order, where the need for order is compromised. Nevertheless where random and unpredictable conduct continues and does not respond to voluntary medical or social constraints, the compromise to the appearance of social order serves to substantiate involuntary

restrictions, as embodied within both the Mental Health Act 2007 (Parliament 2007) and schools retention of the right to exclude.

2.2.8 Reflections – disability is in the eye of the beholder

So how can disability be accurately known, when medical ‘knowing’ is contentious and found linked to abuses of power (Foucault 1973; 1997, Rose 1999, Ronson 2011, Lupton 2012, Heath 2013? Bognar (2016), echoes Barnes (2014) and adopts what may be described as an embodied stance, asserting that disability is different in constitution and incomparable with other forms of difference, not least due to the moral imperatives the state of disability conjures. For example Bognar suggests it to be unthinkable to aspire to disability or to cause disability, in the same manner one might covert the emulation of other forms of difference. Disability according to Bognar has real physical and psychological implications, which need highlighting as the continued disadvantages felt by disabled persons extends on some levels to the shortcomings of positive accommodations, which never fully compensate for the physical or psychological manifestations of disability.

Bognar’s latter assertion resonates with the situation faced in education by pupils with disabilities and identified SEN. Particularly as Beardon (2008) found that for some pupils, accommodations in school led to stigma and social visibility, as such was found to inhibit willingness to accept support in higher and further education. Indeed for pupils posing behavioural difficulties, there appears to be no accommodations available to redress individual disadvantage, rather response is directed to protect others (Parsons 2005, O’Regan 2009, 2010). Thus whilst there has been a sustained campaign for schools and clinicians to address the cause of behavioural disorders (Hardwood 2006, Greene 2008b, Cross 2011), which has been partially realised though the directives of the new SEN code of practice (DfE 2015a), there is little evidence of a move away from responses based on segregation. As Jull (2008) states; ‘surely it is time to re-evaluate the repertoire of responses considered appropriate in the provision for this unique group of SEN students (pupils posing behavioural issues) because an increased risk for punitive disciplinary action is not what I might describe as an inclusive approach to SEN practices’ (pp 14). Indeed the policy of inclusion not only continues to fail ‘challenging pupils, it appears to circumvent them, not least as the practical manifestations of their disabilities erect barriers to full educational participation (AA 2011, OCC 2013, DfE 2014).

As full participation is resisted on the grounds of management difficulty, this serves to place responsibility directly back to the individual rather than into the collective domain in the form of accommodations. Such action also intimates there to be a distance between disability diagnosis and symptomatic effect, opening spaces within which blameworthiness is logically congruent. Problematically behavioural effects are often symptomatically ambiguous and amenable to alternative rationalizations, yet even where disability is recognised, lack of progress or an unwillingness to concede to 'expert' advice can be interpreted negatively, not least as an inability to seize the equality opportunities offered (Jull 2008, Caslin 2014).

The defining of discrete medical labels ('knowing') extends not only from within the medical profession, it is also disseminated through popular media, which may be seen to lead to distorted impressions. Stereotypical representations not only emphasise the heterogeneity of disability presentations, they also embellish attributes and negatives, conjuring impressions and expectations that exceed the bounds of personal experience (Symonds 2006, Draaisma 2009, Sarrett 2011, Runswick–Cole 2016). Runswick–Cole refers to this as the stories which filter all other knowing, a superimposition that serves to deny all the other aspects of being and of potential. Stereo-typical representations are also found to reflect indirectly both social stratifications and contemporary controversies (Barnes 1992, Stiker 1997, Garland–Thompson, 2001, Kanter 2015, BFI 2010, Disability Planet 2015). The British film Institute (BFI) list ten common stereotypes of disability which in itself implicates a longevity of form, but it is also notable that they rely upon emotive referents to illustrate their guise, most typically invoking of pity, fear, tragedy and assertions of heroism. These referents equally effect a distance between the popular impression of childhood disability and its actual reality. This delivers a double blow to families whose children are neither 'typical', not stereotypically 'disabled', and in the case of children who are challenging, the realities of these childhoods remain shrouded (Carpenter and Emerald (2009).

It may be no coincidence that children portrayed in charity fundraising events evoke notions of pity, tragedy and occasionally heroism, but rarely fear. Whereas disability presentations depicting challenge and violence are rarely presented as a worthy cause, or indeed aligned with disability. Of those that are, their implications are often neutralised through comic depictions (Schmitz 2003, Google 2012). It is also telling that Deal (2003) notes evidence of stratification and alignments within the umbrella

population of persons defined as disabled and that these factions are found to be based around access to resources, disability identities and the fear of stigma.

Although disability conjures up notions of vulnerability, contemporary literature suggests there to be a 'dark' side to disability, which remains a social taboo and absent from social representation (Vargas 2013, Anonymous 2014, Berg-Dallara 2014). This is similar in nature to what Carpenter and Emerald (2009) describe as being on the margins. Looking specifically at the experience of mothering, the authors find not only are the mothers of children with ASD and ADHD unable to identify with the maternal scripts of typical children, they are similarly absent from the contemporary scripts of mothering disabled children.

Giroux (2009) and Werner (2015) suggest perceptions of disability and difference are highly responsive to wider social variables and well as perceptions of threat. Thus the accuracy of representation conjures dilemmas: as openly negative depictions could serve to undermine sentimental or whimsical notions of disabled embodiment, further marginalising the disabled population from the main populous. Representations which invoke sentimental associations are most obvious in relation to autism (Murray 2006, 2008), yet are found equally problematic. Most typically because they are generative of unrealistic expectations of autistic presence which is rarely congruent with its reality, as such generates unrealistic expectations which open spaces for disability challenges to emerge when those expectations are not met (Sinclair 2005).

The significance and complication of representational presence and absence is emphasised by Berube (2006) who states that 'the cultural representation of disability affects us all ...it affects public policy, the allocation of social resources, and the meaning of civil rights' (in Symonds 2006, pp. 157). In essence, representation serves to delineate entitlement and non-entitlement. Equally social representations of disability are held to be 'constitutive' of particular relationships (Matthews 2008, pp.1) as such popular media is depicted as a 'vehicle for the articulation of a set of desired social relations' (Fernie-Clarke 2011 pp, 1), exacting the means for persons outside of disability to form impression of both medical labels and the 'types' of persons typical of that label.

To conclude the expansion of disability classifications has been associated with an expansion of aligned professionals, leading to a claim that such expansion represents a profession ploy to generate and satisfy a demand (Grant 2010).

Nevertheless in working practice it's de jure authority is questioned; as the identification of disability has been stated to emerge from the interface of various professional bodies (Rose 2006). Nevertheless questions are found to remain in relation to the objectivity of identification (Caplan and Cosgrove 2004), particularly as accordances for difference appear responsive to wider social factors (Rapp 2012, Ribbens-McCarthy, Hooper and Giles 2013, Wasik 2015).

The integrity of the psychiatric profession has been questioned, both historically (Foucault 1967, Szasz 1974; 1988; 2007; 2012; Laing 1985, Szasz 1987, Rissmiller 2006) and more recently through concerns toward the management and medicalisation of childhood difference (Efron 2015, Mayes 2015, Dunlop and Newman 2016). Notably Sherman (2015) defines medicalisation as 'a process through which social problems and behavioural issues are addressed as symptoms of a medical disorder and "treated" with chemical substances on the basis of a diagnosis. As a result this has heightened concerns around interests served and ethic considered. There is a growing concern that there is an over and unnecessary medication of children, legitimated through the interpretation of school difficulties as a medical issue. This has prompted Busfield (2006) to call for a sociological approach toward an analysis of the role of the pharmaceutical industry. Indeed Bushfield has cautioned that 'in alliance with medicine, the industry is shaping the ways in which society responds to a very broad range of problems' (pp 310). To which one might add it shapes also the way schools receive and respond to difference.

2. 3 Subsection 2: Challenging behaviours

Challenging behaviours command a dual identity, extending between actions that are considered indigenous to the individual, be it though innate disposition or disability, and action that is seen as reactive to familial or social circumstance. The absence of definitive organic markers to differentiate have given rise to a lottery of identification for the children implicated and one suggests that this is a prime site of disadvantage. In education, just as in wider society, formal accordances of disability are determined medically and supported through the notion of reasonable adjustments (Parliament 2010). Special educational needs (SEN) often form part of those adjustments, but it is not axiomatic. In contrast without a formal diagnosis, challenging behaviour may be viewed as evidence of an SEN, but attract explanations outside of the medical domain. Such explanations are complex, informed not only by personal factors, but also social and cultural factors which may or may not intimate disability. Notably

explanations outside of a formal disability diagnosis do not confer equality protection, yet it is found when conduct is an issue, response and entitlements are also informed by concepts of risk and dangerousness (Dullum 2015, Pfeiffer (2015)).

2.3.1 Mixed identities

In common with identifications of disability, determinations made toward challenging behaviour are also informed by wider considerations of culture congruence, political and economic priorities and tensions and finally individual subjectivities (Waterhouse 2004, Bailey 2010, Heeney 2015, McGregor 2015). The interaction of these considerations impact on not only response, but the 'knowing' of the child, which is reflected through the profile the pupil develops and retains. For some this profile results in marginalisation, an effect which is also moderated by wider social factors, not least familial status and the policies of the host school the child attends (Hastings 2003, Graham 2007b, 2008, Adams 2008, Bailey 2010). McLaughlin (2016) summarises these processes (reproduced below), finding them multifaceted and denying of any direct discriminatory intent:

'The exclusionary practices of either children or adults do not necessarily always emerge 'from conscious attempts to exclude and marginalise those who are different. They develop from wider pressures on schools (not least from the pressure on schools to excel academically), from the incorporation of dominant norms from wider society, from the long history of the segregation of those identified as different into 'other' spaces, and from the power of standards of normality in shaping the politics of everyday interaction and recognition across society' (pp 58).

Although current NICE guidelines (2015) appear to take a balanced stance, stating that 'behaviour which challenges is not a diagnosis', rather is to be viewed as 'resultant from the interaction between personal and environmental factors' (pp. 4). Nevertheless the social contexts from which 'challenging' emerges incur moral evaluations (Heeney 2015, Horton-Salway and Davies 2015) which permits accountability. Notably the new SEN code of practice (2015) removes behaviour as a standalone category and demands it be considered symptomatic. This directs schools in the first instance to consider the drivers of behaviour, rather than their impact. The link between disability and behaviour is clearly stated in the code; "learning difficulties and disabilities occur across the range of cognitive ability and left unattended may manifest itself as disaffection, emotional or behavioural difficulties" (DfE 2015, para 6.23, pp 96). Although this acknowledgement is welcomed, it follows, rather than leads the opinions of notable charities. For example CEREBRA

(2013) cautions that behavioural problems are commonly prevalent amongst persons with developmental disabilities, as does BIBIC (2005; 2007).

Challenging behaviours are by definition predominantly social acts as they contravene the norms of conduct. Irrespective of causal attributions (be this disability or intent) this triggers an inevitable relationship between the public and private domains. Disability is described by Holt (2016) as 'the property of both dynamic material bodies and broader socio-spatial processes' (pp 146). This is considered a particularly useful description of the processes set in motion by 'challenging' behaviours. Particularly as they are most typically identified publically in the school and community contexts. Stress is placed on the word publically, as behavioural challenges which present in the context of school are frequently depicted as a pedagogical problem (O'Regan 2009, OFSTED 2012, Neill 2013, NFER 2013), attracting of longitudinal professional attention (Miller 1995, Jones 2003b, MacLeod 2006, Haydn 2007, Grieve 2009, DfE 2012d, Gibbs 2012, Garner 2013).

Such emphasis serves to distort the guise of challenging behaviours, rendering their appearance only visible in respect of school conduct expectations (Graham 2007 a; b; 2008). Without denigrating the difficulties faced in education by challenging behaviours, undue attention to the problems faced in the school arena holds potential to diminish the guise of challenging in the family domain (Parker et al 2016, Vassallo 2016), acting to reinforce the impression that such challenges can and should be managed within the family, frequently by mothers as part of the unstated expectations of motherhood (Maushart 2000, Kingston 2007, Runswick – Cole 2013).

To the contrary the extremes of challenging behaviour are found to have a significant impact on all family members as Dunignan (2015) observed. 'The dominating effect of all but the mildest behaviours, resulted in a loss of choices for other family members which ranged from minor to massive restrictions, sometimes with long term effects on family relationships' (pp 209). Dunignan also found that the sanctuary typically found in the family home was physically and emotionally negatively impacted on. Dunignan's research offers a useful perspective as it focuses upon the minutiae of family relationships and contrasts them against the taken for granted expectations of home life. Dunignan illustrates the practical impact on the family, structural changes such as locked doors, lack of sleep and social isolation, contrasting markedly with the notion of the feckless parent unable to control a child. The social assumptions of parenting, particularly motherhood, acts nevertheless as a

disincentive to public disclosures of the parenting difficulties faced, effecting a silence and invisibility that compounds disadvantages faced (Emerald and Carpenter 2009, Parker et al 2016, Vassallo 2016).

'The absence of people diagnosed with EBD in critical disability studies both reflects and reinforces their marginalised position in a variety of forums' (Holt 2016, pp 148). Holt draws attention to the socio-spatial processes that can serve to disable persons with EBD and calls for their inclusion within the discipline of critical disability studies, despite often holding no formal diagnosis. This call extends a powerful statement disavowing the primacy of medical knowing and medical definition to that of impact. Holt's calls are timely as differentiating between challenging behaviour which is driven by a disability and that which is not is complicated, particularly as negative attitudes can distort judgements made (Sahu and Sahu 2015).

It is notable that despite the persistence of discourses of deficit, personal agency is also evident, denying the idea of absolute subjection. Most notably positive identities are found to emerge in response to negative and restrictive practices, in parallel with medical and social interest in neurological imagery (Rapp 2011). This has given rise to what has been termed the neuro-diversity movement, which holds as its philosophy the disavowal of discourses of deficit, alongside the reframing of atypicality as normal human variance (Sinclair 2005, Wrongplanet.net 2012, Parsloe 2015). These emergent positive identities differ markedly from earlier fictional portrayals of disability (Murray 2006, 2008) which framed its subjects outside of the mainstay of humanity. The increasing alignment of presentations of neurodiversity supports the contention that there is an increasing resistance to 'normalisation' strategies (Boundy 2008), predicated upon human right and minority status (Sinclair 2005).

The increasing acceptance of neurological difference (Robertson and Ne'eman 2008), also supports Holt's (2012) finding that processes of normalisation, rather than being constraining, are themselves acted upon by presentations outside of that norm. Holt's research focused upon pupils attending a mainstream school unit for pupils with ASDs, found that the fostering of a collective identity within the unit acted 'as a launch pad for contesting and transforming norms of appropriate behaviour within the school and potentially beyond' (pp5). As such has led Holt to conclude that as 'normalisation is always a practice of improvisation within a scene of constraint' there is 'an inherent possibility of reworking norms' (pp5), supporting supported conclusion

that processes of normalisation were 'a positive, generative and unstable form of power, which emerges through everyday socio-spatially shifting practices' (pp5). Amidst these pockets of acceptance there is also evidence of unacceptance, namely disabilities which give rise to anti-social behaviours, for which, irrespective of the notion of disability as a protected characteristic, persons remain accountable. As such I liken it to be the last taboo of disability, recognised medically yet shunned socially and legally.

2.3.2 When is behaviour disability?

The notion of behaviour being viewed as a symptomatic in parity with other physical symptoms, rather than a deliberate act of will, has conjured much controversy both in and out of the school context (Caslin 2014, Jimenez 2015, Karpin and O'Connell 2015, O'Connell 2016). Contemporary association of 'behaviour' with disability also challenges many of the stereotypes of disability that underpin the identity of disability as state of vulnerability (BFI 2010).

The combination of youth and 'challenging behaviour' conjures perceptions of threat which is met with both suspicion and defensive response (Giroux 2009, 2011). It is notable that this does not appear to be assuaged by the expansion of medical labels to explain behaviour. To the contrary the migratory implications in terms of personal and familial accountability are unclear. O'Connell (2016) details these tensions below and in doing so points to the crux of the issue of accountability. Namely what can, and should, be done in response to unacceptable behaviours that are problematic to others and to the individual concerned:

'The badly behaved child highlights some of the tensions underpinning law as it integrates an emerging brain-based subject. Such a child already confounds the vulnerability/aggression divide that separates discrimination law and criminal law, showing each to be uncomfortably intertwined' (O'Connell 2016, pp 22).

The implications of 'challenging' behaviour being representative of disability are complex and as the above quotation suggests embedded within wider legal discourses. Such expansion nevertheless signifies explanation for behaviours that may otherwise be seen to defy reason, bringing with it a sense of relief for many families. Indeed recognisability is stated to be a distinguishing feature of any new syndrome as Newsom (1989) attributed with the discovery of pathological demand avoidance syndrome (PDA) states. 'The most useful test of whether a syndrome is distinguishable from other syndromes is whether the children described in these terms make better sense to both parents and teachers as a result' (pp 23).

The association of behaviour with disability does not appear to extend a free pass, rather is found to trigger harsher processes of regulation, including involuntary open ended incarceration under mental health legislation (Parliament 2007) as well as being deemed unsuited to rehabilitative programmes (NACRO 2011, Talbot 2011, Hughes 2012, Trust 2012, Pfeiffer 2015). Notably blaming and shaming persons identified as disabled is not a new phenomenon (Armstrong 2003, Nussbaum 2004, Foucault 1967, 2006), rather is found to reflect the level of threat perceived. The need for social order is emphasised by Foucault (1967) as are the uncertainties which inexplicable difference conjures. 'Madness and the madman became major figures in their ambiguity, menace and mockery, the dizzying unreason of the world' (1967, pp 13).

The implication that persons exhibiting 'challenging' behaviours are 'neurologically different' has acted to justify both segregation and harsh control, founded upon the idea that identified persons are not able to respond to therapeutic intervention (Darwin 1871, Hansen 2001, Rose 2007b). The search for neurological explanations remains a contemporary research endeavour (Blatt 2011, Cukier 2011, Sohrabi 2015) and although not openly premised upon a deterministic mind-set, ethical issues remain, not least when identification is linked to prevention (Walsh et al 2011).

Notably claims to truth within the fields of psychiatry and psychology present as both fluid and subject to regular revision as discussed in the previous section. This is particularly significant in respect of children, who Philo (2010) cautions are vulnerable to psychiatric intervention, which although informed through knowledge shifts becomes definitional of their emergent being. As subsection two has discussed there is also an undercurrent of suspicion in relation to the alliances these knowledge shifts forge (Slee 2013), particularly in respect of the working relationship fostered between the psychiatry profession and the pharmaceutical industry (Read 2005, Mayes 2015b). As Bushfield (2006) impresses, 'pharmaceutical producers use their ideological, economic and political power to play on the anxieties and discontents of life in late modern society creating a market for their products that extends well beyond obvious health needs' (pp 310). Olsen (2004) on the other hand suggests that schools operate as a microscope of conduction embodying panoptical processes Foucault (1977a) identified as inherent to the subjectivism of a mass population. As similarly discussed in relation to the functions served by psychiatric profession

Olsen's contention intimates the nexus of professional medical/pedagogical relationships to be judgemental rather than educative (pp 304).

Unlike their historical counterparts; contemporary responses to neurological difference (including negative depiction and overt shaming practices), are rationalised within a dominant framework of human rights (ECHR 1950, UN 2007), equality legislation (Parliament 1995, Parliament 2010, Parliament 2015) and educational inclusion (Warnock 1978, UNESCO 1990, 1994a, Parliament 2001). The protections implied by these legislative frames, should by their own logic inhibit accountability, particularly where behavioural conduct extends from a disability and is classed medically as a bone fide symptom. However as is discussed within this chapter, challenging behaviours emerge as the only disability marker which is denied accommodation on the basis of symptomatic impact. As a consequence the duty to make 'reasonable adjustments' in both society and school is superseded, through both the logic of criminal law and school sanction protocols.

Armstrong (2003) details three avenues of discourse pertaining to disability, which holds implications for how challenging behaviours are understood and which have impacted on education policy and one might add, social and criminal policy. Firstly the logic of exclusion and segregation (emergent from the Eugenics movement), but which can be seen to endure in both contemporary school systems and the wider society. Secondly the standard of 'normalisation' (which has been foundational to the configuration of modern education) and finally Inclusion which is itself linked to wider social justice legislation), but which has failed to address educational inequalities. The discursive interplay of these three discrete but inter-related fields of discourse are suggested to have had a formative impact on contemporary disability experience in education and society.

Medical explanations for challenging behaviours not only act as labels of forgiveness (Slee 1995, Lloyd and Norris 1999, Riddell 2007), explaining conduct which exceeds the normative referents underpinning the boundaries of acceptable conduct. They also boast ability to offer explanation for groups of behaviours that show presentational similarities, which are then delineated as a discrete medical label or syndrome (Barkley 1997, 2002, 2006, 2008, 2012, Newsom 2003, O'Nion's 2013). Nevertheless despite a lack of definitive organic markers, their alignment to the field of medicine has resulted in their formal accreditation as indication of disability, founding entitlement to disability rights, not only in school but in society generally.

It is significant that disability entitlements are found qualified within the Equality Act when conduct involves physical or sexual infraction (HL 2016). Regulation 4(1) of the 2010 Act states that ‘a tendency to physical or sexual abuse is not to be treated as an impairment for the purposes of the definition of disability. The implication of such qualification is to deny common rights to a select population of persons whose disabilities render them vulnerable to conduct infractions. For example BIBIC (2007) have linked ‘anti-social behaviour with neurological disabilities, finding at the point of survey that 30% of anti-social behaviour orders involved children and teenagers with mental health or learning disorders. Equally the National Autistic Society (NAS) argue that the law’s definition of anti-social behaviour as ‘behaviour that causes or is likely to cause harassment, alarm or distress’ could describe the ordinary actions of many autistic people’ (ibid, pp 11).

O’Connell asks ‘how will law respond to the child or youth at a time when biological explanations are infiltrating and sometimes overtaking traditional moral and social understandings of behaviour’ (pp 1)? This is a question Stone (1984) posed many years previously, suggesting that as the connection between organic changes and behaviour or mental capacity becomes clearer, there will be even more pressure on courts to expand the use of medically certified disability as a defence (pp 6). Over thirty years later the impact on concepts of justice are still debatable. Nevertheless it is now suggested that ‘the ‘badly behaved” child is no longer thought of—or not only thought of —as deficient in discipline or character, but as neurologically disordered’(O’Connell, pp2).

Paradoxically, the lobby to associate ‘challenging behaviour’ with disability is found to compound inequalities by triggering regulative sanctions and treatments (O’Connell) 2016). Indeed Allen (2011) suggests interventionist responses to neurological explanations for disability are seeping into governmental policy raising ethical questions around patient responsibilities and potential for abuse from involuntary remediation. Particular concern is expressed toward abuses of the Mental Health Act (Lockwood 2012) and the continuing policy of involuntary incarceration of persons who are considered a threat to self or others (sections 2, 3 and 5, Parliament 2007). O’Connell (2016) suggests popular conceptualisations of the nature of neurological disorder have impacted on the character of responses deemed to be in the social interest. O’Connell cites two neurological models which have had a specific effect, the first a structural deterministic model, posits deficits to be systemic and

irreversible, rendering therapeutic inputs redundant, secondly a flexible model which views the brain as holding an inherent plasticity (flexibility), as such is neurologically responsive to rehabilitation with appropriate medical intervention (Fein 2011).

These models have serious implications in relation to sanctions and controls imposed in response to actual or perceived dangerousness (Read 2005, Rose 2007b, Jimenez 2015, O'Connell 2016). Hence where conduct is an issue, disposition in law, is still to incarcerate, either through the legal code, or where capacity to plea is questioned, under the powers conferred through the Mental Health Act 2007 (Loucks 2007, Bishop 2008, Hughes 2012, Trust 2013a).

Kudlick (2003) asserts that attitudes toward disability are 'crucial for understanding how Western cultures determine hierarchies, maintain social order and define progress' (ibid pp 765). Behavioural disability in particular is found to challenge the collective mentality through its circumvention of the social consensus, which acts to inhibit more general protective responses to disability. As a consequence, Kudlick asserts that disabled people constitute a 'new other', and warrant the critical address previously accorded to race and gender. This appears particularly pertinent, given the disadvantaged status (both socially and legally) persons with a disability diagnosis known to impact on behaviour are found to hold. Such assertion is equally, if not more pertinent to persons identified with undiagnosed emotional and behavioural difficulties (Hardwood 2006, Graham 2011), as this group occupy a liminal space between 'typicality' and 'disability' and as such lack disability identity or protection (Cross 2011). It is to the logic of exclusion that this chapter now turns, seeking explanation for its continued retention, despite wider discourses of social rights and protections.

2.3.3 Causal attributions and the logic of exclusion

Concerns also surround the identification of EBD, amidst concerns of over-representation and the devaluing of discrete populations based along indices of class, race and culture (Russell 2011, McCoy 2012, Carlile 2013). Such observation makes the concept of othering additionally significant. In the mainstream school context, behavioural difficulties attract responses predicated upon a dichotomy of sanction and pastoral support. The impact of such polemic is both highly significant in relation to decisions about whether to seek wider diagnostic explanation, as well as to school propensity to suggest the familial and social context are contributory to the

challenges a young person exhibits. As Gilles (2012) notes, frequently behaviour support resides upon redress of disadvantage and 'notion that schools must correct and remedy the failings of parents and the wider community' (pp. 158). These determinations effect a powerful statement within social system that privileges medical explanations for difference.

Looking practically at the school system and the indicators of challenging, it is found that persistent disruptive behaviour [PDB] accounts for 32.8 percent of permanent exclusions and 26.3 percent of fixed period exclusions (DfE 2015b). It is stated that exclusionary sanctions are employed to dampen (and deter) incidents of disorder (Ofsted 2012), yet are found wanting by their lack of comprehensiveness. For example these statistics detail vulnerability to exclusion based on SEN status and/or an official statement/Education Health Care Plan, yet do not offer any expansion on association with disability, or internal exclusions that may have been organised prior to exclusion.

Sellgren (2014) notes that the indicators of PDB mirror many of the stated symptomatic effects of behavioural disabilities (APA 2013a). Figure 5 details teachers descriptions of PDB and it can be seen that such behaviours do not stimulate immediate association with disability, rather are highly vulnerable to subjective associations.

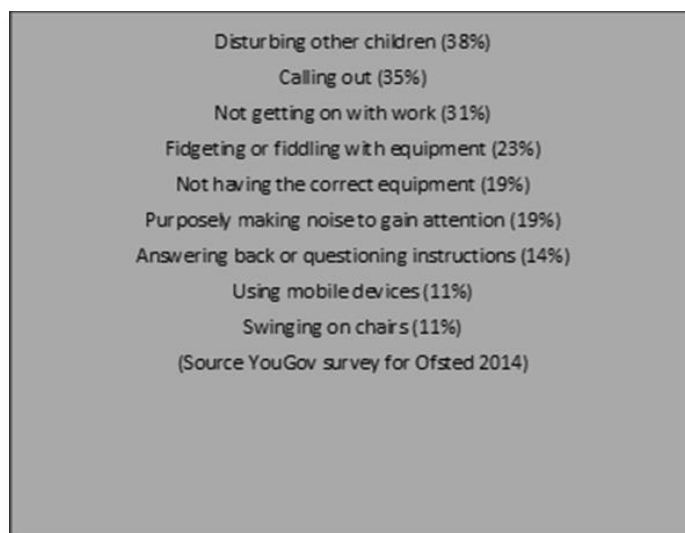


Figure 5: The indicators of PDB

The listing in figure 5 also offers insight into the typical conduct expectations of schools and it from this listing it is easy to understand why schools have been charged with being constitutive of the behavioural differences they identify and

sanction (Waterhouse 2004, Graham 2007a, 2008, Youdell 2010). Reference to DSM 5 (APA 2013a), illustrates further the contextual implications of schooling to the appearance of difference and indeed the incompatibility of schools with the difficulties particular bands of disabilities present. Such view places the onus on change onto the school system, if a strong version of inclusion is observed (Veit-Wilson 1998).

Notably DSM 5 classifies childhood cognitive disabilities under three main bands and it is apparent that each band speaks to competencies essential for successful school assimilation. Firstly neurodevelopmental disorders (including ASD and ADHD) are stated to be characterised by developmental deficits, productive of impairments that impact on personal, social, academic or occupational functioning. Secondly Disruptive, Impulse-Control, and Conduct Disorders (including Oppositional Defiance Disorder) are said to be typified as conditions 'involving problems in the self-control of emotions and behaviours, also typical skill requirements for the successful pupil. Lastly Depressive Disorders, refers to conditions which have a significant impact on a young person's emotional and regulatory functioning. This band includes a new condition called Disruptive Mood Dysregulation Disorder, which is defined behaviourally as unpredictable, but frequent episodes of rage, unrelated to context or circumstances which cause somatic and cognitive changes (APA 2013 a).

The school environment not only necessitates social and emotional competencies, it resides upon a presumption of such competencies. It is thus evident that deficits within any or all of these domains hold capacity to impede ability to follow behavioural and social protocols. Yet, as statistics attest, behavioural differences attract accountability more commonly than referral for a diagnostic assessment. Such disassociation from disability is however discouraged and indeed the DfE emphasise that a schools behaviour policy needs to acknowledge its legal duties as laid down in the Equality Act (2010). Nevertheless as Parsons (2005) and Jull (2008) observed in relation to the preceding Disability Discrimination Act, (Parliament 1995), persons with disabilities of impact on behaviour continue to endure legal disadvantage (Foster 2014).

The school context reveals restricted discourses to explain and respond to pupil conduct. In relation to cause, this consists of considerations of SEN, disability, familial/cultural environment and innate disposition. They share in common the preclusion of any institutional reflexivity to assess the role of schooling as an explanatory factor. Macleod (2006) suggests in relation to response, schools exhibit

a divided approach based on considerations of welfare and punishment. Certainly this appears a comprehensive assessment, as responses inevitably mirror attributions made toward cause. These divide between causes that attract accountability and those that warrant intervention, they converge nevertheless in regards to exclusionary sanction and it is at this point that causal explanation becomes irrelevant to the logic of exclusion. The logic of exclusion states that the young person either cannot, or will not comply. Nevertheless irrespective of determination, the practical implications remain constant, namely that educational needs (either of the individual or his/her peers) cannot be met, rendering the placement unsuitable. At this juncture the notion of accountability is academic and it is hence inevitable that exclusionary logic will unduly disadvantage young people with behavioural differences, regardless of cause.

It is suggested that the mind-set of teachers and educational leaders is pivotal to the logic of exclusion and Greene (2008b) suggests there is urgent need to consider the assumptions underpinning pedagogical practice and educational policy. Greene suggests that poor conduct indicates poor adaptive skills, rather than a deliberate drive to disrupt. Deconstructing the foundation of this assertion, Greene states that the basic premise underpinning this philosophy is that young people want to achieve, but face barriers to doing so. Within this mind-set, blame emerges as incongruent with the basic premise and demands not only address of barriers faced (which can be equally structural), to succeeding, but also a rejection of exclusionary responses.

2.3.4 Blame

The withdrawal of mainstream educational rights is implemented in education through exclusionary sanctions (DfE 2012a, 2013b, 2014a, AA 2011, 2014, HL 2016). Signalling practices which sort pupils eligible for inclusion with support from those vulnerable to what amounts to for others an exclusionary determinism (Allen 2006, Jull 2008, AA 2011, Graham 2011, CAF 2013, Carlisle 2013, OCC 2013, Caslin 2014, Gazeley 2015, Kulz 2015). In working practice this acts to delineate a body of pupils who occupy a similar position to those formally subject to the educative category in the United Kingdom of 'ineducable' (Parliament 1944). The retention of school exclusion may thus be seen as the means by which schools can legitimately renege on responsibility to include, whilst retaining the image of inclusivity. Equally there appears little institutional accountability in respect of the life time impact of exclusion and accountability. (Searle 1996, McCrystal, Percy and

Higgins 2007, Daniels and Cole 2010, Allardyce 2013, Krezmiem 2014, Bacon 2015, Kulz 2015).

It is useful to ask why blame persists and what it achieves. Parsons (2005) states that 'the placing of blame is a most important step in making decisions, managing resources, and generating policy to relate to and manage these young people' (pp188). Equally it is fair to suggest that attributions by teaching staff are bound by complex tensions, not least pupil responsibilities, accountability, institutional culture and governmental policy (Party 2010, Ofsted 2012, Hensaw 2013). These tensions by their nature intimate explanation for the employment of exclusionary responses to behavioural infractions (Arnold 2009). These tensions are found to be embedded within the rhetoric of governmental commitment to discipline (Ofsted 2012), couched as 'raising standards and restoring discipline - so our children can compete with the world's best and enjoy a better future' (Party 2010). Such drive may be seen as a disincentive to retain pupils who cannot or will not deliver results, thus deters any pedagogical or governmental commitment to disavow exclusionary responses or develop creative solutions to re-engage.

Landrum (2003) argues, 'teaching students with emotional or behavioural disorders demands unique interventions' that are beyond that typically available or necessary in general education'. As such implies that 'special education is special for pupils with emotional or behavioural disorders' (pp 148). Statistically 'behaviour problems are three to four times more common in children with developmental disabilities in comparison to those without' (CEREBRA 2013 pp 1). Such statistics cast a more sinister slant on the integrity of proposed plans involving greater powers of restraint (DfE 2010) and enforced discipline. Troublingly disabled children are known to have a greater risk of slipping out of education or training at 18. It is also known that their most common impairments are in the areas of communication, memory, learning, concentration, mobility and recognising when in danger (Trust 2013b). In common with the indices of PDB (Sellgren 2014), these impairments are also vulnerable to attributions of noncompliance and thus exclusionary sanction.

Problematically the term 'challenging' is historically ill-defined; indeed behaviour has only recently been viewed in education as a potential indicator of disability, rather than a standalone category (Parliament 2015). Notably the new SEN guidelines emphasise that challenging behaviour is common amongst persons with a learning difficulty or underlying disability, conferring responsibility onto teaching staff to

consider all possible causes. It is also interesting that the National Institute for Clinical Excellence (NICE 2011) guidelines refer to behaviour that challenges, rather than challenging behaviour.

This terminology impresses upon us that many challenging presentations are fluctuating and contextually responsive, rather than pervasive to the individual. NICE (2011) thus calls for inputting agencies to be alert to the potential causes (triggers) of challenging behaviour. NICE further advises on the supports needed for caregivers, calling for recognition of the impact challenging behaviour has in the domestic domain. It is interesting that McConnell, Savage and Breitzkreuz (2014) find coping ability has more to do with the availability of appropriate local resources, than it has to do with the innate dispositions of the family. Such finding is significant in that it necessitates move from the idea that families are blameworthy by proxy for the challenges metered through their children: to a less confrontational stance that acknowledges the family is impacted by challenging behaviour, rather than a driver of it.

Understandably it is the detail of behaviours that determine response, dividing between those that are tolerable and those that are not. Such division is most openly illustrated through reference to the barriers placed in the path of those seeking recognition for discriminations endured. Such qualification has most recently been highlighted in a House of Lords report (2016) in relation to the limitations of the Equality Act. Similar limitations are in evidence internationally as O'Connell (2016) reports in relation to the Australian legal system. O'Connell reports on the 'palpable reluctance on the part of the judges and magistrates to include a child within the protective framework of discrimination law whose behaviour includes even minor acts of aggression' (pp9). O'Connell also found the pursuit of disability discrimination claims to be inhibited due to the awarding of court costs to unsuccessful complainants. Similar disincentives are emerging in the UK. In education particularly, funding cuts to the Special Educational Needs Teaching and Support Service (SENTASS) and Independent Panel for Special Educational Advice (IPSEA) alongside amendments to the two tier tribunal system (Parliament 2011) have reduced the recourse parents have to address discrimination (HL 2016).

Review of discrimination case histories has led O'Connell (2016) to conclude that legally in respect of disability there are diverging pathways; dividing into two opposing models, disability law and criminal law. It is thus notable that the former

concedes to the dictates of the latter, whereupon ‘the inclusionary agenda of one area of law is perversely inverted in the restrictions on public life and the exclusionary agenda of the other’ (pp 10). These limitations are justified as being in the interests of the social collective and the maintenance of rules that govern social life. The following comment is illustrative, ‘discrimination law, the judges argued, could not be intended to permit criminality’ (pp 10). Thus signalling sentiment which O’Connell (2016) found rendered impotent equality legislation protections for children with behavioural disabilities. Similar sentiment is echoed in UK law, for example section 4(1) of the Equality Act establishes clearly legal qualifications to the principle of disability equity (Foster 2015).

Internationally similar limitations are evident and written into the detail of International Inclusion legislation, serving to retain segregated (special) educational provisions. For example the Salamanca Statement grounded the endorsement of segregation internationally through clauses which served to qualify inclusive rights (UNESCO 1994 pp.7, para 9). Notably however parallel qualifications were already embedded in UK educational policy, extending from the Warnock report (1978), through its enactment (Parliament 1981) and most recently as stated in the Children and Families Act (Parliament 2014).

For example, section 35bc of the afore stated Act makes reference to negative impact on peers as grounds for exclusionary action under the guise of ‘the provision of efficient education for the children with whom he or she will be educated’ and ‘the efficient use of resources’ (Parliament 2014). Thus privileging the needs of the collective as well as placing ambiguous economic constraints through the terminology ‘reasonable allocation of resources’. Indeed it may be said that it is the ambiguity of these qualifications which makes them so efficient and malleable to the changing persuasions of governments. Notably the injustice of such divergence has begun to emerge primarily within the legal profession (Perlin 2000; 2008; 2016 Jimenez 2015, Karpin and O’Connell 2015, O’Connell 2016), yet has been ineffective in generating change, typically as behaviour remains an ambiguous disability attribute unlike physical attributes (O’Connell 2016).

One might anticipate the expanding evidence base extending from neuroscience and genetic research to substantiate the validity of disabilities which impact on behaviour to further disability equity and limit accountability (Cukier 2011, Gallo and Posner 2016, Pinto 2016), however these advances are also found vulnerable to abuse.

Most particularly in respect of forced genetic engineering (Read 2005), which speaks to not only human worth but also trades accountability for a moral obligation to avoid the perpetuation of disability if it is a known genetic vulnerability. Such obligation is reminiscent of Parsons (1952) historic delineation of sick role responsibilities.

Allen's (2011) cautions further, stating that exclusive focus on neurological changes and solutions serves to deflect attention from any structural or legal underpinnings which may act to compound disadvantage. It also serves to position neurological problems as solely individual rather than social. O'Connell echoes these concerns, stating that neurological research strips the subject of 'the markers of identity that have been linked to social inequality, such as gender or race' (O'Connell 2016, pp16). As such is obscuring of the wider indicators of social disadvantage which may act as an impetus to challenge neurology's claims to neutrality and objectivity (Lewis 2009). O'Connell expands further stating:

'Where solutions are taken out of the realm of law and politics, opportunities for public scrutiny are reduced, and population-level responses are de-emphasised, meaning that individuals must have private access to health care and other services in order to remedy the effects of social inequality. The implications of this for children, particularly children with brain-based disabilities, are acute, and I would argue, are in fact creating new forms of stigma and inequality' (pp 15).

Notably a system built upon illness based explanations for challenging behaviours, necessitates the individual accept the identity of 'disabled' to gain the protection of disability discrimination law, acceptance which incurs a potentially stigmatised social identity (HL 2016, pp5). The House of Lords 2016 Report however notes neurodiversity groups are resisting the label of disability, calling for an addendum to the Equality Act, to include neurodiversity as a 10th protected characteristic. Thus forth, enabling this population to gain protection under the act, without having to prove disability. Such lobby illustrates further the shifting conceptualisation of cognitive difference.

Having found that disability status offers no mitigation against accountability for challenging behaviours, one must question whether inclusion under the term minority status would result in any real change. It appears doubtful, and one suggests that whilst medical labels might change, collective disposition to contain behaviours that compromise the norms and rules established societally are less likely to. It is thus telling that O'Connell (2016) identifies three modes of regulation pertaining to behavioural disability. Discrimination Law, criminal law and the neurological approach. In working practice only discrimination law offers to protect the individual

disability discrimination and disadvantage and as has been shown, discrimination law concedes to criminal law, whilst neurological explanations tend toward remediation or restraint. It is thus suggested that challenging behaviours trouble societies, as such are instigating of regulatory sanctions, albeit in varying guises, mirroring the meanings conferred onto both physical, emotive and psychological difference.

2.3.5 Knowing and controlling

Ironically whilst contemporary discourses grapple with the morality of issues of control and mitigation, history suggests control has been a central concern underpinning both disability identification and response. There is therefore an element of irony that identification now conjures mitigation dilemmas. Sagan suggests 'you have to know the past to understand the present' (in Zanders 2011, pp 57). So what does history contribute to our understanding of the constitution of disability and equally so challenging behaviours? In essence history indicates demarcations of disability to emerge from a combination of medical advance, socially disabling barriers and control practices. Looking at the school context as has been discussed in the previous sections, traits of these factors have been identified in the school context; and appear intertwined where behaviour is of issue. Issues of definition, recognition and injustice have also been fundamental to the formation of conceptual models of disability, most notably the Social and Medical models (Laing 1971, Oliver 1990, Shuttleworth 2004, Barnes 2005, Ramanathan 2009 Allan 2010, Ramanathan 2010, SCOPE 2011). These models at times appear arbitrary and irreconcilable, signalling a juxtaposition most clearly illustrated by reference to the anti-psychiatry movement (Foucault 1967, Szasz 1974, 1988; 2012, Laing 1985, Rissmiller 2006).

These claims although contested, pointed to deeper paradigmatic rifts within the medical profession, predicated between psychosocial and biomedical visualisations of psychological illness (Taylor 2014). They also introduced new ways of explaining psychological difference, which evolved to be definitional of how psychological disabilities were viewed (Rafalovich 2001 a; b). The fluidity of explanations present historically and contemporarily to account for difference, highlights the malleable nature of the collective consciousness, particularly as they include not only medical explanation, but also constructivist and relational explanations for stratifications of difference. Thus although medical knowledge claims infer linear progression, history challenges this, implicating wider factors, not least the role played by perceptions of

risk and deferment to the interests of the majority (Stone 1984, Lawrence 2009, Girox 2009, Eyal 2010, Werner 2015). Within the school context, reception and management of challenging behaviour reflects these differing stances and has resulted in inconsistent and at times conflicting attributions for behavioural difficulties.

One consistency is apparent; namely that identifications of difference delineate the very boundaries of what constitutes 'typical'. This observation initially emphasised by Pinchevski (2005), in relation to communication, can equally be transposed to depict the function of disability per se. It is thus suggested that it is not difference per se which is socially unsettling, rather it is the threat to the illusion of a stable state of 'normal' (Armstrong 2003). As Linton (1998) cautions, new names for old phenomenon don't indicate change, rather may simply signify guilt or compliance with wider social and political correctness. Nevertheless identifications of difference operate as divisors and historic review reveal the practices of control they conceal (Foucault 1967, 2006). In this instance too there are educational parallels, as Robinson (2011; 2015) asserts, schools not only sort they define on the basis of priorities which extended from the demands of a rapidly expanding industrial sector.

2.3.6 Legitimising accountability

The principle of social justice is engrained in contemporary society and recently consolidated under an umbrella legislation (Parliament 2010). Nevertheless the consistency of commitment to its principles across the terrain of protected qualities is variable. For example the initial formalisation of disability equity (Parliament 1995) lagged markedly behind that of sexual equality (Parliament 1975) and in addition the House of Lords suggest that the protections accorded to disabled persons are ineffective due to the diversity of disability presentations (HL 2016).

It is suggested that it is such diversity which renders some presentations of disability vulnerable to accountability. Davis (2013) challenges reference to disabled persons as a cohesive group, asserting such visualisation to be unhelpful and shrouding of the varying complexities and challenges persons with disability face. Indeed the finer distinctions of disabilities are found absent in official legislation, alluding only to umbrella protections with little recognition of the range of differing vulnerabilities and protections needed (HL 2016). This produces a grey area in respect of 'difficult difference' (Rogers 2013, pp 132), particularly where disability association is less established and may be unrecognised, serving to jeopardise the rights conferred.

Disability divergence is addressed by O'Connell (2016) who suggests that the 'expansion of biologically determined brain disorders is considered to have generated a generation of disabled persons who confound the vulnerability/aggression divide that separates discrimination law and criminal law' (pp 22). Such situatedness highlights an ongoing equation, inherent to disability response. This equation involves the determination of impact on others, against the rights conferred through equality legislation. Inevitably this impacts most acutely on persons whose disability impacts on their behaviour. It is also an equation which is highly active in schools, notably amongst pupils who present with challenging behaviours, where it is found that entitlement qualifications have been consistently enshrined legislatively (Parliament 1981, 2001, 2014, UNESCO 1994a).

Although disability accountability by the premises of the Equality Act is found to be determined on the basis of action, by the premises of its definition in working practice it remains illogical. Nevertheless amidst the current climate of individualised responsibility for personal well-being Blum (2015), accountability for behavioural issues can appear reasonable when referenced against individual actions irrespective of medical causations. I suggest that 'knowing disability' and identifying disability are dissimilar in respect of the type of knowing stimulated and that these differences hold important implications in respect of tendencies to confer accountability. In respect of identifying disability, pre-existing knowledge and attribution is found to be an integral part of the process of knowing, particularly the knowing of teachers who act in a secondary professional role in respect of disability identification, yet are directed in their identification by the immediate tensions of the teaching role alongside personal knowledges held as laypersons and partial professional knowledge as secondary professionals aligned with the medical profession. (Cook 2001; 2004, Wiley, Tankersley and Simms 2012, Klehm 2014).

The knowledges which accrue around the 'knowing' of disability are found to be fundamentally different to that implicated in identification of disability and by default the accountabilities levelled in respect of presenting behaviours. 'Knowing' disability is stated to be inevitably partial involving a close personal appreciation of the person's embodied and emotional being, by its nature this permits a separation of the individual from the symptoms of that disability (Berube 1996, Dobson 2001, Jackson 2004, Gallagher 2010b), enabling behaviours which are symptomatic to be associated with the disability, rather than the innate dispositions of the individual..

Hence although disability is a protected characteristic (Parliament 2010), the complexity of social engagement distorts the extent to which it is deemed blameworthy.

This is most marked in respect of disabilities which lack distinguishable features (Valeras 2010, Blum 2015, Blum and Felton 2016), effecting alternative interpretations for its manifestations which open spaces for accountability to be accorded (Blum 2007). Maternal blame is stated by Blum (2015) to have been a consistent factor in the explanation for child disability and psychological difference. Nevertheless, Blum (2015) notes a subtle change in the manner in which mother blame in particular is apportioned. Finding whilst neuroscience has expanded to offer an evidence base for 'invisible' disabilities that impact on behaviour, maternal exoneration remains partial. Blum refers to this 'proximate secondary blame', accorded not for causing the difficulties faced, but for inefficient management of them. Thus the onus of responsibility and accountability is retained squarely within the maternal domain, irrespective of the explanations for difference.

Responsibility to remediate behavioural disabilities through medication has been most evident in the school sector and has stimulated intense controversy (Frances 2012). These debates although rarely stated outright are found satirised in both popular and social media (Wahl 1995, Kirkland 1999, Anderson and Anderson 2011, Google 2012). It may be said that the debates in circulation exist as a subtext, imputing into popular consciousness, which as previously discussed affects the way disability is identified and 'known' outside of the personal domain. Additionally given that behavioural disabilities hold association with exclusionary sanctions (OCC 2013, DfE 2014, 2015b; 2016a), this acts as further indication that medical identification alone is insufficient to trigger legal or moral protections.

2.3.7 Mitigation

Disability mitigation might reasonably be assumed to negate accountability given the logic and prominence of the medical model and the medical labels defined within its knowledge base. Nevertheless this emerges as insufficient to satisfy society's corresponding need for collective protections, triggering alternative discourses concerned with punishment, rehabilitation and restorative justice. Indeed Dullum (2015) asserts that a 'new penology' is emerging across much of the Western world (pp 61). Looking specifically at the impact of disability as mitigation for crimes in the Norwegian courts, Dullum found that despite progressive tendencies, described as

'Scandinavian exceptionalism' (Pratt 2008), the extent of mitigation accepted varied, and was mediated through concepts of dangerousness and perceived threat to the collective. Indeed Pfeiffer (2015) found that extreme cases of dangerousness, were often invoked as evidence of a more general disposition inherent to a disability type, a tendency which impacted negatively on future disability responses irrespective of circumstance.

Disability accountability and blame also is found to transcend the context of childhood disability and schooling and is been found entrenched in legal frameworks which legitimate unequal treatment (Karpin and O'Connell 2015, O'Connell 2016). This further reduces the potency of disability as a mitigation for offending and anti-social behaviours, despite medical explanations which highlight neurological alterations (Berkley 2002, 2012). Nussbaum observes that 'shame and disgust were formerly common emotional reactions to disability, of which the residue remain contemporarily prominent in law' (pp2) and one suggests these remain entrenched within punitive responses to offending. Their endurance however conjures questioning toward how (or if) these should impact on legal 'formulation and administration' (ibid), not least in respect of its role as both a deterrent to recidivism and the deterrence of offending replication.

Nussbaum offers two observances which may explicate why disability as mitigation for social infractions is both problematic and generative of irreconcilable tensions. Nussbaum notes firstly that 'shaming penalties encourage the stigmatization of offenders inviting their presence to be viewed as 'shameful' (pp2). In conjunction Nussbaum notes that the contemporary maintains in principle that the disabled are blameless' (pp 2). These two co-occurring positions problematize the reconciliation of persons who are both disabled and offend. As a consequence I suggest that it is the juncture of impact where resolution takes place. Hence where impact is socially unacceptable, disability status concedes its protective capacity, to the needs of justice for the other party or parties. Such equation thus serves to legitimate the shaming of some disabled persons to continue (Briant 2011, Goldberg 2011, Walker 2011, Garthwaite 2011, Hughes 2015).

These inequalities are found linked by O'Connell to differing conceptualisations of the brain itself. Conjuring of both deterministic arguments that speak of physical controls and malleable conception which invites pharmaceutical address as a condition of mitigation. It is therefore unsurprising that such visualisation has important

implications for disability response, management and remediation, both in and outside of the school context. O'Connell (2016) suggests responses to neurological disability link directly to judgments around the physical constitution of the disordered brain. Two explanatory frames are offered, firstly a deterministic perspective that considers the neurological impairment as fixed, thus denying of potential for change and speaks in treatment terms of the need for restraint. The second perspective considers the brain to hold a plasticity, which implies a neurological flexibility which is amenable to remediation, although speculation persists as to whether such remediation should be voluntary or involuntary. As O'Connell notes, where cognitive disability is accepted as mitigation, additional processes of regulation are triggered, invoking less, not more rights (O'Connell 2016). These processes may also be seen to trigger a constitutive cycle, which directs not only response, but is generative of profiles, which are in turn affirm response and subsequent interpretations of action.

It is thus the resolution of the tensions identified which offer explication for accountability practices, in spite of the expansion of medical labels which present neurological and psychological explanations for why some persons are more vulnerable to conducts which run counter to common and school rules (Barkley 2002, 2011, 2012, Haskins 2006, Psychiatrists 2006). In these instances a disabled persona is superseded by that attributed to an offender, cancelling out the protections identification of disability confers (Foster 2015).

It is therefore explicable why, not only do persons with neurodevelopmental disabilities struggle to cope or be understood within the criminal justice system (Rose 2007, Allen 2008, Dein and Woodbury 2010), they also are more likely to periods of incarceration, justified on the basis of perceived threat to the collective (Dullum 2015, Pfeiffer 2015). O'Connell (2016) concurs stating that the medicalisation of behaviour has not reduced inequality, to the contrary, 'the turn to a brain-based approach to identity is creating new forms of stigma and inequality for the child or youth with behavioural disabilities' (pp 2).

2.3.8 Creating and knowing the accountable latter day other

A closer inspection of the disabled population, taking into account both school exclusion figures (DfE 2012b, 2013b, 2014a) and representation in the criminal justice system (Loucks 2007, NACRO 2011, Talbot 2011, Hughes 2012, PRT 2013a, Krezmien, Leone and Wilson 2014), supports conclusion that above all others,

disabled persons of 'typical' intellectual functioning, predisposed to challenging or impulsive behaviours represent a modern day 'other' (Kudlick 2003). The meaning accorded to their disabilities led by its effect, not its impact, which operates to heighten of perceptions of threat, substantiating containment or segregation as reasoned response. Jimenez (2015) suggests disposition to control is underwritten by the concept of 'unsound' mind', a status which is circumventing of the freedoms detailed in the European Convention on Human Rights (ECHR 1950). Jimenez finds nonetheless that the concept of unsound mind is ill-defined and in terms of disability equity, archaic, frequently invoked to substantiate the curtailing of liberty, without the legal protections afforded defendants under criminal law. Its invocation is thus considered to represent an institutionally ratified form of disability discrimination.

Such disavowal of rights reflects the tendency of the legal system to externalise action, without due reference to its drivers. As Jimenez (2015) states 'in criminal law...a person must be punished for his or her acts, not his or her personality or character' (Jimenez, pp, 305). Such tendency is problematic as many neuro-developmental disabilities are cited to be pervasive and distortive of self-control mechanisms (Association 2013). Resulting in effects which not only renders the individual vulnerable to contravening legal codes, but is also definitional of his/her personal makeup. Thus punitive response as opposed to rehabilitative response, serves to punish the individual for his or her personality or character.

These divisions appear irreconcilable and in danger of being obstructive to how research can be conducted. It is thus heartening that Goodley (2007) circumvents this debate by employing a critical pedagogical perspective. Critical pedagogy endeavours to situate pedagogical practice within a socio-cultural and political context. It therefore offers scope for revealing the locus of disability meanings and response outside of the debate surrounding whether disability represents difference or medical/psychological anomaly. Critical pedagogy also offers scope for exposing the social variables which coalesce around children exhibiting behavioural difficulties; which rather than being considered causational in their own right, may indicate the presence of wider discriminatory factors leading to social disadvantage, thus altering the direction of influence.

It is nevertheless troubling that Goodley finds disability to be frequently absent as a social variable in educational research projects, but rather embroiled within aligned discourses of inclusion. The consequence of disability as a research variable being

absorbed into a niche debate arena, is to detract awareness from the wider inequalities in which disability is implicated. As such signals an absence which not only marginalises, but is inhibitive of egalitarian ambitions. Not least because there is danger that the ideal of inclusion and the fallacy of its enactment suggests the problem of disability in education is resolved. But just as the ideal of egalitarian education based on meritocracy failed to close the gaps in educational attainment (Mijs 2016), so too can the ideal of inclusion be seen to have failed to deliver disability equity in education (Cigman 2007, Rix 2015).

This review now considers more fully the impact of conceptual models of disability towards understandings of not only the nature of difference and disability, but also the arenas identified as appropriate research arenas.

2. 4 Subsection 3: Conceptual models of disability

2.4.1 Defining the models of disability

Models of disability are the conceptual schemas employed to make sense of physical and psychological difference. They logically adhere to an underpinning paradigm and may be considered foundational toward how disability is identified and received both in and outside of academia. Smart (2009) states that ‘models of disability define disability, determine which professionals serve people with disabilities and help shape the self –identities of those with disabilities’ (pp 3). The models have also been determining of how disability studies are structured in academia and to which academic departments they are aligned. The models dissemination have shaped not only causal focus, but the nature of social and political response. They have thus had impact through governmental policy on not only rights and entitlements, but on wider professional practice, not least in education through the expansion of the concept of educational needs and inclusion (Oliver 1990; 2013, Thomas 2004, 2007, Florian 2008a, Smart 2009, Allan 2010, Goodley and Runswick-Cole 2012, Hughes 2015, O’Connell 2016, Rogers 2016).

The disciplinary affiliation and impetuses for the development of the models have been directive of the purposes for which they have been developed and employed. For example Smart (2009) writing within the field of health sciences suggests ‘models of disability are the underlying structure for large, complex diagnosing/defining systems’ (pp 3) such as DSM-5. In contrast Oliver (1990) a prominent (disabled) disability activist, developed the Social Model of disability to highlight social injustice

and oppression and in doing so fundamentally altered how disability was conceptualised socially and politically. It is nevertheless suggested that their impact remains an unknown quantity, for as Smart (2009) suggests, despite pervasive societal impact, the power the models exert is rarely questioned, or as a consequence quantified. It is therefore important to consider affiliations and disciplinary alignment as a precursor to evaluation or use.

Llewelyn (2000) offers a further definition which although similar to those proffered, is more generic, suggesting 'that a model represents a particular type of theory, namely structural, which seeks to explain phenomena by reference to an abstract system and mechanism' (pp 157). Llewelyn also cautions that although models may be generative of explanation, 'they do not of themselves constitute explanation' (ibid). Unpicking this statement leads me to conclude that disability models may be most usefully viewed as a conceptual guide, rather than correspondence to truth. Henceforth the truth or falsification of disability models, reside in both detail and the context of the phenomenon they seek to explicate.

Within the remit of this research models of disability are reviewed in regards to their explanatory potential; seeking explanation for the lesser status and accountability of behavioural disabilities within the broad spectrum of disability presentations. Their use is however employed cautiously, acknowledging more general critiques extended toward the development and employment of conceptual referents. For example Lave and Gardner (1993) caution that models per se tend toward simplicity, belying the complexities inherent in the phenomenon observed (cited in Owens 1993, pp 388). It is to the phenomena studied that this section now digresses; looking at how disability has been alternatively viewed as deficit and indication of exceptional skills, for the starting point of any models employment is an appreciation of the phenomenon under study (in this case disability) and it is relevant that there are a range of identities engendered from such classification which hold important implications for the employment of a disability model.

2.4.2 Deficit or Exceptionality?

The positioning of disability is directive of the research lens and conceptual models adopted. For example when disability is viewed from a deficit perspective it acts to direct research attention toward causal factors and support needs, questions which logically link to a medical model. Equally the notion of disability as engendering

disadvantage may direct to either an embodied perspective or to that espoused by the social model in a bid to understand the locus of disadvantage. A further persona which coalesces around disability is that which intimates the existence of compensatory skills and has led to discourses which both rationalise disability successes as unusual, but where present the exception to the norm. This tendency has been referred to as the 'Super Crip' script (BFI 2010).

Illusions of exceptionality are most commonly associated with the psychological functioning called autism (Murray 2006, 2008). Notably Armstrong (2010) calls for an emphasis on the positives of other forms of neurological difference, including ADHD. Equally contemporarily events such as the Paralympics have heightened the value of compensatory physical attributes amongst those with physical impairments. Although such celebration is laudable for the minority implicated, they also raise concerns.

These observations at first glance appear to confirm Swain and French's (2000) claim that an Affirmation Model of Disability is emergent from within the disabled community; and as such represents resistance to deficit identities and the notion of dependency. Yet the Affirmation Model may perhaps be more modestly considered a call to have disabled persons innate humanity acknowledged. For it does not aspire to showcase either extreme of the ability/disability continuum, rather it seeks to highlight the everyday positive achievements of the disabled community, calling for attention to be directed to the things disabled people can do (pp 569). Nevertheless in a small way the Affirmation Model may be seen to challenge tragedy scripts; but I feel as importantly it serves to remind us that a disabled life is essentially a life like any other.

Looking at the expanse of disability models available to elucidate the experience of disability, it is suggested that scripts which allude to extraordinary talents as a by-product of particular types of disability are the most problematic to cater to. By their nature these scripts hold wider implications. Firstly they serve to stratify unequal position within the disabled community, setting up expectations around particular disability labels, which are most likely the exception, not the norm. They thus serve to devalue those who do not meet the criteria for exceptionality and as such deliver a double whammy of failing to those who can neither be deemed 'able', or successfully 'disabled'.

2.4.3 The nature of humanity toward the defining of disability and adoption of an appropriate conceptual model

The rejection of exceptionality and deficit as the de jure markers of disability, leaves only a consideration of the guise of humanity to guide an understanding of the nature of disability, and also the choice of disability models which can most appropriately elucidate its state. There is an increasing volume of work that addresses the nature of humanity and the situation of disabled persons (Baker 2002, Nussbaum 2004, Pickersgill 2011, Rogers 2016). As such they summons questions which link to beliefs about the default human state, both bodily and psychologically (Stiker 1997) which be extension are definitional of the meanings and status accorded to disability. Most typically 'humanness' is defined in terms of biology and psychological development, predicated upon contemporary knowledge claims which have tended toward norm reference, particularly in education to define the pathological (Gabel 2005, 2008). As McLaughlin (2016) states, 'disabled children and young people are still measured against norms of development that define them as lacking, undermining the potential for integration' (pp 17). This begs the question of what would happen if the boundaries of norm referencing were removed, would those previously defined remain lacking.

Goodley (2011) suggests 'to talk of the 'brute facts' of impaired or normal bodies evokes a biology that has already been constructed' (pp119), Goodley further asserts that 'the body is not some entity prior to signification: it has already been through a process of signification' (ibid). Haraway (1990) likewise addresses the space between our bodies and the social world, suggesting it to be the space which incurs wider relationships of power. Most notably these inequalities manifest as processes of regulation, self-regulation from within and overt regulation from without. In operation however, regulation is not only imposed, it is experienced and as such demands rationalisation at a personal level and conceptual level, which is the juncture where resistance to dominant narratives and subjection is most likely (Jackson 2002, Jackson 2004, Gallagher 2012b, McLaughlin 2008b, 2011, Holt 2008; 2010a).

Currently an upsurge in neurological explanations for difference and behavioural disabilities has led to a renewed focus on the brain as the orchestrator of bodily and psychological presence. Fein (2011) states that the influence of neurology as an explanation for difference has led to a resurgence 'of classical questions such as

where the origins of madness lie, how moral responsibility should be adjudicated and what demarcates normality from abnormality' (Fein 2011 pp xiii). In determination the resolution of these questions is not easily determined, as the concept of truth and the nature of knowledge are themselves contested. In particular O'Connell notes that the idea of a reductionist model of humankind predicated on the constitution of the brain (2016) conjures varying conceptualisations of the composition of the brain and the level of its permeability. O'Connell further emphasises that the social world is inevitably collaborative and it is at the level of inter-relation that meaning is made, which is of impacts on both the physical and psychological spheres, as such defining of how difference is 'known'.

Looking back at my experience, this remains inconclusively explained the main (and indeed upcoming) models of disability although each have been employed eclectically at different times to make sense of particular facets of my son's difficulties. Based on this experience I concluded retrospectively that my own reference to these models had been ad hoc and mobile. Their employment as a parent, tailored to fit the situation of the moment, rather than imposed onto my experience based of any philosophical loyalty. Looking back now as a researcher, I concluded that presentations of disability summonsed varied meanings, whose effects were tangible and contextual as well as embodied, politicised and socially inter-relational. For some (as has been my experience) the understanding of others led to the legitimisation of accordances of accountability, which of themselves also alluded to a discrete subtext, which intimated a deeper judgement in regards to human value. Such complexity defies the identification of any default model which can comprehensively explain the range of circumstances faced. I therefore concluded that there is no go to model, either as a researcher or as a parent. Rather the models may be seen as partial explanations, linked to the impetus which gave rise to their establishment. It is to a consideration of the functionality of conceptual models this review now turns, expanding upon those identified as having greatest potential to inform a study focused on disability accountability.

2.4.4 The functionality of conceptual main models

Three main models of disability are identified, emanating out of the professional context, disability activism and popular lobby. They may be seen to act as broad markers within the wider spectrum of derivative models which have subsequently emerged. The models present an overview of how disability has been conceptualised

and reflect the main debates which have coalesced around their determination. The models referred to are the Medical (Laing 1971), Social (Oliver 1990, Barnes 1991b, 2005, SCOPE 2011), and Embodiment models (Shuttleworth 2004, Ramanathan 2009, 2010, Allan 2010) of disability. Although prominent and highly publicised they are far from exhaustive, they may thus be considered to indicate junctures of thought within the parameters of disabled being they collectively delineate. It is further suggested that the emergence of further models, expands rather than detracts from the main models explanatory worth, as more nuanced models add to rather than diminish their relevance.

Smart's (2009) contribution is illustrative; for although eluding to three further models (the Biomedical, Functional and Socio-political models), these models fall within the conceptual parameters the identified main models delineate, thus offer additional detail. Llewellyn (2000) agrees that conceptual models have potential to explicate real world problems, yet cautions that individually none are able to fully elucidate the nature of disability, as they lack needed finer detail to extend their explanatory capability. The models are at times presented as static entities, diametrically opposed, yet Llewellyn denies that the Medical and Social Models compromise each other's integrity, rather it is suggested that they can work in synergy when expanded upon.

To illustrate the explanatory potential of additional conceptual frames, Llewellyn examples how two models commonly used in developmental psychology (the Transactional Model and Systems Theory) are complementary and present a visualisation of disability as a dynamic state in constant motion. For example Llewellyn states that a Systems approach combines the 'synergistic influence of the characteristics of the person and of the environment that produces the behaviour' (pp 160). Consequently because attention is directed to the interplay of the individual and the environment simultaneously, the model is sufficiently malleable to permit a range of research focus, aimed at generating testable hypothesis. The Transactional Model further complements a Systems approach, as it puts forward a view of the environment as an interactive structure, which involves viewing the individual as 'an active synthesiser of information from the environment' (ibid). Henceforth, both approaches display potential to extend the explanatory capacity of each other and I argue that of the main models of disability.

It is therefore reasonable to suggest that an eclectic use of disability models, tailored to their research function, holds greatest promise in the research field; albeit bearing in mind Llewellyn's caution that the models cannot be true of false, rather extend a representation, rather than a theory or snap shot of real life. For as Llewellyn suggests they may usefully be seen as the building blocks of understanding, as an 'essential feature of the model is the application of one (better understood and developed) system to another (less well understood and developed) system' (Llewellyn 2000, pp 157). From this position the models of disability can best be summed as conceptual aids; mapping referent capable of guiding sense making during research endeavours.

Out of the many emergent models of disability, two were identified as particularly useful toward theorising and detailing the embodied reality of disability. These are the Care Ethic's (Rogers 2016) and Socio-Cultural Models' of disability (Goodley and Runswick-Cole 2012). Each approach demonstrates capacity to accommodate the medical referents which contemporarily explain the physical and psychological manifestations of disability, in conjunction with an appreciation of more subtle social processes and regulatory factors which combine to delineate disability and identity profiles within the term disability. Furthermore it was felt both models were able to accommodate shifts in professional thinking. Most particularly in the field of medicine, where esteemed knowledge is fluid and subject to specialism shifts, as exemplified by the shift in medicine from research emphasis on genetic markers of psychological difference, to those based on neurological explanations for psychological difference (Barnartt 2010, Pickersgill 2011, O'Connell 2016).

2.4.5 Concerns towards the use of disability models

Contemporarily one fifth of the UK population are estimated to have a disability; of those one in twenty are children (Papworth Trust (PT) 2010, PT 2012). It is therefore significant that despite medical probability, the profile of disability remains one of a/typicality, serving to 'other' its recipient (Foucault 1980, Gergen 1990, Anderson 1996, Amaral 2007). Such processes have been directly implicated in both direct and indirect discrimination and segregation (Gergen 1985, Gergen 1990, Timimi and Taylor 2004, Amaral 2007, Timimi 2009). As a consequence, undue attention to conceptual models based on simplistic divisions, may further exaggerate the atypicality of disability; similarly it may deflect attention from any wider intersections of disadvantage which are implicated in disability identification and response,

particularly in the education context (McLaughlin 2008b, Begeer 2009, Riddell 2011, Russell, Steer and Goulding 2011, Pickersgill 2011, Liasidou 2012, Tomlinson 2014, O'Connell 2016). An additional caution is that by their nature, models simplify the subject matter studied; and are thus liable to stereotype disability identities and circumstance (Lave and Gardner 1993). Nevertheless despite such caution, the use of conceptual models persist and is welcomed as a means of elucidating contemporary sentiment and effecting social lobby.

Emergent models display increasing complexity, signalling a micro focus on the finer nuances of disabled being. Such approach complements rather than challenges established models as both can be seen to fulfil equally important functions. For example a macro focus holds potential to reveal general trends, as indeed the Social Model succeeded to achieve, highlighting the disabling tendencies endemic within all strata of social life. Nevertheless I suggest that in spite of the therapeutic and healing capacities attributed with a Medical Model and the pioneering spirit of the Social and Embodiment Models; none specifically address the disadvantages which most clearly surround children (and adults) vulnerable through disability to challenging behaviour. To substantiate this point this section now expands on the detail of the main models of disability, noting the aforementioned lack of address.

2.4.6 Medical Model

The medical model (rather than the medicalisation of disability)), was first formalised as a concept by Laing (1971) and remains implicated in medical sociology (Thomas 2004; 2007). Nevertheless it does not exist as a coherent conceptual body in the same manner other models are presented. More helpfully the Medical Model may be seen as illustrative of what has been referred to as the 'lifeworld'. An insular taken for granted conceptual frame (Husserl 1970, Schutz 1973, Habermas 1987) which dominates explanations for, and response to, difference and illness. The Medical Model may thus be defined as the embodiment of the relational and medical assumptions operational within contemporary professional practice.

This medical frame does however display its own insular controversies, which are found to be generative of spaces for disability challenges to emerge. These spaces are discussed discretely in subchapter 4, as it is recognised that such challenges rebound into the sense secondary professional make of medical labels and the medicalisation of childhood generally. Most particularly as all parties to the

educational context remain dependent upon medical validation to gain access to resources, not least disability rights and protection.

Crudely the Medical Model may be seen to extend a reductionist view of illness. Notably one that has been historically rejected by medical schools (Engel 1977) in favour of a biosocial model, focused on the social, psychological and behavioural dimensions of illness. This approach is most clearly evident in the World Health Organisations International Classification of Functioning Disability and Health (WHO 2007), which has been an important influence toward the expansion of preventative medicine. The medical model is also congruent with the ongoing expansion of childhood disabilities, an expansion which summonsed controversy as it has extended to the very core of childhood, informing on issues of behaviour, personality and disposition (Gergen 1990, Conrad and Potter 2000, Conrad 2005; 2007; 2010, Schreibman 2007, Timimi and McCabe 2010, Conrad and Bergey 2014, Runswick – Cole 2016). It is therefore notable that medical explanations for difference have been embraced by parents and schools, potentially as medicalised explanation deflects organisational and familial accountability, whilst holding the promise of medicalised remediation (O'Connell 2016).

The logic of medical explanation is nevertheless found selectively embraced, stalling at the juncture where disability and disruptive conduct are found to co-occur; stimulating tensions in respect of the reconciliation of punishment and protection, both in the education and the legal systems. This tension is contrary to the logic of the medical model for as O'Connell (2016) states, 'behaviour that is perceived as determined by the agent's neurobiology invites primarily medical, instead of legal, intervention' (pp4). Indeed medical explanations through their internal logic of cause and effect offered promise to equalise all classifications of disability, yet appear to have failed to effect such outcome (Jull 2008, Davis 2013, Caslin 2014, and O'Connell 2016). Thus in practice, O'Connell states 'the brain-based subject of law is not emerging in a benign way, but rather with ideas of culpability and innocence attached, depending on how the brain is conceptualised'(pp, 22).

Anastasiou (2013) takes issue with the deterministic principles implicated in the Medical Model, despite suggesting that medical classifications (labels) represent valid approximations of (contemporary) scientific truth. Expanding on this contention Anastasiou makes distinction between subject-independent knowledge (valid approximations to truth) and the experiential subjectivities coalescing around such

truth as subject-dependent knowledge. Thus forth, disability may reasonably be considered the combination of medical fact and social construction. Problematically the boundaries between these two subject positions are more evident in respect of physical disability, yet blur in relation to disabilities of a cognitive nature, which may elucidate why disabilities which impact on behaviour incur accountability whilst those of impact on physicality do not.

The Medical Model does nevertheless continue to prevail within the arenas of diagnosis and treatment (Association 2000, ADHD.org.nz 2011a, Bognar (2016), signalling a prevalence which is particularly apparent in respect of explanations for difference in schools. Indeed schools operate as a primary site of childhood disability identification, particularly in relation to disabilities of a developmental nature, where the normative basis of mass education accentuates deviations from the norm (Waterhouse 2004, Goodley 2011).

Ironically although formal diagnosis is central to disability support and entitlements, the Medical Model has been cited to be an insufficient gatekeeper, unable to inform adequately the supports needed on levels outside of the medical frame. These shortcomings are referred to as the Goldilocks effect (Areheart 2008) and are stated to impact most acutely on persons with psychological and behavioural differences, as a clear treatment plan is problematic due to the absence of definitive organic markers.

2.4.7 The Social Model

The Social Model in comparison classically resides upon distinction between disability and impairment as defined by Barnes (1991). 'Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (pp 2). Anastasiou (2013) expands further, indicating the Social Model to reside upon five central premises which follow inductively. Firstly, an arbitrary distinction between disability and impairment. Secondly that impairment delineates physical or psychological dysfunction, whereas thirdly, disability per se is the result of organisational and societal structures. Fourthly as a consequence, disabled persons are an oppressed social group, which leads to the final premise that disability is not a personal tragedy requiring medical attention. Rather is indicative of social oppression

and a biased response to difference which morally should reap tolerance and acceptance.

The Social Model retains a contemporary credibility particularly in the UK (UPIAS 1975, Oliver 1990, Barnes 2005, SCOPE 2011), despite the continued prominence of medicine as a primary indicator of disability. It has nevertheless been critiqued by Owens (2015) for appearing to indicate that society hosts a unilateral effect, indication which is considered counterproductive. 'Focusing on society as the root cause of disability, not impairment, using the terms 'social and individual models of disability' has arguably become a double-edged sword. It has been used successfully for political activism; while simultaneously creating conflict and tensions in disability studies, sociology and the sociology of the body' (pp 386).

Thus although the distinction between impairment (as an individual and medically knowable state) and disability (a state induced by barriers erected in the social domain) has prompted legislative and organisational change, it stands accused of compounding disadvantage through unbalanced emphasis on the impact of the social, to the detriment of the experiential embodied experience (Hughes 1997, Shakespeare 2001; 2008, Anastasiou 2012). Similarly to Owens (2015) Anastasiou (2013) states the Social Model has been over reliant on a crude distinction between impairment and disability. Further stating that 'the claim that a disability is merely an idea, an arbitrary social creation, rather than a condition with both objective and subjective elements, involves confusing a fact with its description' (pp 443).

The idea that disability delineates a homogenous group is contested by Davis (2013) and by Stamou (2016) who found there to be varied self-representation amongst the on-line disabled community. Furthermore Owens (2015) suggests that 'no mechanism has been offered in the Social Model of Disability that accounts for the variety of ways disability may be experienced' (pp 388). Indeed the varying experiential nature of disability may be primary to differential response, for example Stamou found different forms of disability appeared to impact on the model of disability employed and the level of collective identity fostered. Hence there appears limited scope for detailed disability differentiation within macro conceptual models founded upon a visualisation of the disabled community as a unified collective.

Owens (2015) further suggests that 'the meaning of illness appears defined either in terms of its embodied consequences, or relational impact, implying that both models

hold tendency to construct people with disabilities as 'passive victims of dominant discourses in a negative and somewhat powerless light' (ibid, pp 392). This position signals need for a relational perspective, which can offer greater scope to elucidate differences of presentation and impact.

Notably critiques towards the Social Model of disability have encountered longstanding rebuff. Laing (2001) for example has argued that 'the Social Model of Disability should not be considered a monolithic entry, but rather a cluster of approaches to the understanding of the notion of disablement' (pp 2). Indeed assertion that the Social Model is too simplistic, speaks to more generic concerns surrounding the use of conceptual models as previously addressed by Llewellyn (2000) and Smart (2009). Equally Laing's assertion may be further interpreted as offering permission to extract eclectically from across the models to further appreciate the varied state of disablement. Gabel (2004) finds this to be a frequent practice within the social paradigm, albeit often unrecognised as working practice. Looking toward the school context, the influence of the Social Model of disability is apparent; most typically leading the sentiment of the inclusion agenda, particularly the emphasis on overcoming the social barriers to participation (Carrington 1999, Booth and Ainscow 2002, Carrington and Robinson 2006). Nevertheless in both the detail of inclusion and that of the Social Model of disability, there is no expansion to rationalise why pupils exhibiting challenging behaviours as a consequence of disability are unduly subject to disadvantaging practices, nor why they are not recognised as such.

2.4.8 Expanding upon the Social Model

Goodley and McLaughlin (2008) identify four areas of concern in relation to the Social Model of Disability, which summarise many of the diverse concerns raised. These surround the future of the model, the relationship between disability studies and disability politics, amidst concern that a once radical movement has lost direction, thirdly the role of body within the Social Model and fourthly concerns toward the models inclusivity, not least concern that some forms of disability (particularly those involving behaviour and learning), are not embraced within the model. These concerns, usefully summarised by Goodley and McLaughlin, are echoed widely; most specifically in relation to the Social Model's efficacy and potential for its continued influence (Shakespeare 2001; 2008; 2014, Terzi 2004, Gabel and Peters 2005).

O'Connell moves away from more deterministic interpretations of the Social Model and alludes to a collaborative element, stating that 'in the Social Model, identity is a co-creation, disability resides not in the body of the person but in the society that is structured and constituted so that the individual cannot function fully' (O'Connell 2016, pp 6). Such sentiment intimates the capacity for agency and ability to challenge inequalities faced and is foundational to a Resistance Model of Disability.

Owens (2015) challenges the idea of a single Social Model and dismissing generic critiques calls for greater attention to be directed to the various interpretations the Social Model has stimulated. In illustration Owens draws upon three variations of the Social Model; the Social Model as it has developed in the UK, the Nordic Relational Model, common to Scandinavian countries and the North American Social Model of Disability. Although holding in common emphasis on the social, discrete differences are noted. In particular it is suggested that the UK interpretation offers too severe a distinction between disability and impairment, generating an inflexibility which has been foundational to its critique. In contrast the North American model privileges social rights; positioning persons with disability as a minority, similar in constitution to other marginalised groups. The Nordic Model however is found to differ in emphasis and does not deny either the impact of the physical or psychological, nor that of the social, rather it claims all spheres to be intimately interconnected. It may be said that these differing interpretations serve to address many of the aforementioned concerns and intimate that rather than viewing the model as a static construct, it is more appropriate to view it as dynamic and adaptive.

The Social Model is therefore not immutable and indeed Gabel (2004) has discerned, suggestion of a paradigmatic shift amongst its adherents, which has led to what has been termed the Resistance Model (RM). The RM is an eclectic model, holding at its core the common feature of resistance to disability oppression. Common to varying observations of its existence is a tendency toward paradigmatic fluidity; and this has been foundational to the generation of a hybrid model. Gabel states that 'a growing number of people and theoreticians are using eclectic theories that move across and operate between paradigms, while identifying their work as within the Social Model' (pp 597). The practices identified are found to be compatible with Resistance Theory, which is stated to connect paradigm and theory in a manner which is both conceptual and practical. Whilst the implied enmeshing indicates an evolving recognition of the way structure and agency are interwoven in everyday practices (ibid).

Notably Gabel (2005) maintains that the Social Model does not necessarily reject the role of medicine, as some medical benefits are acknowledged to be beneficial toward the remediation of impairment. Such remediation remains nevertheless the subject of contention (Sinclair 2005, Boundy 2008). For example O'Connell (2016) cautions it to hold potential to legitimate unwarranted medical intervention to remediate the effects of difference, rather than impairment. Difference which through the logic of a medical mind set triggers individualised attributions and solutions. Certainly within the field of education there is significant concern that presentations of disorder are stimulated by contextual triggers rather than organic or innate disorder (Greene 2008b, Robinson 2011; 2015). It is thus notable that such concern is found heightened in relation to behavioural disabilities, most particularly the condition ADHD (Bailey 2006; 2009; 2010, Graham 2007a; b; 2008, Robinson 2011; 2015).

Davis (2013) cautions against simplistic binaries and signals concern toward the lack of disability differentiation or address of differential accountabilities accorded within the broad banner of disability. These cautions are in the minority, yet highlight a major area of disability inequality. Particularly as behavioural disabilities emerge in the school and legal contexts as having a lesser status with fewer legal protections, than persons with other types of disability. Such inequality is most noticeable in the school context and has been illustrated quantitatively through official rates of exclusion (DfE 2015b; 2016). It is nevertheless found addressed more vehemently within legal studies (Perlin 2000; 2008; 2016, O'Connell 2016) rather than the field of disability studies.

Whilst the Social Model of Disability has effected legislative change through the ratification of the 1995 Disability Discrimination Act, it appears to fall short on procuring social equity (Barnes 1991 a; b, 2014, Quarmby 2011) as disabled persons remain subject to well documented and enduring disadvantages in the social domain, subject to suspicions of system abuse for financial gain (Roulstone 2000, 2015, PT 2014, HL 2016). Similar failings are apparent in regard of pupils posing psychological or behavioural challenges and most troublingly rationalised as reasonable action. A response to unacceptable conducts (Youdell 2006, 2011, Allen 2010, DfE 2013b, 2014a), which is embedded within wider debates around the need to control and curb disruptive behaviours (NASUWT 2008, 2012a b, NFER 2012, DfE 2012d, Ofsted 2012, 2014a).

A lack of confidence in the Social Model is further implied by O'Connell's (2016) suggestion that equity law has 'taken on the role of the social model (pp 6). Yet toward a defence of the Social Model on the grounds of efficacy, I suggest that any evaluation needs to take into account the political climate within which it is operational. For although the Social Model is stated to be at core relational (Erevelles 2000), underpinned conceptually by Marxist and Constructivist theory (Owens 2015); it is embedded within a contemporary individualistic Neoliberal climate. This climate errs from state intervention and support and resides upon the sentiment of Adam Smith's premise that 'free exchange was a transaction from which both parties necessarily benefited' (Clarke 2005, pp1). Thus despite Smith's sentiment pertaining to economic relationships, its logic has extended into all other areas of political and institutional life. Most typically being found to pervade both the political and educational spheres, which has been central to the commodification of children assets (Blum 2016, Heeney 2015, Hughes 2015, Roulstone 2015, Tomlinson 2005, 2008).

Owens (2015) therefore calls for the exploration of 'what impact the social relations that are constituted via capitalism have on the disabled subject' (pp 41).

Problematically however the parameters of impact are ill defined within the Social Model, nor are they fully expanded upon by Clarke (2005). They thus offer no real alternative to deterministic theories such as Marxism, which through its focus on the wider relational implications, does not easily tease out the detail and circumstances of disabled persons lives as they are lived. Such detail is nevertheless primary to any contemporary appreciation of the situation of persons with behavioural disabilities. Indeed such inattention may itself foster a disproportionate focus on the medical aspects of behavioural and psychological differences. Attention which has heightened claims of undue influence and involvement by the medical profession in its own and the interests of the pharmaceutical industry (Read 2005). It is also notable that despite the attention directed to the disabling barriers which were identified through the Social Model of disability, the model itself fails to highlight or even acknowledge that there remain active mechanisms operational, which engender stratifications, despite the continued use of the umbrella term 'disabled'.

Taking all of the above concerns and critiques into account, it is only fair that the final word on the relevance of the Social Model should come from its original proponent following a period of reflection. Oliver (2013) whilst acknowledging of the

shortcomings of the model he is attributed to be the creator of, questions what is gained from ongoing internal debates, when these are not productive of any credible alternative that is capable of improving the lives of disabled people. He thus states that, 'those who have talked down the Social Model, while failing to replace it with something more meaningful, or useful, must bear a heavy burden of responsibility for this state of affairs. Remarkably they have been rather silent in speaking out, or building alternative models to address what is happening to disabled people now. Surely it is time to either re-invigorate the Social Model or replace it with something else. One thing is for sure; the talking has to stop' (pp 1026).

2.4.9 The unrecognised oppressed

The nature and pervasiveness of disability inequality was highlighted through the momentum generated by disability lobbyists; and through the extended reach facilitated by the development of the Social Model of Disability (Oliver 1990) which led to broad ranging protections led by the introduction of the Disability Discrimination Act 1995 and the Equality Act 2010 (Parliament 1995; 2010). Despite these protections persistent inequalities are recorded by the Papworth Trust across core areas such as employment, health and education (PT 2012; 2013; 2014; 2016). These disadvantages although of themselves troubling, mask deeper divisions. Most specifically in the school context where pupils with neurodevelopmental disabilities of impact on behaviour are found prone to formal and exclusionary sanctions (Lamb 2009, Autism 2011, 2014, CEREBRA 2013, OCC 2013).

This leads me to question why when the evidence of disadvantage is disseminated is there a continued silence, which is facilitative of its continuance. This lack of response suggests there to be a 'lesser' disability status accorded to persons with neurodevelopmental disabilities as indeed the cartoonist David Lupen (2009) alludes to, intimating those with physical disabilities to have a greater credibility than those without (Davis 2013) as is shown in my appendix. It is also telling that the founding principles of the Social Model of Disability in the UK as stated by UPIAS (1975), establish the precedent of disability as physical rather than psychological difference. Indeed persons displaying psychological impairments held an uncertain status within the disability movement upon its inception, as the following comment indicates:

'If those with invisible impairments decide to self-define as disabled, their claim may be rejected because they do not 'look the part. The Disability Movement may not welcome or

accept these individuals judged to be far too symmetrical in physique to be included' (McNamara, in Tierney 2002, pp10).

It is thus notable that disability status remains of issue both within and without the disability movement (Jull 2008, Boyd 2012, Caslin 2014), despite as Barnes (2012) notes earlier expansion by UPIAS to include all disabled persons. This section now considers the development and contribution of the Embodiment Model of Disability, which directs attention to the personally experienced effects of disability.

2.4.10 The Embodiment Model

The concept of disablement has been pivotal to social and political awareness of disability disadvantage, based on the distinction between impairment and disability (Oliver 1990). Yet despite being the impetus of a rapidly expanding disability lobby, the Social Model of Disability has attracted critique from within its own membership. Most specifically the distinction between impairment and disability (a core distinction within the Social Model) is charged with being disavowing of bodily effect (Shakespeare 2002, Shuttleworth 2004, Ramanathan 2009, Allan 2010, Crow 2010, Ramanathan 2010, Bognar 2016). These concerns have been foundational toward the emergence of an Embodiment Model of Disability which privileges at its core the physical and psychological manifestations of disability, as well as the means by which persons with disability navigate their lives. The charge that the Social Model omits the body can nevertheless be challenged through reference to UPIAS original founding principles which make clear reference to physical impairment as an embodied state whilst disability is described as an additional imposed barrier. UPIAS state 'it is society which disables physically impaired people. Disability is something that is imposed on top of our impairments' (pp4).

Such sentiment supports Owens (2015) claim that it has been the models evolution and interpretation, by both disability activists and Governments, which has created distance between the body and disability (Barnes 2012), rather than the tenets of the model itself. On that basis I suggest that the founding principles of the Social Model remain current and speak to the locus of many social and educational inequalities, particularly amongst pupils whose disabilities impact on their social conduct, but whose appearance does not always allude to disability. Notably Oliver (2013) cautions that an enhanced focus on impairment and difference, is deflative of the wide locus of disablement. Oliver suggests therefore that it serves no useful purpose, as the original impetus behind the Social Model was to improve the lives of persons

with a disability, not to state their shortcomings. The Embodiment Model may be seen to straddle the sentiment of both the Social and Medical Models; committed to exposing the embodied effects of disability, considered lost within both the Social Model (Hughes 1997) and reductionist tendencies of a medical frame.

The body is itself identified as political, as Ramathan (2009) states, it is 'the condition and context through which we have relation to the world' (pp.9). This is a longstanding sentiment as Fuss (1989) indicates suggesting that 'the body is 'composed of a network of effects, continually subject to socio-political determination'...the body thus 'always already culturally mapped' (pp 5-6). Problematically the politicisation of the body implies there to be structural limitations to self – definition. It also implies that what presents to the individual as embodiment, (emergent disability identity from within), is in fact manipulated from without, co-constructed through diagnosis and the identities medical labels conjure. As Christensen (2004) asserts 'after being labelled disabled, or a category of disabled... the label tends to become the defining feature of the person, rather than being viewed as a complex multifaceted fully human being' (pp 19).

The call for an embodied approach may be viewed at base to represent an incentive to reclaim latent humanness, it also offers an important rational and direction from which to found disability research when conducted in conjunction with appreciation of the structural barriers faced. For example an embodied approach has been applied by Stephens (2015), building upon Deleuze's visualisation of the body as an entity in constant state of motion. In practice this constituted the interwoven poetics of motion and capability evaluation, 'wherein bodies, social expectations and built form intersect in embodied experiences in specific environments to increase or decrease the capacity of disabled children to act in those environments' (pp 194).

Referring back to the difficulties of children displaying challenging behaviour, adopting this approach it is reasonable to suggest that that the barriers faced, neither stem from individual or institutional intransigence. Rather they emerge from a complex interplay of the individual and social structure, whereby the form of structure is incongruent with the capabilities of the child. As Christensen (2004) states 'it can be argued that student disability extends from organisational pathology rather than student pathology' (pp 19). Thus an analytical deconstruction at the intersection of the student and the organisation holds potential to explicate the locus and nature of disability more expansively than individualised accounts of school experience alone

(Humphries 2008a; b). It is further suggested that by exposing key areas of disjuncture, the possibilities for their solution may be revealed. There is nevertheless a body of thought that suggests disablement and indeed delineations of disability are defined at the level of structure, not the body. It is thus necessary to consider the implications of this position in relation to disability as a social or embodied state.

2.4.11 Combining embodiment with a structural address

Stephens (2015) indicates that an embodied narrative focused on symptomatic effects is insufficient to allude fully to how disability is experienced, because such experience is linked to wider external factors. Stephens continues to state that personal account can 'yield deeper conceptual insight' (pp 196), but only where there is parallel observation of the social structures that person inhabits. Stephens's employment of the Embodiment Model examples such interconnectedness; referencing social and embodied existence against the constraints delivered through structure. Approached in this manner it is possible to observe 'how different environments (regardless of the physical accessibility they afford) signal inclusion or exclusion in different normative contexts' (pp 196). Employing an embodied approach in this manner opens spaces to appreciate not only personal barriers to full social participation, but also the structural barriers that preclude such participation.

Deleuze (1995) maintains to be human is to be in a state of 'becoming', a flux which represents a site of negotiation and struggle and it is notable that Stephen's approach to embodiment extends means to expose such struggle. A similar approach is detected in the work of Youdell (2006; 2010; 2011), who emphasises the role schools play toward the appearance of troubled and disruptive pupils. Youdell's findings, similarly to those of Graham (2007; 2008), impress upon us that the embodied effects of disability can only be fully appreciated through method which privileges the social circumstances of its presence. In regards to my research focus, a combined approach holds promise to inform how behavioural disabilities are heightened or modified in the school context. It equally holds capacity to elucidate the dynamics of identity construction, in particular how the identities that coalesce around behavioural challenges are conferred, sought or resisted.

Within the frame of identity construction, it is suggested the roots of medical labels, particularly those of a behavioural and psychological nature may be traced to the sorting functions schools perform and the categories of success and failure which

adhere to the wider political and economic structure (Erevelles 2000). Thus an education system punctuated by a standardised curriculum, necessitates the delineation of categories which can both rationalise difference and affirm the centrality of the norm. Indeed Erevelles suggests ‘the category of “disability” is crucial for the ability of schools to perform sorting practices effectively (pp 45).

Research initiatives which foreground structure only are according to Hughes residing upon deterministic conceptions of power, which are diminishing of disabled agency (Hughes 2005). In address Hughes also advocates a combined embodied/structural address, suggesting that research foregrounded from an embodied perspective offers scope to elucidate not only the effects of disability but also the processes which inhibit equality, in conjunction with any alongside counter resistance to such process (Titchkosky 2012). Indeed it may be argued that the nature of embodied accounts, challenge the notion that disabled oppression is levelled onto a passive recipient by an omnipotent source of power.

Hughes (2005) levels such critique against Foucault, considering Foucault’s philosophies of power to be distortive of the agency of disabled persons. This contention has been contested by Blackmore and Hodgkin’s (2012), who argue that inherent within Foucault’s conception of power is acknowledgement of the potential for counter resistance through embrace and direction of discourse. Blackmore argues disabled persons display resistance through language and discourse and in particular the counter knowledges created by lobby groups and disabled persons organisations (DPO) generally. Blackmore and Hodgkin’s conclude that the very existence of models of disability and DPOs who have successfully deflected definition against the norm are evidence of such resistance.

Nevertheless the claims of Blackmore and Hodgkin’s are tempered with a corresponding caution that disability resistance is now subject to colonisation through ‘the assimilation of the social model and independent living discourses’ into the mainstream of governmental and traditional charity rhetoric (pp 83), signalling ‘the emergence of a disabling corporatism’ (pp 84). The process cautioned against highlight the fluidity of relations of power, as well as the vulnerability of radical movements to neutralisation over time. Notably Hughes (2005) has called for a research approach which foregrounds practices of oppression and breeches of human rights, alongside watchfulness toward processes of assimilation which may

hold an undisclosed intent, fundamentally different from that which it seeks to assimilate.

Returning to the utility of an embodiment approach, it is useful to emphasise that acts of resistance may take many forms and that a detailed intimate knowledge may be in some instances the only means available to identify their presence and significance. An embodied approach holds capacity to reveal such intent, yet because by its nature it is local only to the parties immediately concerned, it is useful to question whether ineffective or small acts of resistance are as research significant in terms of agency as larger scale DPOs. In answer I deducted that an embodied perspective may be most usefully viewed as another research tool and that its usefulness is determined by the research purposes for which it is employed.

To further support the use of an eclectic approach, it is useful to reference the most recent thinking of Shakespeare who despite classically challenging the Social Model of disability and advocating for an embodied approach (2001, 2006), most recently indicates a change of direction (2014). Shakespeare suggests that the Social Model warrants revisiting in the face of what is suggested to be a lack of rigorous empirical endeavour within disability studies generally. Extending an overarching critique, Shakespeare claims the various approaches to disability research, including not only the Social Model, but also Post-Structuralist and Materialistic approaches, have failed to tailor their endeavours to changing the social and material conditions of persons with physical or intellectual disabilities. In essence Shakespeare suggests that not only has the body been lost, but now also direction and rational too.

Shakespeare's concerns remind us that a transformative commitment was the founding impetus to disability studies; its goal the address of an identified inertia and openly discriminative practices. In address Shakespeare advocates an integrated approach, which draws upon interdisciplinary sources as well as personal experiences of disability across a range of social roles and contexts. The overarching aim fundamental to Shakespeare's approach is to further progressive changes in policy and practice to the benefit of persons with disability. Such approach demands consideration of disability in not only an embodied sense, it also requires address of the political and economic circumstances of the contemporary period. This I suggest is fundamental to any identification of changes needed and of the means necessary to effect such change.

Shakespeare's concerns may be seen to be founded upon a perceived contemporary disconnect between the radical intentions of the founding fathers of disability theory and its current tendencies. Whilst this may be considered indicative of the colonisation Blackmore (2012) cautioned against, such assertion is also vulnerable to over emphasis and presumption of the integrity of intent. Nevertheless the notion of keeping as a central focus the benefits of research to persons with disability is both timely and relevant to this research. Most specifically because persons with behavioural disabilities remain poorly acknowledged within disability studies and surface most frequently on the margins of aligned disciplines and sub disciplinary themes. Thus my research may be seen to highlight the need for a more formal embodied appreciation of 'challenging disability' in conjunction with a wider structural approach. Such approach may be seen to hold the potential to expose not the impact of disadvantage, but also the sites of disadvantage and the functions such sites serve.

2.4.12 The role of structure

It is reasonable to suggest that the models of disability can be usefully visualised as conceptual angles, thus that the main models discussed are complementary to an overall picture of the nature of disability. They do not operate in isolation however, they may be seen to be anchored to the overarching belief and governmental systems of the society of which they are a part; what has essentially be termed structure.

Erevelles (2000) argues that the roots of exclusion and school failure are linked to economic imperatives. In particular finding that in spite of social and educational initiatives to foster equality 'these redefinitions still exist within a social and economic context that nevertheless demands "productivity" and "efficiency" as the hallmarks of success within capitalism' (pp 45). Erevelles contention is important and holds wider implications. It suggests that local experiences of disadvantage are stimulated through degrees of separation from distanced economic and political structures. Such a view destabilises the ideal of human freedoms and personal agency, it also implicates structural influences to be deterministic and directive. As such this position may not only explicate why there is a continued lack of disability equity, it may also lead to the conclusion that an embodied approach alone, is insufficient to elucidate disability experience.

In the school context, the narrowness of the national curriculum, the relational norms of schools and the primacy of individualised summative assessment, may be seen as the means through which pupil differentiations are channelled. Differentiations which are invoked to legitimate segregation as well as individualised accordances of success and failure. Indeed the school curricular from Erevelles perspective is modelled after and serves the interests of a capitalist employment economy.

Consequently, the disadvantages faced by disabled pupils may reflect not only their embodied differences, but their worth as future employee assets. Notably the notion of worth is itself bound to the benevolence of a given society and can be illustrated by reference to contemporary social and political sentiment. Most particularly the contemporary drive to reduce the welfare budget, through the reigning back of state support, without an accompanying address of individual capacities to meet such enforced responsibility (Garthwaite 2011, Hughes 2015, Roulstone 2015). The disregard intimated by these policies does not imply respect, but burdensomeness.

A similar impression is generated in schools as exemplified by the steady and indeed increasing rates of exclusion (DfE 2016) c in the secondary sector. Such dismissal from an embodied perspective directs attention to the individual difficulties presenting, it also speaks to individualised solutions, such as reasonable adjustments and intervention programmes. From a structural perspective attention is directed to the functions served by schools per se and it is through this lens that it is possible to isolate the nature of disablement, not to the individual, but to the system which is directive of the shape of education. Thus as Christensen (2004) suggests continued inequality in schools reflects 'the critical social function of special education...in maintaining a relatively homogenous and controllable population within general education' (pp 23). This approach directs attention from the 'what' of disabling practices, to the 'why'. Thus in this instance, the key factor is not what disabled children can or cannot do which determines their worth and status in schools, it is rather what disabled children can offer futuristically which determines both their worth and support.

Baker (2002) raises a moral point which resonates with the acceptability of social divisors and asks whether 'it is ever ok to think of some humans as normal and some humans as not, some humans as positively able and some as disabled in a negative way' (pp 697)? These questions against the backdrop of school failure and exclusion begs address not of the social standing of the disabled child, but rather of the

function of schools and the morality upon which they stand. This perspective also positions schools as disabling institutions, which following Erevelles's argument, operate in the interests of an entrenched economic system which is directed to the maintenance of economic and political inequality.

Embracing an integrated perspective one can begin to see the limitations of individual models of disability. For whilst a medical model functions to identify the presence of a syndrome and an embodied and social approach to enlighten on what it is like to have a particular disability and the societal barriers to participation inherent. None of these accounts are able in isolation to produce a complete picture, for although their guise is anchored to wider social structures and the mind-set within they operate, such structures remain beneath the surface in all three approaches. It is therefore imperative to combine any model employed with a deeper consideration of the role of structure.

This contention, more than any others, has potential to add flesh to the models of disability, which although at times political in their demands, have not fully highlighted the economic roots of oppression, or the functions served by the subjection of some as less than. The Embodiment Model rather than operating as an opposition, holds potential to support the tenets of the Social Model as equally a Medical Model serves to explain physical and psychological difference at a local level. They are therefore in combination and conjunction with an appreciation of structure a formidable force and following Shakespeare's (2014) sentiment I would concur that the immediate need is to employ these models to improve the situation of disabled persons and this requires collaboration, rather than semantic debate.

2.4.13 Calling for a multifaceted Meta – model of disability

The nature of critiques levelled toward the main models of disability serve to indicate that segmented either or models in isolation cannot do justice to the complexity of disability, nor its situatedness within the wider matrix of social life. Rather the complexity of disability requires a Meta – model of disability, one that embraces the various arenas each model has discretely focused upon. Such viewpoint indicates not that current models are wrong, rather that they are partial. Each contributing segmentally to our understanding. Nevertheless emergent models as previously stated display a finer detail in their orientation and thus offer example of how they have scope to work alongside, rather than act as a substitute for, more established

models of disability. Two models in particular illustrate this point, these are the Care Ethics Model (Rogers 2016) and the Socio-Cultural Models (Goodley and Runswick-Cole (2012) of disability.

Rogers (2016) Care Ethics Model, neither denies nor privileges the Medical and Social models of disability. Rather it seeks deeper appreciation of the social position of persons with an intellectual impairment, drawing upon the reality of the contexts they inhabit and the relationships inherent. The Care Ethics Model exposes the socio-political nature of caring within three spheres founded upon normative socio-political relations, spheres which are also described as care-less spaces (pp 6). These consist of the 'emotional caring sphere where love and care are psycho-socially questioned and critiqued, the practical caring sphere where day-to-day care is carried out relationally predicated upon the norms of social roles and the socio-political caring sphere where social intolerance and aversion to difficult differences are played out in terms of response and consequence' (pp2).

Applying a Care Ethics model to the maternal navigation of the 'challenging' child offers means to expose discrete sites of injustice where identities are constructed founded upon blame rather than recognition of needs accrued from disability. Problematically the nature of difficult difference may be seen to engender a reluctance on the part of families to challenge deficit accordances as personal exposure may heighten, rather than discredit the deficit assumptions underpinning accountability (Gallagher 2010b). Interestingly research amongst parents subject to mandatory parenting orders (Holt 2008, 2010a), indicated that families resist locally accordances of deficit, most typically through identity work conducted during conversation with peers and family members which offer internal affirmation. These small acts of resistance afford not only vital personal reassurance, they also countermand the idea that persons caring for a child with a behavioural disability are passive and accepting of accountabilities accorded.

The need for personal reassurances is well documented: stemming from tangible and multifaceted accountabilities levelled at particularly mothers and their children (Tardy 2000, Home 2002, Blum 2007, Hutchings 2007, Kingston 2007, Gallagher 2010b, Rogers 2011, Tomlinson 2013) both in and out of education. These accountabilities reflect not only the infringement of social codes, but also reinforce to the majority desirable childhood (Moran-Ellis 2010, Buckingham 2013) and the parenting role towards it (Kaplan 1992, Kingston 2007, Landsman 2009). As McLaughlin (2016)

states, childhood disability is produced from the inter-relation of multiple sources, founded upon the ideal of normal development and socio-cultural conceptions of childhood.

My research poses the 'but what about' question. Specifically asking, but what about the many children and young persons who are educationally excluded, drift, or are sucked into criminality, or inappropriate social conduct by virtue of skills deficiencies which are not identified in the school context (Greene 2005). Many of these young people according to the medical labels offered to explain their difficulties, are host to symptomatic effects which distort their ability to respond to social and contextual norms, yet whose intellectual competency masks the appearance of a disability. These symptomatic effects, although documented within diagnostic manuals as criteria for diagnosis (WHO 1992, APA 2013a), appear not to inhibit accordances of blame for the symptoms they describe. These symptoms are thus vulnerable to generating deviant personas, which is itself deflative of any research activity from the perspective of disability, stimulating instead activity based upon impact.

It is therefore necessary to consider how existing and upcoming models of disability could combine to address the social situatedness of both children and families affected by disabilities of impact on their social conduct and competency. Particularly as such situatedness appears to render this population straddled between two competing discourses, that of disability and criminal justice (Karpin and O'Connell 2015, O'Connell 2016).

Rogers (2016) alludes to the vulnerability of intellectually impaired persons to harsh and inappropriate management within the criminal justice system, acknowledging the role that family plays toward the navigation of such processes. Indeed the spheres of caring delineated within Rogers (2016) Care Ethics Model frame many personal and private arenas from which blame emerges. Consequently although the Care Ethics Model has developed from consideration of the social situation of persons with intellectual impairments, it is transferable, holding potential to expose the sites of disablement within the very private practice of caring for children who pose behavioural challenges. Nevertheless an important ethical question is posed, namely whether the role of caring can be sustained when to care also means to contain? As a parent to children whose disabilities impact on behaviour, it is suggested that the two things can and should be seen as one and the same, conjoined through the sentiment of caring about and best interest of in the longer term.

Overall of the models discussed, all excepting the Affirmation Model, share a common feature, namely focus on the negative aspects of disability and processes of disablement. In address, Goodley and Runswick – Cole (2012) illustrate how conceptual models serve to ‘read’ the nature of disability in research, driving discourses ‘that construct objects’ (pp 53). To emphasise this tendency four separate readings were applied to a case study child diagnosed with autism¹ and found to be not only directive of the conceptual lenses applied, but the interpretation of the child’s social and biological being (medical, social, relational and socio-cultural). Significantly Goodley and Runswick – Cole found that the medical, social and relational lens directed attention to what the child lacked or was denied, placing the child and its family in a position of dependency or need. Whereas in contrast a Socio – Cultural stance, drawing upon the child’s private perspective through the use of digital imagery enabled a contrasting profile to emerge, separated from deficit discourses. Notably this served to highlight the areas of value and worth the child inhabits and most importantly recognised.

Looking at the nature of disability research and models of disability generally, they show a tendency to derive from a pre-identified social problem. As a result the affirming aspects of lives lived with disability can become submerged beneath the narratives of need and lack the models construct. This tendency may be said to generate a distance from the smaller features that comprise the tapestry of private life. There is therefore a need to employ methods which can not only reveal relationships of power and inequality, but can also expose disability as it is lived from the familial perspective. This necessitates avoiding the over stating of special advantages as advocated by the Affirmational model. Rather it is more appropriate to highlight the comparability between disabled children and non-disabled children. The Socio-Cultural approach may be seen as directed to this approach, highlighting the common humanity between children. In this sense the Socio–Cultural model speaks to sameness rather than difference, thus disinclining to processes or ‘othering’.

The Socio-Cultural approach struck a chord personally, offering means of seeing both the child and family in a way that is personally meaningful. Not as ‘disabled’ or ‘able’, but simply as child and family, bonded at a primal level through emotional ties.

¹ Medical, social, Nordic relational and socio-cultural

This method also reminds one that disability research need not seek to generate 'big' theories, but can through attention to the minutiae of daily life, create new and affirming schemas which emphasise human commonalities irrespective of difference. This approach has been usefully applied within a research initiative entitled disabled childrens childhood studies. This approach draws upon the stories and personas disabled children and their families share (Curran and Runswick – Cole 2013) within the simple context of childhood. In doing so it is possible to see the ruptures to such normality, more clearly than studies which focus on difference.

2.4.14 In summation

Overall the main conceptual models of disability have neither fostered causal stability, nor brokered disability equality. Not through an inattentiveness, but as a result of unintended consequence. The partiality of the models has inhibited an interrelatedness which could usefully have projected a more complete picture, not only of the organic causes of physical and psychological difference, but their reception socially. More specifically the main models of disability fail to address fully the position of intellectually competent persons, who because of neurodevelopmental impairments, present as 'challenging' socially and behaviourally. Indeed both the Medical and Social models can be seen to have perpetuated further rather than less uncertainties. From a Medical stance, historic review of the medical expansion of categorisations of disability support contention that medicalised explanations are fluid, negotiated and unstable (Ronson 2011, Southall 200, Frances 2012). This is countermining of claims to linear knowledge progression and destabilising of confidence toward diagnostic criteria. Even the turn to neurology to explain behavioural disabilities has opened spaces for increased regulation through the founding of divergent pathways which either deny change is possible, or that demand change through medical and social interventions (O'Connell 2016).

Similarly, although the Social Model of Disability has extended serious challenge to medicalised explanations for difference, its logic of viewing disability as a social, rather than individual state may inhibit appreciation of how disability impacts on childhoods lived. It may be said to be thus shrouding of the embodied reality of neurodisability, making blame appear a reasoned response to unacceptable action. Anastasiou (2013) states, 'dubious theories about disability, grounded on the denial of biological conditions, cannot serve the interests of all people with disabilities in the long run', not least because it is a 'flawed concept of disability which makes it

susceptible to negative socio-political shifts' (pp. 456). Looking at the educational context, such shifts are can be evidenced through the disadvantaging responses disabilities that are incompatible with wider school priorities attract (NASUWT 2008, 2012a, b, NFER 2012, DfE 2012d, Ofsted 2012, 2014a). These responses signify the vilification, rather than creative tolerance of pupils unable to comply by virtue of disability and is contrary to the sentiment of educational inclusion and disability equity.

I assert therefore that the Social Model has resulted for some to their being vulnerable to greater, not less, personal accountability for difference, particularly where such difference is less obviously disability derived (Valeras 2010). The following excerpt expresses succinctly the Social Model's perceived shortcomings:

'Instead of tackling the contradictions and complexities head on, we have chosen instead in our campaigns to present impairment as irrelevant, neutral and, sometimes, positive, but never, ever as the quandary it really is'(Crow 2010, pp3).

Crow's commentary resonates strongly with the difficulties faced by persons who do not look 'disabled', but present differently and often challengingly; thus presenting impression that the effects of disability are personal will, not symptom. Crow's call for greater emphasis on practices which contribute to a 'conspiracy of silence' (pp. 4), which is generative of greater taboos around the practical manifestations of disability is thus timely. These silences within the scope of this research are most clearly alluded to by Carpenter and Emerald (2009) and stated to be led not from a lack of research activity, but through a lack of family narrative able to elucidate that practical circumstances of such disabilities. Such silence in respect of behavioural challenge emerges as personally familiar; and on reflection I would consider myself contributory to this identified silence. Most specifically through a maternal inclination to put a positive spin onto mothering situations that have been at times unmanageable. Maushart (2000) defines this tendency as the mask of motherhood, a silent acceptance of responsibility (Freire 1996), which colludes with charges of accountability (Muller 2008).

It is therefore concluded that whilst conceptual models are useful for abstractly mapping the nature and situatedness of disability in contemporary societies; excepting the Socio-Cultural Model, these models display limited capacity to elucidate discretely or eclectically, the reality of disabilities which challenge behaviourally. The Socio-Cultural Model in contrast privileges 'being', across the

range of lived contexts, rather than seeking causal attributions for disability. Henceforth it offers means to see the person holistically, not as 'other' (disabled or impaired), but simply as a person, with multiple identities and strengths as well as particular weaknesses as such has scope to close the distance between able and disabled.

Notably in education the medical model dominates explanations for difference, despite the shift to educational rather than medical needs. Such explanations are also primary toward legal and educative entitlements. Nevertheless medicalised explanations, upon closer inspection, reveal numerous sites of disagreement which hold potential to foster challenge. This review will now focus on these areas, followed by review of wider sites of challenge which emerge from alternative explanations for presentations of difference as disability. These explanations are chiefly social and relational and this review finds that they are equally implicated in the disadvantages accorded to children and families, for whom disability incurs effects which are mainly behavioural.

2. 5 Subsection 4: Exploring the sites of challenge

2.5.1 Introduction

Typically, identification of disability and the defining of categories of disability has developed under the dominant jurisdiction of the medical profession. Jurisdiction which Blackmore (2012) notes evolved during the 19th Century, in conjunction with the study of disability from a more objective stance, directed at cure and rehabilitation, rather than spectacle. This direction is stated by Blackmore to have been the impetus to a more nuanced classification of disability presentations, resulting in the identification of many medical labels to denote disability. This expansion of disability classifications has seen a corresponding expansion of departments and groups directed to the task of remediating the conditions they represent. In addition, Blackmore suggests that a climate of medicalisation has fostered a climate where organic disability is perceived to be the most logical explanation for challenging behaviours. Thus resulting in the claim that ‘biophysical abnormality’ or ‘maladaptation’, leads to, or is the cause of ‘social abnormality’ or ‘maladaptation’ (pp 71). The association of disability with ‘behaviour’ has led to practices of separation, which may be considered both punitive and rehabilitative (Riddell 2007). Contemporarily, identifications of disability remain the remit of the medical profession, which has overtime generated the impression of an incontestable right, inhibitive of alternative explanations for difference.

This positioning limits the grounds upon which challenge can be congruently levelled without accusation of radicalism or politicisation and as Wedge (2015) observes challenge and dissent bounded within a medical paradigm is common, frequently originating from within the medical profession itself (Frances 2012). Causing greatest controversy are the medical explanations offered to account for symptoms which are not physically visible, and as such, contestable. Most typically these are of developmental, psychological or behavioural orientation. The Autistic Spectrum is illustrative of the dilemmas a broad range of differences can conjure as for those deemed to be at the higher functioning end of the spectrum, debates have coalesced around how to stratify a multifaceted spectrum (Wing 2011, Kaufman 2012, Smith 2015, Parsloe 2016). Equally there is evidence of controversy as to whether Autism represents a disability (O’Reilly 2015) or is simply indicative of cognitive difference (Sinclair 1993, 2005), the pursuit of which has been the impetus to multiple research

projects (Smalley 1991, Cukier et al 2011, Hohmann et al 2015, Pinto et al 2016). Glackin (2010) broadens the research lens beyond organic markers and points to an interplay between social and medical determinations, whereupon it is considered that 'all judgments of medical dysfunction ... reflect our collective willingness or reluctance to tolerate and accommodate the conditions in question' (pp2). It would appear therefore that the final judgement in respect of what is or is not indicative of disability is social.

Wedge (2015) offers a useful example of how differing interpretations of the same phenomena can alter in meaning and implication, by illustrating how causal attributions toward the commonly diagnosed condition ADHD have differed internationally. Wedge notes that when the majority of Europe and America looked toward organic and neurological explanations for ADHD, extending corresponding medical intervention to remediate symptoms (Efron 2015); the French psychiatric profession tempered such attribution with belief that cultural and parenting factors were of equal effect on the presentation of symptoms. Such contention has served to reduce dramatically the prevalence of ADHD diagnosis within the French system and by extension the use of medication to address the difficulties perceived.

Irrespective of the rightness of either position, the wider implications of this attributional division is the generation of spaces for challenges to surface outside of the medical profession. For where nurture and environment are implicated as variables causing symptomatic effects, it summonses criticism in the craft of living. Equally the divisions in etiology which surround conditions such as Autism and ADHD, have destabilised certainties around their status as medical conditions (Armstrong 1995, Eyal 2010, Timimi 2009, 2010). Equally such instability has also had a destabilising effect on other medical labels (disabilities) of a similar type (Conrad 2005, 2007, Bursztyn 2011, Smith 2012).

ADHD particularly has attracted controversy in respect of its claim to medical status; led by the contention that it is in essence a social construction (Faraone 2003, Bailey 2006, Cohen 2006, Amaral 2007, Graham 2007b, 2008, Conrad 2010). Notably as ADHD is heavily associated with behaviour, the search for causal explanations outside of a medical frame have led for some to the levelling of personal and familial accountability.

Attitudinal divisions charted by Lloyd (2003) reveal three main positions regarding the status of ADHD. These range from an unquestioning adherence to medical causation, to those who adhere in principle but indicate concerns towards over identification and finally those that challenge the foundations of the claim to medical status. This latter position is found stimulating of a deeper interrogation around the relationships that underpin the medical status of ADHD and its medical response (pp. 106). Not unsurprisingly these divisions of opinion appear to endure most prominently in schools (NASUWT 2008, 2012 a, b, Neil 2013), where their impact is most openly on display. This has been an impetus to further consideration around what is an appropriate response to not only ADHD, but other disabilities of a similar ilk. Looking at the divisions fostered, it is clear that challenge has not only been levelled at the integrity of discrete medical labels, but also doctors diagnostic judgements (Shaughnessy 2015). These challenges as importantly exceed the professional domain and rebound onto pupils and families areas through the potential for accordances of blameworthiness.

Blameworthiness is logically implicated in the decision as to whether to make, or recommend medical referral and can be usefully defined as the primary means professionals employ to make sense made of difference. It is also according to Nunkoosing (2012), the primary mechanism that connects aligned professionals and importantly initiates the 'othering' process. Notably the new SEN Code of Practice (DfE 2015a), requires schools to consider the causes of difference, particularly challenging behaviours. At this juncture there is a clear emphasis on psychological drivers, which is also reflected in the renaming of behavioural, emotional and social difficulties (BSED) to social, emotional and mental health difficulties (SEMH). Nevertheless whilst this move suggests a greater association of 'challenging' with disability, it also necessitates teachers act in a secondary medical capacity. It is thus of concern that there is no obvious commitment to provide additional training or the invitation to familiarise with, or engage in, ongoing debates linked to the delineation or challenge to medical labels. This leaves one to question how informed teachers judgements are.

Equally the identification responsibilities accorded to teachers may also be swayed in their judgement by the presence of wider pedagogical tensions which are themselves directive of dispositions to identify either disability or SEN. The Special Education Needs and Disability Review (Ofsted 2010) illustrates this concern and has prompted

a sensationalised summary by some UK media sources (Maddern 2012 a, b). In particular it is claimed that teachers identification responsibilities were being discharged with overzealous application, inflating the true incidence rate of disability and SEN. This too may be seen to have furthered diagnostic doubt, not least because Ofsted suggest that some underperformance can be more truthfully attributed to teaching failings, not learning difficulty. Ofsted's report is found to have radically reduced the rates of disability/SEN identification in schools and has had implications for the identities of pupils already identified (Runswick-Cole 2008, Maddern 2012a, and Klehm 2014, Curran 2015). These effects have also fostered concerns that some children will be denied needed school and clinical support (Bolea – Almanac et al 2013).

It is nonetheless noteworthy that Ofsted's 2010 review and the current SEN code of practice (DfE 2015a), appear to be extending conflicting messages; the former calling for less identification, the latter more nuanced determination as to the causes of behaviour. Irrespective of the rightness of either position, the incongruence displayed holds potential to undermine confidence in the identification process as well as toward the medical labels themselves. Thus by default it introduces discourses that invite blame and imply external accountability.

2.5.2. Challenging, explicating and defending truth claims

Medical labels and the identities of ability/disability they confer may be usefully described as claims to truth and it is the integrity of these claims to truth which are found to open spaces for challenge. The history of psychiatry is illustrative as Szasz (2012) details, showing the antipsychiatry movement to have been foundational to challenging medical authority and intent. This movement may also be seen to have acted as the impetus to wider medical challenges, particularly toward emergent medical labels used to define neurodevelopmental childhood disability. These are discussed in greater detail later in this subsection and demonstrate further the tenuous nature of what are considered disabilities based on medical facts.

Debates toward the nature (and indeed possibility) of truth are a mainstay of the sociology of knowledge and most commonly associated with the contemporary philosophy known as post-structuralism. Foucault (1972; 1982; 1997 a, b) in particular has cast doubt on the linearity of knowledge production and by doing so destabilises the notion that medical debate and reclassifications signal progress.

Equally, in a similar sentiment to Szasz (1998; 2007; 2012), Foucault casts doubt upon notions of medical beneficence; claiming medical scrutiny and especially diagnosis (colloquially referred to as 'the gaze'), to be the primary means employed toward the control and subjection of difference (Foucault 1967; 1973; 1982 and 2006). The contentions of Szasz and Foucault have been central to challenges which contest that medicalisation of difference signifies objective scientific endeavour (Foucault 1967, Szasz 1974; 2012, Laing 1985, Rissmiller 2006, Conrad 2007). To the contrary medical truths are alternatively described as the output of professional choices, based frequently on alliances forged within a bounded paradigm of sense making. As such they may be seen to resemble the collective which Foucault (1997a) refers to as 'technical ensembles' (pp 12) and invite a deeper address of interest and function.

Mallet and Runswick-Cole (2012) offer a further dimension from which to consider the medical label Autism; namely from the position that Autism exceeds descriptive nomenclature and has evolved into a commodified product within the field of academia. Employing a critical theoretical frame, Mallet and Runswick-Cole demonstrate how Autism as a concept has been expanded and reproduced through social and scientific study into both a 'commodity and an unsatisfied desire' (pp 36). This process is stated to set in motion a chain of both supply and demand, which alters in integrity the potential for diagnostic objectivity as it introduces wider priorities which preside over decisions made. Indeed thinking of the professional positions, organisations and therapeutic environments aligned to Autism, it is reasonable to extend this perspective beyond academia and question more closely the rationale for their input. These contentions are beyond the scope of this review, nevertheless they may be said to alter the guise of explanations for diagnostic expansion and prevalence. In doing so they also destabilise medical certainties and secondary professional confidences. They also invite further address of commodification practices across a wider range of professional contexts, not least the pharmaceutical industry, as has been the case in relation to the medical management of ADHD (Read 2005, Phillips 2006, Smith 2012) and the management of what are termed behavioural disorders (Hardwood 2006, Cross 2011, Hardwood and Allen 2014).

Mallett and Runswick-Cole proceed to discuss how the object of commodification is distanced from the labour that produced it, affording it the appearance of tangibility. They conclude that these 'processes of abstraction (the assigning of real and

discernible characteristics to an entity across a range of other entities) can be seen to not only create Autism as a 'thing', but specifically as a 'commoditised thing' (pp 37). On this basis they asserted that 'informationally Autism has become big business' (pp 40).

The processes depicted by Mallett and Runswick – Cole stimulate a further avenue of thought which is generative of insecurities around discrete classifications of disability. Hence although Mallett and Runswick-Cole acknowledge that 'categories of impairment have not been subject to such analysis' (pp35); the assertion that medical labels are being exploited as capitalist commodities, demands a deeper address of whose interests have been served through the expansion of medical labels? The answers to this query holds potential to extend across a range of professional posts, yet indicates there to be a much less favourable impact on those identified as having a disability. Particularly in respect of 'challenging' behaviours, where medical explanation appears not to have extended mitigation or acceptance. To the contrary, in many cases it has fostered a deterministic attitude which has legitimated disadvantaged position and accountability (Parsons 2005, Jull 2008, Karpin and O'Connell 2015, O'Connell 2016).

Titchkosky (2012) contends that it is necessary to question why disability is always seen as a problem and as such framed negatively and in address it has been suggested that the answer derives from the conceptual anchors used to define ability (Campbell 2008; 2009). Indeed the notion of disability being the inverse of ability resonates with Kelly's (1963) philosophy of Constructive Alternativism and the contention that oppositions guide meaning.

Notably Glackin (2010) suggests it is the juncture at which an individual problem becomes a social problem that triggers collective response. Certainly in education this also seems to be a trigger as impact on other pupils is recurrently stated to be one of the chief factors which revokes mainstream educational entitlements (Parliament 1981; 2001; 2010b; 2014). It is interesting nevertheless that whilst disability is viewed medically to be a physical or psychological anomaly, socially it invokes superficially, protection and sympathy, but only to a certain point. For where there is an intersection of adverse impact on the social collective, there are subtle processes of distancing detected, which derail associations of disability and reroute to discourses of accountability (Parsons 2005, Jull 2008, Karpin and O'Connell 2015, O'Connell 2016). Such diversion not only speaks to the parameters of social

tolerance, it also directs one to avenues which open spaces for wider challenges to claims of disability status. Indeed the point of diversion from a discourse of disability to that of accountability is fundamental to the logic of blameworthiness.

2.5.3 Medical Insularity

The range of challenges medical explanations for difference conjure is nevertheless limited due to the protective effects of the paradigm of which they are an integral part. As Titchkosky (2012) asserts 'the world comes to us as given' (pp 129) and thus differences are explained (and indeed challenged) within it. This serves to localise challenge most typically to within, rather than against, a legitimated body of knowledge. In practical terms the most common challenges levelled in respect of medical labels are around issues of etiology, the criteria for diagnosis and appropriate response (Karlović, Zoričić, Buljan, Crnković and Martinac 2002, First and Spritzer 2003, First, Reed, Hymen and Saxena 2015). Even challenges which claim a particular instance of difference is led by social rather than medical factors, rarely take issue with the truth claims of medicine overall, despite having real life implications for those whose disability status is compromised (Barkley 2002, Bolea – Almanac et al 2015).

Notably medical labels hold economic value as they remain central to educational provisions and support (Florian 2008a), classically through the sorting of pupils into educative life pathways. This function was most clearly formalised within the 1944 Education Act (Parliament 1944, Atkinson 1997, Armstrong 2003) and despite being railed against in the recommendations of the Warnock Report (1978), medical labels continue to act as gatekeeper for educative and rehabilitative services and support (Florian 2008a).

Problematically, even though medical labels per se, logically attract the protections of the medical paradigm and the disability protections built upon it, their currency in terms of resource access, invites a further avenue of challenge. Most particularly the charge that schools inflate prevalence rates of disability and SEN to increase additional funding and deflect poor teaching (Ofsted 2010). These avenues of challenge constitute part of a wider body of thought that critically assesses the role of context and environment to the appearance of difference. Notably this has been most evident in respect of the conditions of ADHD and Autism, both of which are

commonly diagnosed in childhood (Danforth 2001, Jones 2003b, Cohen 2006, Moffitt 2007, Graham 2008, Timimi 2009, Conrad 2010).

Three areas in particular are implicated in contemporary disability challenge; these being the rapid expansion of medical labels, the scope of behaviours that are deemed open to medicalisation and the treatment protocols they have given rise to. These challenges may be seen to have had a deleterious impact on the credulity of classificatory expansion, the legitimacy and confidence in treatment protocols and by default the placement protocols of children identified as having a disability (Gergen 1990, Rafalovich 2001 a; b, Cigman 2007, Conrad 2007; 2014, Humphries 2008, a, b, Bursztyn 2011, Elliot 2014). This subsection now turns attention to these debates to illustrate the varied factors which may be implicated in my own and indeed my parent respondents experiences of disability response in education.

2.5.3 Debates within the medical field –fostering of insecurity

Medical debates frequently polarise around diagnostic protocols and are most clearly visible during the revision period of classificatory manuals such as DSM and the ICD (WHO 1992, APA 2013 a). Discord has been most vehemently stated in relation to the commonly diagnosed conditions of Autism and ADHD (Tripp 1999, Karlović 2002, Said et al 2015, Wilson et al 2013, Smith et al 2015). These conditions in particular are found to attract inconsistent medical opinion (Bekle 2004) as do behavioural difficulties generally amongst teachers (Cook 2000, 2001, 2004, Cassady 2011). As a result medical debates which imply uncertainty hold potential to not only destabilise secondary professionals attitudes, but to also impact on the support provisions offered (Bolea – Almanac et al 2013).

The fit of diagnostic criteria is central to the credibility of knowledge progression within the medical field, yet professionally it is perhaps more credible to suggest it to be work in progress. Medical labels hence presents as less than certain and whilst these processes may be an accepted working practice within the medical profession, they may be misinterpreted as unsound practice by those outside of it. Particularly as the debates emanating from within the medical profession are vulnerable to misreporting in more general media and as such extend a further avenue of doubt (Lahey 2006, Wilson 2013). Medical discourses are stated by Levy (2014) to have dual implications; on the one hand signifying healthy professional debate, which emphasises the complexity of diagnosis criteria, the resolution of which is vital to

knowledge progression. On the other hand such debates serve to destabilise professional authority and the legitimation of implicated medical labels (Tripp 1999, First 2003, Sorenson 2005, Polanczyk 2005, Thomsen 2005, Eyal 2010).

The recent revision of the DSM illustrates how persons identified with a particular medical label are in essence hostages to fate. The disbanding of the medical label Asperger's syndrome and its subsuming under the broader term Autistic Spectrum Disorders is a pertinent example, reminding us that medical labels are vulnerable to reconfiguration (Frances 2012, Kaufman 2012, American Psychiatric Association 2013, Bolton 2013, Koriath 2013, Mayes 2015 a). Reconfiguration nevertheless not only rebounds onto the identities the medical labels conjure, from a popular perspective, reconfiguration processes may be also be considered to imply that the label being reconfigured was essentially unstable, thus extends further grounds for challenges to emerge. At the very least reconfiguration generates insecurities and places in jeopardy the social and legal status of disabled persons left holding defunct labels.

Giles (2014) has addressed the impact of these changes on the 'Aspie' online community and found mixed response punctuated by both adjustment and acceptance alongside insecurity and worry. Of equal significance were the signs of ownership Giles describes, which indicated that the online autistic community appeared to be moving toward a self-definitional state, which was not dependent for its identity on the vagaries of the medical profession. These are as Giles suggests, untested times; facilitated by the rallying potential of online communication networks. It will therefore be interesting to observe whether online networks serve to mitigate against the insecurities posed through medical debate and reclassification schedules.

Although medical labels may be generally considered to represent claims to truth, it is the purposes behind these claims which hold implication. Szasz (2012) in particular has emphasised this point stating that in the field of psychiatry medical truths are appropriated as instruments of control, whereupon the psychiatrist is empowered to 'impose 'help' (pp 354). From this perspective the reconfigurations previously noted may be alternatively considered representative of societies control needs, rather than the output of medical progress.

Looking at the contentions of Szasz (2012) and the findings of Giles (2014), there appears two juxtaposed positions implicated. The first elucidates the imposition of

medical labels and that of therapeutic interventions, whereas Giles notes a growing momentum of those who hold and embrace a medical label and who appear to be definitional upon it. It is hard to visualise this latter group as subordinated, indeed they may be seen as highly proactive in respect of its common meaning outside and within the medical profession.

Parslow and Babrow's (2016) have similarly canvassed the reaction of the autistic community on the social network site "Wrongplanet" and offer useful insights into the types of insecurities generated through diagnostic change. Most notably the discussions highlighted confirm Giles findings that there appears to be a lesser reliance on the medical profession for diagnostic validation than theorists such as Szasz maintain. The discussions recorded do not confirm an impression that an autistic diagnosis was imposed. To the contrary, many contributors were actively evaluative of their own status and the criteria used to diagnose, some also avoided a diagnostic route, preferring to self-identify.

Significantly of the concerns identified by Parslow and Babrow (2016) and also those of Giles (2014) a significant percentage surrounded the practical (financial and legal) implications of the changes proposed, rather than any insecurity in respect of identity. Indeed it was in respect of identity and abilities, that the autistic community displayed the greatest confidence and laid down its own challenge to the conventional wisdom of medical orthodoxy. Most notably the conventional claims of lack of empathy, communication and need for companionship are found disputed (Sinclair 2005), although the guise of these factors are openly acknowledged as differing from those defined as normal by persons termed 'neurotypical' (Wrongplanet 2012, 2016). In respect of adaption, there is ongoing evidence that the submerging of former medical labels to denote autism under the single label 'autistic spectrum disorders' (APA 2013a) is leading to the widening of the autistic community. 'Spectrumites' (2016) is an online support group which is illustrative of this initiative, focused on three specific arenas; 'autistic rights activism, connections between autistic people, and support'. This example suggests a level of resistance and thus agency from within a defined community and it will be interesting to observe over time the extent to which it is able to lobby for its own defined rights. As such may prove an invaluable tool to combat the disadvantages the young people in this study have indicated.

Nevertheless to make sense of the two extremities outlined by Szasz (2012), Giles (2014), Parslow and Babrow (2016) it is useful to refer to Szasz's differentiation

between voluntary and involuntary psychiatric intervention, particularly his contention that the term 'psychiatry' cannot be usefully applied to both extremes (pp xii). For within the bounds of this thesis and indeed childhood diagnosis per se, I would argue that it does and it can. Chiefly because none of the young people implicated in my research, including my own sons, did not seek diagnosis personally, nor did they have capacity to resist. They represent therefore a grey area, a group of involuntary patients, whose assessment was voluntarily sought by familial proxy. This has important implications for Giles (2014) and Parslow and Babrow's (2016) findings. Most specifically because although the adults within the autistic community appear self-definitional and defensively so, it is likely the impetus to their identity was pursued by proxy, despite their evident capacity to mould it collectively.

This grey area holds significance in relation to the perpetuation of medical labels generally, for the identities established in their name signifies an important means by which any critique around validation can be neutralised from within. It was also evident from both Giles and Parslow and Babrow's findings that medical ratification is not the de jure factor of validation for those claiming a condition. Rather validation is found heavily aligned to group affirmation and may be seen to confirm the contentions of group theory as is discussed in the following subsection (Barr 2014). The generation and adaptability of identity may thus forth, be seen as the buy in which fosters the continuance from within of a medical label or spectrum.

What is apparent from this brief consideration of debates within the medical profession is that they are found to open sites of challenge and generate insecurities that compromise medical wellbeing and exceed the bounds of the medical profession. Yet simultaneously debates and label revisions are also found to be stimulating of adaptive responses which foster and protect disabled identities through group cohesion. Problematically when behaviour was a major factor my experience was that diagnostic insecurities led to unwarranted effects. Of these the most damaging were challenges made to my sons held diagnosis which were invoked to legitimate wider accordances of accountability. These were hard to defend in the moment and it also became clear that there was a delicate line between reference to a diagnosis to explain actions and such reference being reinterpreted as evidence of incapacity or dangerousness. This more than anything else instilled in me the idea that medical debates were important and game changing, not least because they introduced uncertainties which revealed incongruent beliefs.

2.5.4 Categorisation Expansion – the significance of DSM 5

Although reference has been made to the effects of the expansion of medical labels and the incidence of diagnosis made, it is useful to briefly expand more fully on the breath of these expansions to illustrate why they are considered so significant and destabilising of label validation. The table reproduced below offers a snapshot of the rate of expansion witnessed since the first edition of DSM was published. At first glance it is understandable why the conclusion may be drawn that such expansion could not really reflect the rate of medical advance. This subsection therefore looks at the implications of the newest edition DSM 5. Most specifically because the publication of previous editions and corresponding expansion have raised significant concerns. Most specifically DSM revisions have been found to have been a significant factor used to discredit many medical labels aligned to neurodevelopmental disability and learning disabilities (Armstrong 1995, Bailey 2010, Graham 2010, Timimi and McCabe 2010, Gibbs and Elliott 2012, Aftab 2014).

The growth of the <i>DSM</i> since first publication		
<i>DSM</i>	1952	100 pages (containing about 60 disorders)
<i>DSM-II</i>	1968	150 pages
<i>DSM-III</i>	1980	500 pages
<i>DSM-III-R</i>	1987	567 pages
<i>DSM-IV</i>	1994	900 pages

Table 1: The Growth of the DSM (*Southall 2007 pp. 7*)

DSM throughout its publication history has witnessed steady expansion as is detailed in table 2. This has impacted significantly on how the range of presenting disorders in schools are understood and responded to. It also conjures questioning around the extent to which teachers and aligned secondary professionals can be expected to, or are motivated to keep pace as their identification and pedagogical responsibilities have expanded (DfE 2015a). Classificatory expansion impacts heavily on how presentations of difference are interpreted, extending potential for challenge as diagnostic shifts may not command axiomatic acceptance, particularly in the school environment where staffs are not always privy to clinical rationale. Notably table 2 predates the most recent revision of the DSM, however interestingly the scope of changes contained within DSM 5 are not intimated through reference to its

pagination, which is in volume comparable to its predecessor. The scope of amendments nevertheless offer indication of why challenges and confusion may be conjured outside of the profession (APA 2013b).

One particular area of instability witnessed from the revisions is the reconfiguring of the breath of the Autistic Spectrum through the consolidation of several conditions including Pervasive Developmental Disorder (non-specified) under the common nomenclature 'Autistic Spectrum Disorders'. Similarly destabilising as previously discussed is the discontinuation of other familiar classifications such as Asperger's Syndrome, whose removal is found to 'destabilise 'Aspies' self-advocacy and cultural constructing efforts' (Parsloe and Babrow 2016, pp. 493). These changes hold potential to impact negatively on those holding pre-existing diagnosis, both within and without the school context, although Wilson's (2013) preliminary comparison suggests the effects on the diagnostic rates of ASDs to be minimal.

Markedly some changes within DSM 5 hold potential to reduce accountability toward behavioural differences, despite the potential of new medical labels to stimulate challenge. Most significant is the rebranding of ADHD as a neurodevelopmental condition, moving it from its former status as a disruptive behavioural disorder. This change has been accompanied by a corresponding revised protocol recognising the continuation of Attention Deficit Hyperactivity Disorder into adulthood (Miller 2010).

Disruptive Mood Dysregulation Disorder (Association 2013a, b), represents a new medical label whose criteria for diagnosis is based on the presence of non-contextual atypical anger outbursts in adolescence over a sustained period of time. It is also a controversial label as adolescence stereotypes frequently typify this developmental state and perpetuate its stereotype as a developmental phase. The introduction of this new label is thus a site of potential challenge, as its introduction cannot guarantee popular acceptance, nor indeed wider medical acceptance (Mayes 2015a). Consequently during the period immediately following its introduction, such uncertainties may result in secondary challenges toward any pupils presenting with this new label and it remains to be seen how accepted this new label is in the wider domain.

Equally the new additions to DSM 5 are not guaranteed to be included across other classificatory manuals and it is unclear whether DMDD will be included in its present form when the ICD 11 is produced. Differences between classificatory manuals are

found have been generative of challenges, both from within the medical profession and without. This is exemplified by reference to the International Classification of Diseases (ICD) which similarly operates to aid diagnosis (W.H.O 1992). Nevertheless comparisons between DSM and ICD demonstrate inconsistencies in diagnostic protocols which impact on the accuracy of prevalence levels globally (Said et al 2015, Smith et al 2015, Wilson et al 2013, Karlovic 2002, Tripp 1999). These incongruences further problematize categorisation confidence and add weight to the argument that asserts medical labels are essentially a social construction (Gergen 1985; 1990, Anderson 1996, Thomas 1997, Danforth 2001, Molloy 2002, Rapley 2004, Amaral 2007, Timimi and Leo 2009, Graham 2010, Hodge 2016).

In the school context these judgements are in the first instance the remit of teachers and SENCOs, who may usefully be described as secondary professionals. It is likely therefore that their judgement may be influenced (if not represent) pedagogical responsibilities and priorities and that these may not necessarily mirror clinical judgements. McLaughlin (2006) states that 'unlike classification that may take place in clinical settings, classification in school systems is a messy process influenced by many individuals and conducted in an environment of rationed resources'(pp 46). Thus whilst secondary professionals operating essentially as laypersons may assert they do not consciously form opinions and make attributions about pupil presentations based on wider school priorities and tensions; it is reasonable to suggest that their judgements are unlikely to be totally disrespecting of such factors. For at the very least, what is considered outside of the range of 'normal' pupil behaviour is itself likely to reflect school priorities, rather than reasoned medical evaluation.

Notably of the central arguments challenging the legitimacy of medical explanations for conduct is that which cites organisational factors to be heavily implicated toward the appearance of symptoms. Graham in particular has reiterated this charge, stating that school organisations, not innate physical factors lead to the appearance of ADHD symptoms (Graham 2007 a; b, 2008, 2010 and 2015) Graham (2015) states that contemporary identifications of childhood disabilities, lead not from symptom presentation but from the opposite, the absence of 'wellness', 'to be well is to be not 'unwell' (pp 12). This may appear as a simple semantic reversal, yet if interrogated further, it becomes clear that the concept of 'wellness' in the school context is strongly imbued with value judgements, pertaining to the qualities considered

foundational for school success. Affirmation which is itself determined by the priorities set by the UK government not the teaching or medical profession.

A further complication to the objectivity of identifications of disability in working practice is that such judgement appears to be reconciled on the basis of wider social factors, not least social class and ethnicity (Nind 2008, Russell, Steer and Golding 2011, Heilker 2012). In addition it is suggested that what is defined as problematic behaviour is denoted by organisational codes of conduct, not clinical criterion (Bailey 2006, 2009, 2010, Conrad 2010, Bursztyn 2011). These factors taken in conjunction not only undermine the capacity of schools to appropriately identify the presentation of clinical symptoms, they also foster the idea that the school is complicit in the appearance of symptoms. It is thus paradoxical that on the one hand there are concerns raised in relation to over identification of childhood disorders, when in parallel the school context is being charged with being complicit toward the appearance of symptoms. It is nevertheless useful to expand on the concerns raised in relation to the expansion and increased diagnosis of childhood disabilities.

2.5.5 Challenges extending from classification and prevalence expansion

The expansion and increased prevalence of childhood disabilities is controversial (Gergen 1990, Foucault 1997 b, Glackin 2010, Bursztyn 2011), attracting various explanations which have been a stimulus to disability challenge and can be usefully illustrated through reference to the medical label Autism. Autism was historically an uncommon medical state (Bleuler 1908, Kanner 1943) which has witnessed prolific expansion (Leonard, Dixon, Whitehouse, Bourke, Aiberti, Nassar, Bower, and Glasson 2010). Although now commonly identified, questions surround the impetus to expansion (Gernsbacher, Dawson and Goldsmith 2005, Eyal 2010) which may be seen to have an impact on the nature of challenges levelled.

Initial reaction to the increasing identification of autism was a search for causative triggers, resulting in the imputation that routine immunisation was at cause (Wakefield 1998). Such claim spread panic amongst parents, prompting legal action and division within the medical profession (Cohly 2004, Baker 2002, Godlee, Smith and Marcovitch 2011). Irrespective of validity, these claims to truth held palpable effect, not least on vaccine uptake, whose decline was linked to the emergence of illnesses formerly considered eradicated (Casiday, Cresswell, Wilson, and Panter-Brick 2006). Notably the eventual discretisation of Wakefield's research (Flaherty

2011) prompted alternative explanations for the continued expansion (Leonard 2010, Matson 2011) which in determination led to questioning around the diagnostic process, particular the protocol for diagnosis (Jasanoff, 2004, Frances 2012). These controversy persists as most recently witnessed during the revision of DSM 5 (Wing 2011, Frances 2012, Kaufman 2012, Koriath 2013, Smith 2015 and Parsloe 2016) and have led to increasing concerns around the integrity of the autistic spectrum. These concerns are further heightened through concerns of identification biases, most typically in relation to also found in relation to gender, social position and ethnicity (Gregory 2009, Heilker 2012, Delobel-Ayoub, Ehlinger, Klapouszczak, Maffre, Raynaud, Delpierre and Arnaud 2015).

These challenges, although discrete to the prevalence of autism, reveal general points of challenge which can equally levelled across the spectrum of emergent medial labels. Indeed it may be said that the shift from (behind closed doors) subjective clinician assessment, to accessible standardised classificatory systems which state diagnostic protocols openly (Spitzer 1992, 2001), have through transparency and accessibility increased the scope for challenge, which in itself has called the medical profession to account in a manner which was previously unprecedented.

The move to diagnostic transparency has been attributed to a paradigmatic shift linked to the diminishing of psychoanalysis as the dominant psychiatric frame of reference (Rafalovich 2001 a; b); and resulted in the development of standardised checklists of diagnostic criteria across practitioners (Spitzer 1992, 2001). Such shift has also facilitated the epidemiological comparison both nationally and internationally of diagnostic trends, which has further widened the scope for challenge, particularly where prevalence rates and diagnostic criteria are found to differ internationally (Anderson 1996, Tripp 1999, Faraone 2003, Amaral 2007, Polanczyk 2007, Wedge 2015). Even though contemporarily the diagnostic process remains guided by the authority (and interpretation) of diagnostic manuals and the criteria for diagnosis they consolidate (W.H.O 1992, Association 2013, Spitzer 1992, 2001, Suris 2016); prevalence disparities have ignited a more general questioning of the robustness of classificatory systems generally (Gergen 1990, Prior 1997, Rohde 2005, Lloyd and Stead 2006, Amaral 2007, Conrad 2007, Southall 2007, Timimi 2009, 2010, Bursztyn 2011, Smith 2012, Whitely 2014).

The standardisation of the diagnostic process may thus be seen to have opened a forum for debate outside of the medical profession, composed of laypersons and aligned secondary professionals. These processes have been most fiercely exemplified in respect of the commonly diagnosed condition ADHD (Barkley 2002, Timimi 2004, Rohde 2005, Polanczyk and Rohde 2007). Thus resulting in what may be described as a trial by media (Goldberg 2011, Walker 2011, Ronson 2011, Reilly 2013, Liddle 2014, Moody 2014). Notably the points of argument exposed are not bound by, or even informed by professional standards, rather are vulnerable to being partial and creatively packaged for public consumption. They thus act as powerful vehicles for the dissemination of propaganda, engendering of insecurities toward the robustness of medical labels generally.

Collectively these challenges although embedded in professional discourse have generated wider insecurities, strengthening the previously stated contention that many behaviours depicted as constitutive of a syndrome or condition, yield not from organic disorder, but social constructs, cultural norms, deficit child management and inconsistent parenting (Faraone 2005, Bailey 2006, Jasanoff 2004, Neely – Barnes 2011). Such sentiment is formative not only to a culture of accountability, but to the fostering of diagnostic insecurities which impact on the inclination of social institutions to provide familial and school supports as can be seen by recent changes to the benefit system (Garthwaite 2011, Roulstone 2015). Such disinclination is ironically 'disabling' not only to the child, but his/her immediate family and the community of which they are a part (Holt 2008, 2010a, Rogers 2007a). As Ridge (2013) cautions, austerity measures are impacting strongly on the most vulnerable sectors of society, particularly children and families in poverty, which the Papworth trust (2016) identifies as being disproportionately represented by families with a disabled family member. Equally Ridge points to an exacerbation of discourses of entitlement serving to not only marginalise dependent families further, but to position them as reasonably accountable for their own dependency.

What is less stated, but notable, is that the challenges identified rarely compromise the overall validity of the medical labels per se, rather they induce scepticism around the robustness of precise diagnostic criteria and its application (Tripp 1999, Moffitt 2007, Polanczyk 2007, Bauermeister 2010, Frances 2012), which is seen as supporting of Lupton's (2012) contention that medicine operates in society as a culture.

In conclusion it is evident that the rapid expansion of classifications of childhood disability alongside shifts in how diagnosis are made has transformed how difference is viewed. Yet it has also been an impetus to challenges outside of a medical frame, led in the first instance by the contesting of claims to scientific status, (Sleeter 1987, Rhode 2005, Dudley-Marling 2010), which have been foundational to social constructionist explanations (Conrad 2000, Molloy 2002, Amaral 2007), which have led by extension to a conjecturing around the functions medical labels fulfil (Tomlinson 1982, Benjamin 2002, Armstrong 2005, Tomlinson 2008). These concerns are not without merit and hold a statistical integrity as Southall (2007) demonstrates, 'following the broadening of diagnostic criteria for ADHD in 1991 the numbers of children diagnosed with ADHD shot up[sic] by approximately 60%' (pp. 7). Such statistics, in conjunction with increasing concerns towards diagnostic discrepancies further foster doubts. Uncertainty which Mueller (2012) also notes hosts deleterious effect, most typically in the form of stigma conferred onto the child and family from multifarious sources, including peers, teachers and the wider community.

Disability uncertainties appear particularly potent when harnessed by interested parties outside of the medical profession, and especially damaging in respect of disabilities which impact on social conduct (Jull 2008, Boyd 2012, Caslin 2014), as they are vulnerable to dismissal, leaving symptomatic indicators to be rationalised in other ways (Trust 2007, Valeras 2010, Roig 2011, and Klehm 2014). It would also appear that increased exposure to medical debates and jurisdictions, results in secondary professionals feeling more entitled and confident to confer judgements, which were formally the exclusive domain of the medical profession.

Holt (2016) also cautions that because contemporary medical labels are tenuous in nature and subject to change and reclassification, they have the capacity to undermine official recognitions of need and indeed causation. As such deflect attention from other potential explanations of difficulty, which in the case of behaviour may be triggered by the school organisation or indeed the home culture. Hence it is suggested that in relation to behavioural difficulties 'the behaviour underpinning of the diagnosis, operates as a *carte blanche* to explain any differences with learning or peers, without seeking explanation within the socio-spatial context of the school (Holt 2016, pp 153). Nor it would appear any deeper consideration of the social and political relations which underpin the identification of disability or disorder. The

following subsection addresses the need for such consideration and suggests it to be a vital factor directing how difference becomes to be accountable, both inside and outside of a disability frame.

2.5.6 Power and its impact relationally on the defining of disability and bounding of challenge

Disability status due to its medical association and value as currency in respect of financial and legal entitlements is inevitably a relational transaction. This contention echoes Baglieri (2011) and indeed the sentiment that led to the development of the Social Model of Disability (UPIAS 1975, Finkelstein 1980 Oliver 1990) that there is an important distinction between impairment and disability. Most specifically that whilst the former is defining of physical or psychological disadvantage, the latter emanates from distinct socio, political and cultural practices. The distinction is further telling as 'impairment' does not of itself attract legislative protections, whilst 'disability' irrespective of origin does. It may therefore in its determination be seen to incur value judgements around entitlement.

Thus although the detail of disability challenge speaks to the logic of specific instances of contestation, the range of challenges as a combined force may be seen to offer insight into how a social system coalesces within a congruent conceptual frame to determine status and entitlements in a coherent and seemingly rational way. Which also by extension define their corollary, disentanglement and potential accountability for differences displayed. Finkelstein (1980) refers to the relational exigencies of disability as the 'paradox of disability' (pp 1), stating disability to be the outcome of 'an oppressive social relationship' (Summary), within which 'people stand in definite relationships to the disabled individual' (pp 5). It is interesting that Finkelstein's contentions predate the advent of equality legislation (Parliament 1995; 2010) and could reasonably be considered partially addressed by its introduction; were it not for the ongoing evidence of disability disadvantage across a range of spheres as is discussed at point 3.26. It may also be considered prophetic that Finkelstein foresaw that 'almost every aspect of the life of a person who is disabled has its counterpart in a "profession" or voluntary organisation' (pp1). Particularly as this is a tendency in the school context which is stated to have vastly expanded following the introduction of what is termed special educational need (Tomlinson 2012).

Inevitably the relational circumstances conjured by disability and disability challenge enters into the equation vested interest, unsettling of notions of objective identification or response on the basis of need. This observation in the school context points to strategy emanating from wider relationships of power, exceeding of the individual and directed toward regulation and normalisation. Dale (2006) states 'it is possible to interpret the growing medical control over the services for mentally defective children as the outcome of a strategic alliance between social workers and medical practitioners to undermine the lay expertise which was embodied in the early management of the idiot asylum'(pp 13). From this stance, what is termed medicalisation (Conrad 2005; 2007) may also be considered relational, as the process of medicalisation has given rise to a skilful apparatus that protects and expands professional interests, whilst serving to define and foster patient dependencies and identities of deficit.

Irrespective of debate as to whether disability needs are real or created, the collective structures erected in their name have material consequences. It is also significant that conceptualisations of childhood disability and educative need align to the economic and employability needs within which they are embedded. Henceforth accepting Ball's (2013) assertion of move toward a 'knowledge' society, aligned with and reflective of the needs of a global economy, it might be considered more than coincidental that the parameters of ability/disability appear to have also moved in alignment with contemporary skills and conduct requirements. Equally as Kudlick (2003) emphasises, disability is also an economic relationship and a significant factor in the development of the modern state, 'raising questions of who deserves the government's assistance and protection, what constitutes a capable citizen, and who merits the full rights of citizenship' (Kudlick 2003, pp 766). These dilemmas are most evident in education, where disability classifications as Hobbs (1975) and most recently Florian (2008a) emphasise are important factors used to determine who merits support and to what extent disability effects can and should be accommodated.

Bauman (2004) adds a more disturbing dimension to the relational perspective, which may be seen to address issues of accountability and the rational for blameworthiness. Bauman argues that the nature of modernity is such that it creates through the logic of its economic base and means of production surplus populations; which require rationalisation to subjugate and deflect discontent. It may be argued

that Bauman's contention supports the claim that disability and SEN constitute the inverse of abilities privileged in the contemporary global workforce. Thus the nature of esteemed abilities, inevitably result in unequal educational and employment opportunities, which medical labels hold potential to explain (Benjamin 2002, Armstrong 2005, Tomlinson 1982, Tomlinson 2008).

Rose (2007) similarly proffers a relational explanation for the guise of disability and the expansion of medicalisation, linking biomedicine, genetic/biological determinism and social control, in a manner congruent with Foucault's earlier writing on the birth of the clinic (1973). Indeed Rose suggest biomedicine engenders a contemporary association with modern eugenics (Rose 2007), notably in relation to predictive criminology. On this basis Rose holds that far from disability identification acting in a migratory or explanatory manner, its identification holds potential to position the individual in a less equal position, outside of help, not in need of help. These contentions resonated for me and I felt them to be paralleled in education whereupon some excluded pupils appear to be accorded the status of commonly ineducable, because of their inability to be rehabilitated into the mainstream. Notably the discourses I was privy to did not privilege longer term outcomes, school exclusion are found to affect (McCrystal, Percy and Higgins 2007).

Behavioural disabilities in particular have conjured both controversy and challenge toward explanations for their existence and expansion (Parsons 2005, Jull 2008, Cross 2011, Hardwood 2006; 2014). This has resulted in divided explanations oscillating between social and medical factors. Preceding Bauman (2004), Young (1999) also felt late modernity to be less tolerant to difference, offering a rationale for what has been described as 'difficult difference' (Rogers 2013, pp 132). Thus the expansion of behaviour disabilities may reflect an increasing drive to control and provide a medicalised rationale for that control. Indeed the vulnerability of persons displaying behavioural, psychological and communication disabilities to incarceration, not rehabilitation is an ongoing concern (Becrow 2008, Bishop 2008, Talbot 2011, Hughes 2012). Indeed it appears that it is the notion of 'difficult' which diverts disabilities of impact on behaviour away from discourses of social equity, to that of justice (Karpin and O'Connell 2015, O'Connell 2015). For example in education, although 'difficult' holds association with both misbehaviour as well as disability, in response 'difficult' frequently incurs a common sanction led script, irrespective of any

diagnosis (OCC 2013, DfE 2012d, 2013b, CAF 2013, AA 2014). Thus implying 'difficult' does not conjure association with medical factors (Gillies 2012).

The term intersectionality has been used to describe 'the 'ways in which numerous discourses together create multidimensional experiences, complicating notions of how people come to know and understand their lives' (Gabel 2008 pp. 470) and within educational studies critical pedagogy holds potential to extend deeper appreciation not only of how social strata are maintained, but why. Notably in common with Young (1999) and Bauman (2004), the economic base is not only charged with being primarily directive of the nature of school systems and the abilities sought (Armstrong 2003, 2005, Tomlinson 2008, Robinson 2011). It is also seen to be perpetuating of vested interest (Liasidou 2012) which holds implications for how difference is explained across social groupings.

For example Hubert (2000) finds identifications and explanations for difference vary across cultures, linked to socio-political practices and priorities. Disability challenge and accountability from this perspective leads from the privileging of particular ways of being, rather than necessarily the acts themselves. Such view supports Winance (2007) contention that processes of 'normalisation' are foundational to the appearance of disability and ability in education, referenced against a standardised system based on norms of childhood ability and conduct.

It is thus significant that disparities of disability identification are found linked to factors of culture (Faraone 2003, Mah 2007), ethnicity (Begeer 2009, Polanczyk 2005), gender (Gould 2011) and typically notions of what it means to be 'normal' (Molloy 2002, Paivi 2008). Equally so in regards to what constitutes an SEN. Duffy and Kitayama (2010) for example note cultural variations in relation to what constitutes 'normal' information processing. Such finding intimates there to be a fluid, culturally derived conception of what is a commonly identified learning disability/SEN, supporting further the contention that demarcations of disability extend from socially negotiated markers of what is seen to constitute ableness (Boundy 2008, Campbell 2008).

Referring back to the school context, the aforementioned findings offer contentious explanation for disparities of disability identification. It is particularly significant that pupils from disadvantaged school contexts are found more vulnerable to identification of behavioural disorders than specific learning difficulties, that pupils from more

advantaged school areas (Croll 2002, McCoy 2012). Notably as the former may be considered accountable whilst the latter not. Such tendency is also echoed by Riddell (2011) and Russell, Steer and Goulding (2011), finding socio-economic status to be implicated in diagnosis propensity and in particular whether 'difference' is viewed as disability or malevolence (Molloy 2002, Faraone 2003, Polanczyk 2005, Mah 2007, Paivi 2008, Begeer 2009 and Tomlinson 2014). These findings speak not only to disability discrimination, they also speak to cultural discrimination and add weight to Bourdieu and Passeron (1977) claim that the education system acts as a primary vehicle of the reproduction of existing privilege and inequalities. Such view has significant implications for the concept of agency and it is to this issue this section now turns as it is the final layer which is implicated in considerations of disability challenge and importantly the capacity for counter challenge.

2.5.7 The scope for agency?

The idea that schools act to reproduce inequality, both relationally and in terms of achievement, raises questions not only in terms of ethics, it also demands consideration of the extent to which pupils and indeed their parents are malleable and what factors facilitate or inhibit such compliance. McLaughlin, Phillimore and Richardson (2011) observe how parents resist the identities of disability given to their children and in doing so, suggest that deterministic relational models of social action are distortive. Hacking (2007) for example denies a deterministic stance, developing a theory which bridges human agency and structure. Coined the 'Looping Effect', Hacking's model asserts an inter-relational dimension to disability and suggests engagement between the structural and the personal is mutually impacted upon, in a manner reminiscent of Giddens's (1997) concept of the double hermeneutic.

A transactional model offers scope to elucidate the complexity of disability challenge and equally so reveals the potential for its resistance. In particular focus on the relational production of disability illustrates there to be multiple drivers, which impact on appearances of difference and indeed the range of responses possible to such difference. As a consequence it would appear too simplistic to claim unequal relations of power are a sufficient explanation for why some disabilities incur accountability and others do not. For example Reay (2008) describes how power differentials between peers, led by a drive to fit in socially, was undermining of official school incentives to include; and as a result have had a negative impact on schools willingness to respond sympathetically to some forms of difference.

Equally drawing upon Bourdieu's (1986) theory of social capital; on the one hand it is reasonable to posit that a prime motivation behind pupils rejection of school values is to bolster their social kudos amongst peers. But it is on its own insufficient; for it is equally necessary to trace the factors that set in motion the necessity for such action. Thus forth, closer scrutiny leads to the conclusion that pupils social engagement exceeds the immediately relational and is led by wider institutional and political priorities, which have resulted in pro-school successes being less attainable for some pupils, particularly those children with difficulties in learning or conduct (Benjamin 2002, Youdell 2011, Nind 2012). Thus in this instance the impetus to school rejection at both school and individual level may be attributed to both the individual and organisational level. Equally reviewing teachers motivations from the position of social capital, illustrates similar processes. For whilst teachers may be seen to be motivated toward the fostering of professional (and personal) capital, through the accomplishments of their pupils. The guise of the validations that attract recognition are determined outside of the school context, led in the first instance by political will which is itself responsive to wider economic and employability factors (Tomlinson 2005).

There is therefore a chain of effect and it is possible to see that within the links that compose this chain there are junctures where agency is possible, but in the exercise of this agency, unwarranted impressions can be generated, not least the impression of behavioural or learning disorder. It is also notable that the system of rules and expectations that Bourdieu's (1977, 1980) defined as habitus, may serve to accentuate difference, by highlighting those who do not assimilate within the dominant value system operating within a given social field.

The habitus has been described as the fundamental means by which dominant value systems are maintained and perpetuated, yet it is paradoxical that on the one hand Bourdieu and Passeron (1977) claim there to be a self-perpetuating cycle of ideological subordination inherent within the school system, when the nature of its existence may serve to prompt those who cannot accrue social or educational capital under its value system to seek alternative means of affirmation through acts of counter resistance. When viewed in this manner it is possible to see how failure to assimilate into school systems not only takes on the guise of individualised disorder, but is vulnerable to being perceived as undermining of the broader social order,

legitimizing the triggering of processes of control (DfES 2005, DfE 2012d, NFER 2012).

Looking at the breadth of literature, it emerges that the way disability and behavioural difficulties are understood and rationalised, is determined significantly by the research lens adopted. Equally the scope for individual agency is similarly implicated. To illustrate this point it is useful to distinguish between the lens applied to 'disability' by disability scholars and activists and that of medical sociologists. The former grouping may be seen to have tended toward a conceptualisation of 'disability' as a state of social oppression, seeking to highlight instances of such oppression toward its address. In contrast medical sociology has approached 'disability' from a social deviance perspective (Thomas 2007) and developed within the structural functional tradition, toward an appreciation of the relational engagement of the collective (Parsons 1952), although more recently has tended toward an interpretivist and relational perspective, focused on the negotiation and stigmas inherent to both identification and response (Goffman 1968b, Garfinkel 1984).

Both approaches reference a negotiated element to both the definition of and response to illness and disability which supports the contention that individual agency is possible. Nevertheless as was previously suggested, structural factors are equally (albeit covertly) implicated in what is seen as difference and disability and the way it is responded to. For example Aneshensel (2013) notes that it is typically following periods of crisis that the role of social forces are most apparent; for it is at this point that individuals with essentially the same disorder 'may often follow divergent sequences of societal response which determine (at least in part) the course of the disorder' (pp. x). This observation is considered highly significant to considerations of whether behavioural differences denote disability or malevolence; equally so the guise of challenges made and accountabilities conferred.

Thus from both perspectives, disability studies and medical sociology, what constitutes disability and what is accountable is on one level a political or moral judgement' (Kudlick 2003, pp 767). The same may be said for judgements of difference in education, substantiating claims that deeper questions surrounding the purposes and functions of identification is fundamental to an understanding of the guise of difference and disability accountability. For example Florian (2008a) suggests the 'increased identification of children with disabilities and special educational needs, may also be an indication of an inadequate general education

system as well as increasing diversity among children in today's schools' (pp. 3). These deeper functions Slee (2013) suggests remain obscured as only a partial research lens is employed within the domain of childhood disorder, focused on psychological explanations, which logically preclude comprehensive examination of its socio-political nature. Yet is notably revealed through a closer inspection of the epidemiological patterns that align to it, for as Dyson and Kozleski (2013) have observed 'groups whose members tend to do badly in the general education system supply more students to the special education system' (in Slee 2013, pp. 13). These patterns return us full circle to the contention that any appreciation on the nature of disability, difference and accountability, needs to trace the links of impact which may be said to radiate both outwards from the individual and inwards from the core structural base of society, based on the economic and political tensions it is itself impacted by. The nature of disability, the rights of the disabled and indeed the levels of accountability accorded are all implicated by the complex interaction of these overlapping multifarious factors. Thus any attempt to explain disability accountability, even that which I personally experienced and witnessed on behalf of my children, needs to be mindful of such interplay.

Looking towards practical means of implementing such scrutiny in the research context, Schwartz's (2010) positioning templates have been developed to extend a series of scenarios which depict how persons with intellectual differences are situated. The first frame detailed posits those identified as the object of paternalism and may be seen to reflect the former Labour administration's policy of state intervention into private family life (Armstrong 2005, Docking 2012, Hodkinson 2012). Schwartz second frame situates the identified as being the object of professional gaze, a position which has been linked to the functioning of the education system generally, not least because of the increased responsibilities levelled at schools through the new code of practice (DfE 2015a). The aforementioned contention alters in integrity practices of mass cognitive screening initiatives now common in schools. As Gere (2005) drawing upon Foucault notes, 'gaze' is a preliminary pedagogical practice conducted upon each new pupil cohort (in Gabel 2005 pp 54), an assertion that begs address of functions served. Frame three situates the identified as that of a failed human, which may be seen to be a highly powerful template which may logically operate to disseminate accountability and conferment of deserving and undeserving. This profile I suggest may be seen as most typically reflecting of the

social and educational position of pupils displaying behavioural difficulties, for which they are likely to have their educational entitlements withdrawn. Not least because the notion of 'failed', implies an individual failing, not organisational insufficiency. It is therefore congruent with exclusionary discourses, from which resistance is of limited effectiveness.

It is also notable that Schwartz templates imply there to be a restricted scope for social and educational success, which of itself limits the scope of resistance and supports concerns levelled toward the labelling effects of medical labels (Terzi 2005, Florian 2006, Florian 2008a, and Maddern 2012a). These concerns are supported by the findings of Cook (2001), who details four emotional responses made by teachers to their students with disabilities, these are listed as, attachment, concern, indifference and rejection (pp 204). It is thus considered relevant that the responses noted by Cook mirror in emotional terms, the three positioning templates referenced by Schwartz. Which by the nature of their guise intimate that there are significant variations in the capacity of pupils and families to resist either disability or deficit positioning and by default accountability.

It may therefore be suggested that the issues raised in this subsection, challenge the conceptualisation of disability as an objective, scientifically determined state. Rather they suggested that disability emerges out of the interplay of individual, social, medical and political factors and it is at the junctures of overlap that the conditions and possibility for agency are most likely to be revealed. For as Liasidou (2012) asserts, 'the gaze is squarely placed on students presumed deficits and common practice is to silence the ways in which disability is to a significant extent, an ideologically and socially mediated phenomenon that emanates from and rests upon wider socio-political and cultural factors'(pp, 171).

Disability identification, response and accountability from Liasidou's perspective, may thus be seen to stem from a desire to manage and contain certain sectors of the population (Armstrong 2003, Foucault 1967, 2006, Stiker 97, Szasz 1987; 2007; 2012). A contention which the exclusionary tendencies of schools both historically and contemporarily would appear to support, through the inclusion of educational entitlement qualifications in successive acts of legislation (Parliament 1981, 2001, 2010b). These qualifications are discussed more fully in Chapter 3, raising doubts to whether disability identification in education can ever be considered a conducted in the child's best interest. Disadvantage in education implicates accountability to be a

major disadvantaging factor; yet despite the level of school exclusions linked to factors of disability or special educational need, there is limited association of this as overt discrimination. Nor is it highlighted in wider publications that allude to disability disadvantage. For example the Papworth Trust (2016) in their annual statistical report do not allude to the effects of neurodevelopmental disabilities or challenging behaviour, despite charting systematic disadvantages experienced by disabled persons across a wide range of social variables. It may be concluded thus that the capacity for agency and resistance, is irrevocably linked to the capacity of those who are disadvantaged to appreciate both the source and injustice of disadvantage. The discussions engaged with in this subsection, suggests that such identification is inhibited by the complexity of the relational interplay inevitable in complex societies. As such the position for some pupils and families resembles that put forward by Freire (1996) and termed the silence of the oppressed.

Chapter two has explored how disability has and currently is known, toward this it has considered how and why difference is defined in medical terms and the pervasiveness of its legitimation to define. Subsection one considers in detail the implications of claims to truth and the often under acknowledged relations of power which underpin these. In particular changes in psychiatric practice are identified as a key factor which has enabled critique to develop. The transparency of diagnostic criteria is seen to undermine the authority of emergent categories of childhood disability. Subchapter two considers similarly how challenging behaviours are identified and the associations they conjure. In this instance also, subjectivities and wider social factors are found to intersect, which conjures questioning around the functions served through identification.

Toward an appreciation of the conceptual tools developed to make sense of the intersection of disability in the social context, I explore what are known as the models of disability, finding none able to account for the vulnerability of some disabled persons to accountability. Chapter two concludes with an exploration of the sites of challenge, both within and without the medical domain. Of primary concern is the recognition of discrete patterns to diagnosis and accountability which is itself suggestive of bias and is further implicated in issues of social control and discrimination. In response it was determined necessary to consider in more depth the social and legislative contexts a child inhabits, in order to widen understanding of their role in regards to inhibiting or exacerbating tendencies to accountability.

Chapter 3. Exploring the social and legislative contexts of childhood disability

Chapter three concludes the literature review and focuses upon the primary social and legislative contexts pertinent to childhood. Four key areas are identified, consisting of the social contexts of the family and school as well as the legislative frameworks of inclusion and equality legislation. These contexts are found to be symbiotically intertwined in relation to both impressions made and identities constructed (Mills and Pini 2015, Courtney 2016). The social contexts of the family and school are primary to the identities a child develops; and although discrete domains, they merge in respect of jurisdictions over, and knowing, of the child. They are thus both private and public (Mills 2000), holding in common a definitional role toward the sense made of childhood difference, ability and conduct. As a mother making sense of atypical children, I found that I not only presented my children to their school, outlining the nature of their difficulties and the medical labels they held, but I also had them presented back to me by school. At times these presentations were incongruent and generative of conflict.

I determined that the bridge which straddles the school and familial domains could be typified as being founded on what is 'known', filtered through considerations of what is 'seen', absent, and considered needed. For me personally, these common conceptual cues yielded very differing perspectives of the same child, to that which was conjured in the school context. It was thus notable that the families in my study indicated this also to be their experience. This chapter considers how a child comes to be known in these two broad domains, mindful of the aforementioned cues of what is seen, absent and considered needed. In conjunction Rogers distinction between processes of 'caring for' and 'caring about' (Rogers 2013, pp 136) are considered pertinent to the situation of families managing 'challenging' behaviours.

A fundamental issue is both the potential for, and the absence of, objectivity of knowing. In relation to the 'knowing' of a child, the processes of knowing may be described as purposeful; channelled through role and circumstance of engagement, which is found to lead to a form of knowing which is partial and negotiated. 'Knowing' in the familial and school context may thus be seen to be productive of both identity and social positioning. Processes of 'knowing' therefore exceed informational reference and are directed to specific goals. It is therefore important to consider not

only the 'what' of 'knowing', but the why. Such inquiry involves seeking clarification of interests served and objectives pursued as 'knowing' from this perspective exceeds individual cognition and is implicated in wider relational dynamics. These relations are considered significant as the dynamics of negotiation generally are stated to be inherently unequal (Harre 1999, Anderson 2009, Harre et al 2009). The relational dynamics of knowing a child may be seen to be additionally complex, as a child's identity emanates not only from the presentation of self, but from the reflected impressions of both school and home, in a manner which Cooley (2010) termed the 'looking glass self'.

This relationship is represented diagrammatically below (figure 6), illustrating that the two poles of knowing are mutually impacted upon by each other and linked to the function of respective roles. This review now looks toward the social contexts of the family and the school towards an appreciation of how 'knowing' is conducted and produced.

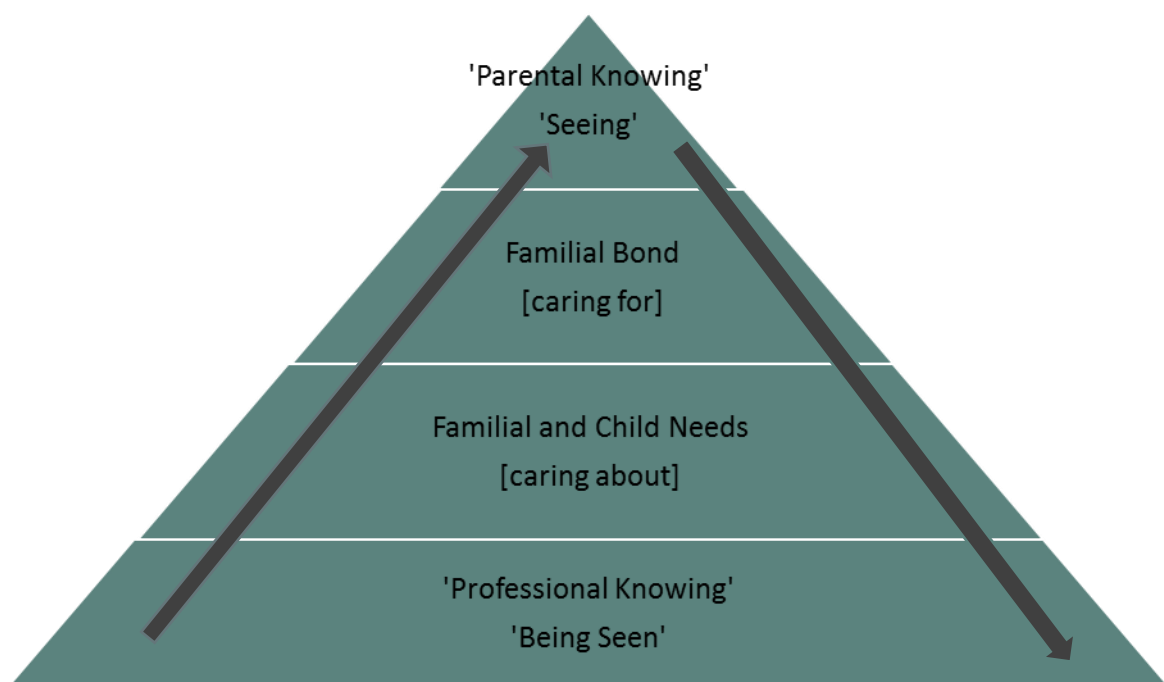


Figure 6: Familial and Professional Knowing

3.1 Subsection 1: The cultural contexts of family and school and their relevance to 'knowing'.

'In talking with parents of disabled children and children with special educational needs (SEN), we met some of the happiest parents in the country and some of the angriest. Many had children who are well-supported and making good progress. But we also met parents for whom the education system represents a battle to get the needs of their child identified and for these to be met' (Lamb 2009, pp 2).

The Lamb Report (2009) explored parental opinions and experiences of SEN/disability response in the school context and found as the summary statement above indicates, that parents experienced barriers in regards to having their children's needs recognised. The term battle is itself telling, as it suggests there to be not only barriers to exposing or conveying what a child needs, but of having that need accepted as legitimate. This metaphoric battlefield may be summed up as the stage where 'knowing' is negotiated, which by extension implicates there to be differing versions of 'knowing'. These versions of 'knowing' may be usefully distinguished as 'formal' and 'familial knowing'. Thus the battle alluded to in the Lamb report may be stated to be the process of promoting or resisting these differing versions of 'knowing'.

Problematically the processes implicated in 'knowing' may be seen to extend from unequal exchange, as the guise of 'knowing' that each party holds and trades, differs in both substance and on the basis of the status each party holds. By necessity parents of children with, or being assessed for disability, are recipients of 'expert' services. This results in an evidence based 'formal knowing' of the child, yet in terms of personal substance, may also be viewed as partial, reflecting only the lens of professional interest. In contrast, parents may be considered to 'know' their children in a personal sense, privileging aspects of 'being' of lesser relevance in the formal domain. Yet as 'external knowing' extends from the status of professional truth claims, it holds claim to the status of objectivity, of 'fact'. Whereas in contrast, parental knowledge lacks formalised credibility and is thus vulnerable to dismissal as being conjectural.

The objectivity of professional claims to truth are contested by Skinner (2007) who suggests disability to be a 'sociocultural phenomenon', occupying a defined and negotiated space within a wider system of meaning. From this perspective what is framed as objective formal knowing is questioned in its integrity: not least because it is found to be responsive to the impressions made and assumptions drawn in respect

of the child's family. Nind's (2008) observations are illustrative, showing that familial impressions, skills and identities were central to the conclusions drawn in respect of childhood difference and accountability for such difference.

Nind's findings suggest that the similarity or dissimilarity of the familial culture and schools was a leading factor in regards to the propensity by school and aligned bodies to accord parental accountability where 'behaviour' was of issue. Equally Reay (2015) suggests the dynamic of pupil and familial presentation set within the busy dynamic of the school context is more complicated than the ideal of cultural congruency would suggest; which further rejects the possibility of objective 'knowing' being the preserve of the formal context.

Drawing upon Bourdieu's (1980) notion of Habitus, Reay demonstrates how in the daily routine of school life, the 'knowing' which accrues from a professional observation of the child in terms of behaviour is reflective not of what is 'seen' in the moment, but of an already formed 'knowing' (as embodied by the habitus) and common to the bounded social collective as a whole. Bourdieu (1980) depicts the habitus as being comprised of an embodied history, which is internalised and appears as second nature. As a consequence, 'its historic guise is obscured, enabling it to remain an active presence within the field it encompasses' (pp 56). Bourdieu further suggests that as dispositions and sense-making bounded by the habitus are unconscious, they exude the illusion of both agency and relative autonomy in respect of 'knowing' in the moment; a 'spontaneity without consciousness or will' (pp 56) which is directive of 'knowing'.

Bourdieu's concept of 'field' is equally pertinent to the way a person/group can present or 'know' self. The concept of field as visualised by Bourdieu, can be summed as a bounded arena of social engagement; directed to a given purpose. 'To think in terms of 'field', is to think relationally' (Bourdieu in Wacquant 1989, pp 39) and is thus central to Bourdieu's theory of social relations. Jenkins (2013) offers a useful definition of 'field', stating it to be 'a structured system of social positions, occupied by either individuals or institutions, the nature of which defines the situation for their occupants' (pp 85). Extending this theory of social relations, Bourdieu's (1986) concept of 'capital', defines the guise of currencies that can effect influence during social relations. These take varying forms embracing social status (social and cultural capital) economic and educational capital (Bourdieu and Wacquant 1996). Of particular significance to processes of 'knowing' and how one seeks to be known, is

the notion of social capital, which is itself defined by the core features of the field within which social engagement takes place, and its corresponding habitus. Barr and Bracchitta (2015) suggest the amassing and expenditure of social capital to be central toward the fostering and perpetuation of in-group status. In-group status may be described as founded upon both self and others identification, thus is itself a form of 'knowing'. Problematically in working practice, the social context comprises many fields which overlap (Davey 2009) and it is at the interface of such overlap that complications (and conversely creativity) can arise, particularly where there are multiple field memberships across interlocking social networks which do not value the same capital referents.

For example, where a child displays challenging behaviours and there is cultural congruence between home and school, such action may become 'known' as a sign of disability, not poor parenting or will. Problematically the converse scenario is equally of issue, leaving children from incongruent backgrounds vulnerable to accountabilities as a consequence of wider attributions about background and parenting (Holt 2008, 2010a, Holt 2012, Bunting 2015). The presentation of the family is thus primary to what becomes 'known' about the child; and as Adams (2014) reports, extreme cases of dissonance can lead to difficulties reported by parents being dismissed or alternatively explained.

Skinner (2007) defines culture as a 'system of meanings and practices that evolve between families, the medical and service community and larger political, social, and economic worlds' (pp 310). Such a definition is not dissimilar to Lupton's notion of culture in respect of medicine, or the philosophical concept termed the lifeworld (Husserl 1970, Schutz 1973, Habermas 1987). Consequently 'knowing' in both the familial and the formal domains would appear to extend from what is already (thought to be) known culturally. 'Knowing' is not therefore unbounded, rather it is as Fuss (1989) stated 'culturally mapped' (pp 6), compromising further the notion that 'formal knowing' accrues on the basis of objective professional truths.

The concept of culture as delineated by Lupton (2012) is also reminiscent of Kuhn's (1962) notion of paradigm and as such projects the impression of limited conceptual scope outside of radical change to inform knowing. There is, however, disagreement in respect of the level of scope for agency and it is here that the concept of multiple fields are most significant. For example Davey (2009), finds that the interlocking spaces created where field memberships overlap can also be stimulating of change

and new knowledge within the habitus. Davey's visualisation of habitus is dynamic, 'a never ending process of construction, with individuals biographies and stocks of capital in constant tension or alignment with the field' (pp 278). Such contention in contrast to more culturally deterministic positions, suggests that the conceptual referents underpinning 'knowing' are highly complex and not irrevocably bound to professional knowledge stocks or familial presentation. But rather are more liable to be led by the motivations leading the pursuit of 'knowing'. On that basis it would appear imperative that as much consideration is given to the purposes of 'knowing', as it is to the 'what' of 'knowing'.

Families may be seen to differ from external agencies in their motivations to make meaning, as the emotive referents inherent to 'familial knowing' alters the motivation for knowing and also the propensity for seeking positives. In contrast, the narrower boundaries of the professional lens facilitate a more tightly bounded and purposeful pursuit of 'knowing', catering to specific objectives. Merton (1936) defines human action as purposeful and indicates there to be a differentiation between unorganised and formally organised action (pp 896), which is relevant to the types of 'knowing' pursued. 'Formal knowing' as already suggested whilst partial, is purposeful, driven by the purposes for which it is collated. In contrast, 'familial knowing' may be likened to unorganised activity, driven by both practical and emotive referents. Yet as suggested families are more likely to identify and embellish the positive attributes of family members as indeed many family studies indicate (Jackson 2004, Fisher 2007, Gallagher 2010b, McLaughlin, Phillimore and Richardson 2011). As a result, although 'knowing' in the familial sector is less formally organised, it may be as partial in its constitution as 'formal knowing'. This suspicion suggests that partiality it is in the nature of 'knowing', which supports the position that it is the purposes and uses of 'knowing' which are of primary concern.

'Knowing' is thus transactional, rather than informational, aligned to wider motivations as indeed Harre (1990) contends. Harre finds 'knowing' to be the mechanisms through which individual personas are manifested and social positions procured. Such a position has implications for my study as it intimates that the 'knowing' generated between schools and parents is actively purposeful, exceeding knowledge for its own sake. This alters in integrity the implications of what is 'known' and indeed what inferences can be drawn from 'knowing' demonstrated; particularly when 'knowing' is controversial and involves judgements about presentations that are

misaligned with dominant social values and codes of conduct. Looking objectively at the impact of behavioural challenges in the school context, they may be seen to compromise both schools and parents, as both parties are liable to charges of accountability and or complicity for challenges posed. From this perspective blame may be considered a primary means of deflecting personal and/or organisational accountability.

The diagnostic process is central to such judgement, yet may be seen to exceed explanatory function, as it is also constitutive of identity. Newsom (2003), suggests diagnosis extends relief, enabling parents to make sense of their children's difficulties. Nevertheless as Berube (1996) has emphasised, 'formal knowing' is considered partial in comparison to an imputed 'familial knowing':

'I have tried on occasion to step back, and see him as others might see him, as an instance of a category, one item on the long list of human subgroups...I have even tried to imagine him as he would have been in other eras, other places: This is a retarded child. And even this is a Mongoloid child, but I cannot imagine how they might think them in a way that prevents them from seeing Jamie as Jamie' (Berube 1996, pp xii).

For parents the emotive referents of 'knowing' are not only intimated by Gallagher (2010b) below, they also suggest that such 'knowing' is itself bounded to an anticipated 'knowing', thus incongruence can also be generative of loss:

'Though we recognise the gifts our children have brought us, we'll never get over the loss of our dreams for them – those shattered plans and expectations we had even before they were born...there have been and will continue to be days when the loss of our dreams is very real' (pp 221):

'Familial knowing' is further defined by Dobson (2001), who states in prose the evolutionary and emotive nature of 'familial knowing'. In doing so Dobson stakes a claim to 'knowing' which privileges the essential humanness of all children outside of difference:

'You never expect this and you're never prepared. For a brief moment your hopes vanish and you're left holding your fears literally. But, then, all you feel is love; the worry, the guilt comes later but so does the joy and the pride – all you really have is a child, not a child who is this or that but a child' (pp 25).

It may be concluded that the lens applied by professionals and families toward 'knowing' not only differs (Rogers 2007a), but is in working practice negotiated, rather than observed. Thus the 'knowing' which coalesces around the child may be alternatively summed up as the output of an unequal engagement between the formal and familial contexts. Such engagement is particularly marked where 'knowing' is directed toward explanations for challenging behaviour; not least because this scenario extends the range of professionals inputting to such 'knowing'

and problematizes further the motivations and agendas implicated. These complications are discussed more fully in the following section.

3.1.1 Troubling 'Troubling'.

The title of this section eludes to its function, for it is necessary to question how troubling or more appropriately challenging, children are recognised. With the expansion of medical explanations, it would appear pertinent to question where the line is drawn that tips behaviour attracting of colloquialisms such as 'testing the boundaries', to those that suggest excess and thus disability or indeed malevolence. So what is a behavioural disability, how can it be known when there are no organic tests to arbitrarily validate its existence?

Holt, Lea and Bowlby (2013) expands our understanding of what constitutes 'trouble' through reference to practices of normalisation which are stated to be inherent to the school context and implicated in what is accepted or unaccepted behaviour. Thus 'in schools young people are taught to embody and reproduce norms of acceptable behaviour' (pp2192). This nevertheless holds major ramifications for those pupils who cannot conform and stimulates discourses of accountability which mirror in their punitive intent, discourses identified by O'Connell (2016) and legally delineated by Perlin (2000; 2008; 2016), as discussed later.

Kaufmann (2001) asserts 'an emotional or behavioural disorder is whatever a culture's chosen authority figures designate as intolerable. Typically it is that which is perceived to threaten the stability, security or values of that society' (Kauffman (2001), cited in Goulding (2016), pp178). Kauffman's (2001) assertion remains pertinent, because the presentation of challenging behaviours continues to conjure in the immediate, a search for explanation and those explanations may be seen to be led by unspoken subjectivities. Toward this exercise, the child's culture and familial context remain primary areas of causal interest, which is found by Broomhead (2013a) to detract, rather than inform, the child's needs. Jull (2008) states parents of behaviourally impacted children are doubly disadvantaged: maintaining all of the practical and economic challenges of parenting a disabled child, whilst lacking status both within and without the realms of disability or ableness. Families in crisis are also found exploited within popular media, offering spectacle through shows such as Jeremy Kyle (2015) and sensational narratives of accountability in popular press (Moody 2014).

This genre of broadcasting is found to have exacerbated amidst the increasing dominance of a Neoliberal climate. Most particularly, 'fly on the wall' pseudo-documentaries serve to situate particular populations as feckless, classically benefit recipients and the unemployed. Jenson (2013) refers to this as 'poverty porn', which serves to mould public perceptions without reasoned response to tangible circumstances. Jenson refers to the deliberate simulation of a divide between what are described as workers and shirkers. It is also clear that the subtext is one of burden and entitlement which has serious implications for parents with disabled children, more so for parents whose children's disability has an uncertain status.

Runswick–Cole and Goodley (2015) alert us to the ways in which medical labels disturb 'scrounging' discourses and as such are manipulated within these genres of broadcasting. Notably in the case of the reviewed Channel 4 'Benefits Street' Runswick–Cole and Goodley find there to be a divide between the forgiveness accorded to learning difficulties and those denied to mental illness. Taking issue with the absence of 'dis/ability' as a social variable in much sociological analysis, the authors conclude that within the remit of 'poverty porn', 'it is necessary for dis/ability to be made both visible and invisible: sometimes dis/ability takes 'centre-stage', sometimes it is simply 'noises off'. It lurks around as a quintessential object of disavowal: to be desired and erased when necessary in order to say something particular about those living in poverty' (pp 646).

It is notable that the undertones of scepticism reported toward mental health issues resonate with those experienced personally in respect of my children's diagnosed behavioural disabilities. What was striking in Runswick–Cole's analysis was the realisation that some labels attracted forgiveness, but only if certain conditions were met, most specifically the embrace of the sick role and the acceptance of a life less than. The difficulties raised by varying legitimization of medical labels is that where there is a dual diagnosis there is a grey area which leaves space for discourses of blame. This scenario was faced personally as one of my sons held dual diagnosis, although common now, this was for a point uncommon and summonsed incongruent discourses of benevolence and vilification simultaneously. Worryingly Runswick-Cole and Goodley found there was purpose to the way medical labels were put to work. In my case, an open negativity to the label ADHD was used to justify exclusionary sanctions and to derail the entitlement discourses that coalesces sentimentally around autism (Murray 2006; 2008).

Looking more closely at the macro perspective, Runswick-Cole and Goodley (forthcoming) suggest there to be an association between the economic stability of a society and its disposition to blame. These dispositions are found reflected in State commitment to reduce welfare responsibilities, which in order to legitimate, necessitates an active policy of disentanglement. It is thus unsurprising (yet disconcerting) that Runswick–Cole and Goodley find that, ‘in a context of austerity, more than ever, mothers and their disabled children are represented as a financial burden to the state and, conversely, expected to take on the dual roles of worker and carer (roles which are of course often under-paid and devalued)’ (pp 6/7). Not only are these roles often underpaid and unstable (Runswick–Cole and Goodley 2015), they are also unpractical when there are the demands of inconsistent school placement to consider (CERBRA 2013, AA 2014, DfE 2015b), which is itself responsive to the unpredictability of behavioural disability (Cross 2011).

Mothers with behaviourally challenging children are therefore caught in a conundrum; they cannot meet the demands of the workplace because of schooling issues, and as Runswick-Cole and Goodley (forthcoming) note, to have support entitlements validated, mothers are expected to adopt ‘traditional ‘sick roles’ (Parsons 1952) for their child’ (pp 7). This is additionally problematic when behaviour is also a symptom of disability, for as Holt (2008; 2010) observed, for some parents the discourses coalescing around ‘behaviour’ demand parental acknowledgement of failing as a means of regaining support entitlement (Blum 2007, 2015). It is at this juncture that one can see most clearly how both discourses (paradoxically pointed toward the same phenomenon) act to direct the lens of attribution, either toward, or away from the mothering relationship.

The discourses referenced may be seen to deflect any causal responsibility from the organisational and structural domains. Nevertheless Cross (2011) emphasises there to be a tangibility to behavioural challenges; both for the individual concerned and their wider associates, stating them to extend from an impetus, be it an indigenous disorder or a responsive reaction to social and economic disadvantage. Such a view challenges the idea that behavioural disabilities are punctuated by random acts although the notion of randomness supports the logic of exclusionary responses on the basis of unpredictable risk (Giroux 2009). The triggers Cross (2011) intimates warrants a particular style of address; necessitating individual and social/economic address. Thus where Runswick-Cole and Goodley (cite the macro

economic climate as the key trigger to disability disadvantages, Cross calls for address across both the macro and micro domains, toward an appreciation of the individual circumstances of behavioural disabilities.

Runswick-Cole and Goodley (2015) observation of the retracting of State support amidst a Neoliberal agenda of individualism, further impresses upon us that there will be a corresponding reduction of discourses available to rationalise any inability to promote the welfare of the family. As a consequence serving to heighten the capacity for blame and shame toward those who cannot rise to the challenge; effects which resonate with Rogers's (2013) distinction between 'caring for' and 'caring about' (pp 136). For in the case of behavioural challenges, an inability to 'care for' is considered neglectful and can trigger evaluative practices, which at worst result in prosecution, or the removal of the child into local authority or medical care. These scenarios are not only responsive to circumstance, they may be also be seen to constitute the opposite of good parenting scripts (Carpenter and Emerald (2009). Notably the good mother is deemed able to cope, dedicated to remediate her child's difficulty (Landsman 2009) whilst maintaining the illusion of maternal altruism (Maushart 2000). It may be found nevertheless that the scripts of mothering a disabled child, mirror closely the disability stereotypes previously noted (BFI 2010) which range in identity and integrity. For as (Keith 2001) classically observed, childhood disability which is physical in origin retains an association with classic tragedy scripts of disability, whereas despite an expansion of medical labels to denote behavioural disabilities, the scripts around these disabilities have evolved aligned to discourses of parental responsibility (Kingston 2007, Rogers 2007; 2012, Holt 2008; 2010).

Undoubtedly Runswick-Cole's (2015) identification of the exigencies established by a climate of Neoliberal ableism holds major implications for all parents struggling to manage a child's disability; and it is notable that from the inception of the Coalition government to the current Conservative administration, support has been radically and unashamedly tapered back, founded upon the reestablishment of notions of deserving and undeserving needs (Garthwaite 2011, Roulstone 2015). Media releases confirm that children and their families are subject to an increased scrutiny (Goldberg 2011, Walker 2011, Jensen 2013, Runswick-Cole and Goodley 2015). It is nevertheless uncertain to what extent the association between disability and disadvantage will be made given Runswick-Cole and Goodley's (2015) observation that disability is insufficiently employed as a variable of disadvantage. The

implications of such omission is that exploitation is able to remain beneath the sociological radar, lending credence to idealised notions that mothers can remediate their children's disadvantages. Thus forth, despite Runswick–Cole and Goodley's assertion that mothers (commonly) are directed to 'adopt the traditional 'sick role' (Parsons, 1952) for their child' (pp7) to radiate blame away from the familial domain, such blame persists, directed to the type of disability presenting as the chief test of entitlement. In this sense I suggest all disabilities are not equal (Parsons 2005, Jull 2008, Boyd 2012).

3.1.2 On the margins

Carpenter and Austin (2007) draw attention to the maternal realities of parenting a child with ASD and autism, conditions known to be associated with challenging behaviour (CEBRA 2013). They liken such experience to being on the margins, using the terminology purposefully, to highlight the absence of some mothering experience from the mainstay of mothering scripts (discourses). This absence is stated by Carpenter and Austin (2007) to leave this group of mothers unable to situate their lives in mainstream maternal discourse. For these women, they caution, there is no compensatory sympathy, no script of sacrifice, or compensatory gifts, rather there is absence and the lack of common reference to guide or make sense of their experience. They are by circumstance relegated to the margins, outside of the main texts of mothering.

Such description speaks of alienation; typically through the absences described and as importantly those imposed from within, as women try to make sense of the challenges faced (Gallagher 2010b). This is found to be compounded upon where behaviour is an issue (Carpenter 1999, Carpenter and Emerald 2009, Emerald and Carpenter 2010), not least because of social stigmas conferred and intimated. It is thus notable that Carpenter and Austin (2007), likewise Carpenter and Emerald (2009) find such maternal absence to be accompanied by a corresponding silence, which operates to negate the potential for counter-challenge to deficit discourses. As a result any maternal sacrifices made to support a challenging child as well as the efforts to control behaviours remain hidden, as do the practical difficulties faced, including the very real physical dangers many of the mothers faced (Carpenter and Austin 2007, Carpenter and Emerald 2009).

Drawing upon my own experience, I would argue that mothers of challenging children are embedded within a maternal script, but it is a script of failure, as the mothers in this script are producers of flawed and uncontrolled children. Thus unlike the successful mother with responsive potentially productive children, these scripts speak to its converse; typically the mother who has failed to instil control or respect, nor seemingly appreciates the effect of her child on others. Thus as Carpenter and Austin's (2007) research records show: 'the women tell of being silenced by not being heard. A frequent experience of these mothers is to be misunderstood and judged by medical and educational professionals and to be told rather than listened to' (pp 663). This emphasises my point, for these mothers (and I acknowledge the efforts to include myself within their camp) the script dictates the need for education, to be shown where the maternal wrongs were made and as Holt (2008; 2010) found through the introduction of compulsory parenting orders, how to put the wrongs right. It would therefore appear that irrespective of societal buy-in to medical discourses, the dominant script remains one of failing and as such cannot easily combat prejudice, nor guard against accountability and blame.

Rogers (2016) likewise calls for attention to be directed to the dark side of mothering, not only to dispel the myths of the mothering role, but to highlight that 'caring for' is often inhibited by what is termed institutional carelessness. Rogers skilfully highlights narrative record which dispels the myths of maternal selflessness, but speaks to the harsh realities and commitment that is part and parcel of some forms of disability. It is also notable that Rogers cites several cases which have been brought to public attention as a result of tragic outcomes. In doing she illustrates how these cases demonstrate, not familial or maternal failings, but failings within the network of caring institutions. These are described by Rogers (2016) as 'careless spaces' (pp6), within which the potential for tragic outcomes is both timely and unpalatable, contrasting uncomfortably with idealised images of maternal sacrifice and unconditional affirmation. The charge of 'careless spaces' (ibid) and identifications of marginalisation discussed previously call into question Runswick-Cole and Goodley's (2016) call for emphasis on maternal commonality. Indeed I would argue from the position of a 'failed' mother, that the majority of mothers remain (unknowingly) complicit in the affirmation of dominant 'successful' mothering scripts, punctuated by school, employment and relationship successes, which for some children are unrealisable. The tragic cases detailed by Rogers (2016), upon closer

inspection reveal combined failings in all sectors of the caring professions, including that of education.

Institutional failings not only compound disadvantage on the families implicated, they perpetuate the idea of familial failure, thus although the work of Rogers concentrates on the challenges faced by parents of children who have intellectual disabilities, one can equally apply the notion of carelessness to the situation faced by families managing behavioural disabilities. Problematically however these parents carry the additional burden of accountability; accountability for their children's disabilities, accountability for their actions and accountability in terms of parenting competency. One therefore moves away from the notion of careless spaces to accountable, blameworthy spaces, where despite a medical label offering exoneration, explanation and supposed forgiveness (Slee 1995, Lloyd 2003, Ryan and Runswick-Cole 2009), formal responses intimate a lack of such forgiveness.

Moreover, despite scientific research claiming advances in etiological understanding in respect of behavioural disabilities (Collins 2013, Luby 2013), these consistently fail to capture the public imagination with the same impact that conjectural accountability narratives do (Briant 2011, Goldberg 2011, Walker 2011, Jensen 2013, Runswick-Cole and Goodley 2015). Hence although the NICE (2015) guidelines acknowledge that 'challenging' behaviour is most commonly found amongst adolescents and young adults, linked to neurodevelopmental conditions such as autism; these medical and psychological associations remain firmly outside of dominant mothering scripts.

It is nevertheless worthy of note that the NICE guidelines phraseology, makes reference to 'behaviour which challenges', rather than 'challenging behaviour' (pp4). This may be said to reflect the reports assertion that presentations of 'challenging' are fluctuating and symptomatic, rather than pervasive to the individual's personality or dispositions. Is this a small step out of the margins? If it is, it requires a more openly stated embrace, not only by aligned professionals working with 'challenging' children, but by the mothers themselves. For although the NICE report, similarly to Cross (2011), calls for inputting agencies to be alert to the potential causes of presentations of challenging, (citing various examples of extreme and hostile triggers which may underpin negative behaviours), it is mothers themselves who are in the position to advise on such issues through a finely nuanced 'knowing' of their children. Paradoxically such engagement may also act as a preliminary first step to regaining a level of maternal respect that such complicated mothering merits. This review now

turns to the family and looks toward its constitution as a variable which is not only implicated in the sense made of behavioural disabilities, but also active toward the identities such disabilities engender.

3.1.3 The family – spaces of attribution and counter attribution

The family emerge as a prime site of accountability, held to account for the social presentation of their children on the basis of expectations which coalesce around the parenting role. These expectations may be seen to be historically and culturally situated (Cologon and Thomas 2014), reflecting popular notions of childhood and typical childhood development. As a consequence they operate to frame a profile of the successful parent which does not reflect wider intersecting circumstances (including disability) which may act to interrupt the expectations generated.

The constitution of the family as a homogenous social unit has been challenged. Deluze (in Donzelot 1979) for example has found the mediation of class and ethnicity, as well as the impact of family law and social opinion, generative of diversities vulnerable to the stratification of good and bad parenting. Reay (2008) cites similar divisions, finding class to be a primary mediator of disability/SEN experience, favouring of middle class parents. These disparities intimate unequal relations of power, effected with limited resistance. It is necessary, therefore, to consider the way these relations are rationalised and legitimated within a social system predicated upon the ideals of meritocracy, welfare and equality. Toward this the understandings parents forge toward their personal situation is a key factor.

Cologon's (2016) research amongst Australian parents addressed this question and found both the Medical and Social Models of Disability impacted on understandings forged. The opinions expressed echoed strongly those contained within the Lamb report (2009). In particular Cologon found parents experienced multiple barriers and accordances of stigma in their daily lives. Of significant concern was the effects of deficit labelling in the wider social domain, revealing junctures of oppression and exclusion founded upon established prejudices and stereotypes. These experiences are congruent with the premises of the Social Model of Disability, even though parents had engaged with a medical model to make sense of their child's physiological and psychological difficulties. Cologon's (2016) study also supports the notion that there is a difference between 'formal knowing' and 'familial knowing'; the

former depicted by parents to be a label which was not defining of their child's their child's core being ('familial knowing').

Notably, despite the introduction of the Equality Act (2010), rendering discrimination by association illegal, familial and particularly maternal oppression is found to persist; frequently responsive to childhood behaviour that parents are unable to moderate (Carpenter and Emerald 2009). Goffman (1968b) termed this 'courtesy stigma', as a means of describing negative connotations levelled toward an individual on account of their association with a disabled person. Although Goffman's observations were directed mainly to stigma directed at adults, which rebounded onto their children, the inverse of such relationship appears to endure contemporarily. Most particularly this is evidenced through the accountability for childhood conduct parents are imbued with, irrespective of capacity to deliver (Rogers 2007; 2013, Doublet and Ostrosky 2015). The diagnosis of a disability appears to be dismissed as mitigation (Parsons 2005, Jull 2008, O'Regan 2009; 2010, Karpin and O'Connell 2015, O'Connell 2016). It also at times has been used to imply that parents seek diagnosis for their own gain (Goldberg 2011, Walker 2011). Parental accountability thus remains contemporarily pervasive (Carpenter 1999, Blum 2007, Carpenter and Austin 2007, Austin and Carpenter 2008, Carpenter and Emerald 2009) and legally enforceable, as has been demonstrated in the UK through the introduction of parenting orders (Walters 2007, Holt 2008, 2010).

Accountability is found by Honkasilta, Vehkakoski and Vehmas (2015) to be moderated by maternal ability; as mothers of children with ADHD adopted various subject positions which were productive of varying influence. Conspicuously these positions included efforts to work in partnership with the school to improve the material circumstances of their children. Nevertheless Honkasilta et al also found that the demands of parenting a child with ADHD took its toll, henceforth some mothers, their subject position was one of personal need. This was defined as the 'worn out mother' (pp 684). Correspondingly for other mothers, the expertise needed to engage schools on an equal level was inaccessible. These mothers were depicted by Honkasilta et al as 'powerless bystanders' (pp 683). Nevertheless Honkasilta et al's research concluded that the relationships mothers had with schools and the identities they conjured were dynamic and not inevitably of deficit. In this respect they were confirmatory of Nind's (2008) observations. Markedly Holt (2008, 2010) found that for some parents their children's challenges exceeded the school system, forcing them

into the remit of the criminal justice system, whereupon court orders were less malleable to the influences of education and class.

Parental (particularly mothers) capabilities appear foundational toward how a child's challenges are viewed. This tendency speaks to Barr's (2014) ITTP, as it would appear that the skills generative of parental leverage in schools are the very skills coveted by schools and reflective of the educational and class position of teachers. From this position, despite the challenges a child might pose, the presentation of the family is a mediating factor, reducing the threats perceived. Thus despite the agency implied by Honkasilta et al's (2015) research findings, the realities that parents depict imply otherwise. Rogers (2011) notes that despite the egalitarian sentiment implied through the concept of parental partnership, there are impediments to such partnership. Most specifically a limited appreciation of the practical reality of parents circumstance. Carpenter and Emerald's (2009) notion of mothers on the margin highlights the way dominant scripts of mothering result in some mothers being unable to identify their own circumstances. This is found to be particularly marked for mothers of challenging children and sets in motion a tautology, serving to inhibit future maternal disclosures. These omissions not only act to confirm maternal failings and the child's atypicality, the dynamics also foster conditions rife for accountability and perpetuate a climate hostile to resistance.

Smith (2015) alludes to the historical consistency of parental blame particularly where youth offending is a problem despite there being a known association of neurodevelopmental disorders with offending behaviour, (Loucks 2007, Bishop 2008, Talbot 2010; 2011). Toward an understanding Rodger (2008) points to the increasing regulation of the family as a contributory factor fuelling accountability and calls for transparent delineation of when it is right to intervene and when it is not. Such call demands a transparent definition of what signifies dysfunction and functionality, exceeding that attempted by the 'troubled families programme' (Casey 2012 a; b) as in the case of behavioural disability, the familial circumstance may be distorted by the practical impacts accrued from managing a child who presents challenges.

Rogers (2013) focuses upon the caring relationships engendered by childhood disability, including a maternal expectation that children will reflect an extension of the mother's self (Rogers 2013). Although it is hard to generalise whether such disposition is innate, its potential holds important ramifications for mothers whose children have a behavioural disability. Not least because it may serve as a prompt to

not only external discourses of accountability, but also internal ones founded upon blame and regret and unrecognizability. In combination these discourses hold potential to dampen any maternal resources available which might mitigate against negative identities. Rogers (2013) interrogates the complexity and contradictions of caring relationships, finding them to be both empowering and disempowering, linked inexorably to political economic and moral imperatives.

The activity which accrues around the maternal role is described by Runswick–Cole (2013) as emotional labour and it is a useful way to describe the additional energies necessary to steer a child with behavioural disabilities to adulthood. It is also a useful way to depict the tensions of the maternal role, particularly in regards to external and internal attributions of accountability. Rogers (2013) makes the distinction about ‘caring for’ and ‘caring about’ (pp 136), which in the frame of maternal labour speaks to the impact of the strains associated with mothering a child with disabilities. This is significant as it offers distinction between the practical act of caring for, which of itself does not necessitate any emotional connection and that of caring about, which is inherently emotive. Looking at the terrain of parenting children with behavioural difficulties and/or indeed mental health issues, for some parents ‘caring about’ demands familial recognition that they can no longer ‘care for’. Such distinction is, however, uncommon in the popular domain and as Carpenter and Emerald (2009) observed, the dominant scripts of mothering and maternal success do not permit enclaves of recognition for the mothering experiences generated by behavioural disability or mental illness, serving further to a heightened sense of isolation.

Attributions toward the family and sense made within the family, may thus be seen to emerge not only from exuding circumstances and specific acts, but from pre-existing discourses and stereotypes that serve to define both maternal and familial life. It is therefore pertinent to reiterate Carpenter and Emeralds (2009) call for mothers to come out of the margins and demand a space within the dominant maternal narrative, reinforcing the practical reality that mothers and families are not a homogenous group, but impact and are impacted upon by wider social conventions, myth and stereotype. In this way it may be possible to deter the disadvantages and discriminatory potential faced by families and, in particular, mothers. Particularly as behavioural disabilities appear additionally vulnerable to challenge and denial, which as Adams (2014) reports has for one family led to the assertion of Munchausen’s by proxy.

3.1.4 Rationalising the blame game

The NICE report stands in contrast to the conventional management of challenging children in schools, where the tradition of dispensing exclusionary sanctions for behavioural issues persists (DfE 2015b; 2016a). Notably through this resort to an exclusionary response, schools impute a pervasiveness to the child's presentation as 'challenging', which may also be seen to imply a reluctance to accept the possibility of, or indeed responsibility for mitigating triggers, be they medical or environmental. Notably NICE also call for recognition of the impact of living with a person who displays behaviour that challenges (pp 9). This stands in marked contrast to the prevailing attitude in schools where parents, particularly mothers are found to be further disadvantaged by school exclusionary procedures when their child is considered a management issue (Kingston 2007, Gallagher 2010b).

In the educational domain, emphasis is weighted toward the impact of behavioural challenges (NFER 20012, Neil 2013) and as such operates as an important positioning tool, moving the focus from the disadvantages faced by the challenging child and his/her family, to that of those the child's challenges impact on. Hence despite studies which detail adversities faced (Carpenter 1999, Carpenter and Austin 2007, Carpenter and Emerald 2009, Emerald and Carpenter 2010, Gallagher 2010), these are of limited relevance within the educational domain as they are not the primary organisational consideration.

This absence of recognition hints at a deliberate turning of the eye; for it is notable that childhood disability generally, is found to encroach upon the privacy of the family and is therefore liable to reveal the difficulties faced (Rogers 2007, 2007a, 2007b, 2011, McLaughlin 2008b; 2011; 2016, Dowse 2009). Markedly this encroachment is found to be historically cumulative and suggested to be an extension of the development of general cultures of familial surveillance and accountability (Donzelot 1979). Childhood disability and SEN 'specifies and legitimises certain intrusions by education and health professionals' (Rogers 2007, pp 26), which are additional to those experienced by other parents, it is therefore reasonable to assume that the challenges depicted by Carpenter and Austin (2007) and Carpenter and Emerald (2009) are known, but overlooked. Equally given the persistence of deficit discourses, this additional attention cannot be viewed as innocuous, rather it emerges at the core to be evaluative, as such is inconsistently welcomed or resisted

depending on the deductions of accountability or exoneration made (Blum 2007, Kingston 2007, Rogers 2007, Runswick – Cole 2013).

It is at the juncture of accountability and exoneration that it becomes most apparent that behavioural challenges do not always resonate with disability and as such serve to position the family as the locus of the problem (Casey 2012a; b, Heeney 2015). Paradoxically such disconnect may also be seen to be an additional motivation for the families implicated to resort to what I term a 'defensive diagnosis'. A defensive diagnosis acts not only to explain difference (Lister 2010), to render understandable the differences the child exhibits (Newsom 2003). Rather its impetus may be seen as a direct response to the negative attributions of others, which impact not only on the child but also on the parenting competencies of the family (Wells 1998, Singh 2004, Peters 2012, Frigerio 2013). The function of diagnosis is therefore altered in its guise and extends beyond medical utility.

Diagnosis, is however, found to be of limited utility, when the predominant signifiers of the medical label conferred are behavioural; for when symptomatic behaviour contravenes criminal codes, it is found to conjure legal and moral dilemmas of accountability, appropriate response and future identities. The field of law is the most pertinent example and it is one area in which these inherent complexities are being increasingly debated. O'Connell (2016) for example considers the impact of anti-discrimination legislation on the legal rights of children with behavioural disabilities. O'Connell cites three areas of regulation pertinent to challenging behaviour: disability discrimination law; criminal law and the medical regulation of behaviour. Whilst O'Connell's research does not offer solution to the dilemmas posed, it points not only to the implications of likely scenarios, but also their regulative intent. It also shows how rights in law concede to the punitive principles enshrined in criminal law. Principles which in substance are similar in guise to the qualifications found embedded in discourses of inclusion which are discussed at section 3.2 and found to be negating of educational rights (Parliament 2001, 2010b, 2011).

O'Connell finds that the level of deterministic response to behavioural disabilities attributed to a neurodevelopmental condition are led by the extent to which potential for change is considered viable. This is found by O'Connell to be linked to what is termed the 'plasticity' of the brain (pp16). Neurologically children are considered to exhibit a high capacity for plasticity as O'Connell explains; 'within a neurochemical framework, children are the exemplars of plasticity: their minds are commonly

understood as highly malleable, structured by relationships, social context, and environment' (pp16). This indication of optimism also opens spaces for accountability through the idea that the impetus for change extends from the cultural and parenting influences on the child, led by the notion of behavioural modification techniques. Interestingly such position has capacity to confer accountability for failings onto both school and family.

Ribbens McCarthy, Hooper and Gillies (2013) suggest that response to challenging behaviours and indeed acknowledgement of the locus of challenges are impacted upon by idealised notions of childhood which shroud the social and medical realities faced by some children. The authors emphasise the social factors that contribute to the 'troubles' families and children face, yet caution that responsibility for such factors is often masked behind the effects that manifest. The government initiated troubled families programme is illustrative of how deprivations faced can be deflected by a focus on the effects of deprivation, rather than the root causes (Casey 2012a; b). The programme clearly sets out what it considers to be the indicators of being a 'troubled family', citing unemployment, school disengagement, poverty and criminal activity as core factors. Thus at first glance the scheme appears socially laudable, but on closer inspection is laden with emotive referents to getting families back on track and as such individualises accountability for the deprivations faced.

Tellingly there is an inadequate address of the social and economic circumstances which lead to families being socially positioned as 'troubled'. Bunting (2015) explored the premise that troubled families were cyclic, transmitted from one generation to another, and indeed in some instances this was found to be the fact, but for other families, Bunting found that it was material circumstance which led to disadvantage.

In a similar vein Ribbens McCarthy et al (2013) problematize the objectivity of developmental models of child development, suggesting they extend not from scientific fact, but from the structural exigencies of political and economic structures. Thus doctrines of child development, need and attachment are found to be distortive of deficit, when presented as the de jure authority, rather than one of several equally valid models. It is therefore significant that Ribbens McCarthy et al (2013) impress upon us the importance and implications of troubling the normal, which equally speaks to the effects of its opposite, normalising trouble. In this way, what constitutes challenging behaviour invites alternative explanation and can equally be seen as reasoned response to unacceptable circumstance or stimuli. It is also useful to

consider both the origins of normal and the interests that are served by its maintenance. Francis (2013) applies a social constructivist perspective to this issue, suggesting that all 'problems emerge from social interaction' and are the 'outcomes of micro-political processes' (pp 85).

The perspectives outlined have implications for how 'challenging behaviour' could usefully be researched; not least as they move beyond individualised explanations for action, towards a focus on the micro and macro relationships and circumstances that may trigger challenging behaviours. This perspective is similar in nature to that expanded by Holt (2013) and has wider implications in regards to the social and political functions 'troubling' behaviour may be seen to fulfil, an issue which is addressed in more depth further in this chapter.

The research of Francis (2013) serves to elucidate the complex relational pathways that lead to the definition of troublesome; charting the various engagements between family members, the child, other parents and professionals which combine to profile a young person as troublesome. Francis highlights how collaboration and social construction are integral to what is eventually determined grounds to substantiate a deficit identity and it is notable that mothers were heavily swayed in their judgment of what troubling was, through reference to popular images of 'successful' non troubling childhoods. In these scenarios Francis (2013) found that mothers are not only primary to the identification of trouble, but central to the consideration of a medical explanation. Francis attributes this lead to an appreciation of a heightened vulnerability to discourses of blame, as such supports the pursuit of what I have termed 'defensive diagnoses.

It may also be said that familial difficulties are inevitable over the life course of parenting, which invites consideration of what the bounds of 'normal' difficulty are. Ribbens McCarthy (2013), like Francis (2013) and Holt (2013) point to how adults and social institutions shape the meaning of troubles in childrens family lives and in doing so further support the contention that delineations of troubling are socially constructed. Such a position directs causation away from individualised medical discourses and invites address of the factors which conspire to define troubling as an individual problem and is so doing also serve to problematize what is considered within the bounds of normal. McLaughlin and Goodley (2008) describe these processes as 'unmaking children' (pp 53), stating that 'normal narratives of childhood

come apart when something about a child is read as out of place within the normal' (pp 53).

McLaughlin and Goodley (2008) point to an ever escalating governmentality in the categorising of children into different kinds. Noting that in the UK particularly, 'state mechanisms are increasing for monitoring and disciplining such disruptive children' (pp53). These claims are further supported by the ongoing drive to give schools greater disciplinary powers, which by default encroaches on the jurisdictions of the family (HCC 2011). McLaughlin and Goodley find that 'disabled children occupy the disruptive child identity in two ways, firstly through the identities attached to medical labels associated with 'challenging behaviour' and secondly, because the disabled child's non-normativity 'contrasts with the 'normal' child' (pp54), reinforcing the 'latter's potential productivity as the future good citizen' (ibid).

These contentions hold significance in two respects; firstly they underscore that medial labels are host to particular identities, thus diagnosis confers not only an explanation for the symptoms presented, it also confers an identity which is underpinned by expectations, which are active in ongoing social engagement. Secondly they point to the institutional processes which underpin a disruptive identity and the functions served by such identity. McLaughlin and Goodley (ibid) term this 'medical othering' (pp 61), which prompts us to reflect on the arbitrariness of diagnosis and the powerlessness the child has in the process although Francis (2013) and McLaughlin and Goodley (2008) note that parents are active participants to this process. Notably both school staff and parents, particularly mothers, engage medical services to make sense of differences which deviate from prescribed norms. They may thus be seen as the architects of classificatory processes, rather than as passive recipients. Such view challenges the view of medicine as a dominating truth, rather it suggests that medicine is harnessed for wider purposes, which in these instances are the vested interests of parents and schools.

Holt, Bowlby and Lea (2013) suggests behavioural differences are socio-spatially complex, involving an interplay between the emotive, social and medical domains and contributes to our understanding of the identification of challenging behaviour by developing Bourdieu's (1986) notion of habitus and capital. Holt et al purport that it is the fluidity of the socio-relational context which gives rise to not only the appearance of 'challenging' behaviours, but also the functions served in terms of emotional gratification. They further suggest it to be the relationship between the emotional and

social domains where multiple habitus conjoin and overlap which is central to the appearance of behavioural difficulties.

Holt, Bowlby and Lea's (2013) depiction of the school system is as a 'complex site of interlocking and at times incompatible habitus' which are marked by fluid and shifting 'norms' of appropriate behaviour' (pp1). More specifically it is suggested to be persons whose identities do not adapt seamlessly in and between transitions, which are most vulnerable to presenting the appearance of individualised difference. Which amidst the backdrop of an increasing medicalisation of both conduct and physiology (Conrad 2007; 2010, Conrad and Bergey 2014) and increasing emphasis on school powers (DfE 2012d) may incur either interpretation as a medical disorder or as need for tighter discipline and/or school supports (NFER 2012).

It would appear that Holt et al (2013) consider the ability to adapt and differentiate between contexts, a key factor implicated in the appearance of typicality. Hence for some young people irreconcilable incongruences serve to define them as challenging. Moving from a medical versus deviance binary (Thomas 2007) and expanding Bourdieu's range of capitals to include emotional capital, Holt et al (2013) develop a theory of motivation which is founded upon the claim that the problems young people face are 'socio-spatially constituted'; led in the first instance by the need for positive affirmation, a socio-emotional state they term 'emotional capital' (pp 38). From this perspective Emotional and Behavioural Difficulties in school can be seen as behaviours which are 'out of place' (Holt et al 2013, pp1), which as a consequence erect barriers to self and others learning. Yet these actions may also be seen as a strategic response rather than chaotic action, undertaken in order to maximise their capacity to accrue emotional capital.

It is particularly significant that relationships are considered to be a key factor in the stability of the habitus, stated to be 'forged and maintained specifically because individuals are emotionally co-dependent and seek satisfying and supportive relationships and networks' (Holt et al 2013, pp1). Notably because it suggests that far from being emotional immature, pupils choice of social groupings are emotionally astute and strategic, seeking networks that affirm rather than deny. As a consequence this places the onus back on to schools rather than pupils to remediate barriers to school success. In so doing this would ensure emotional capital could be amassed by all pupils through school engagement.

On this basis Holt et al (2013) call for emotions to be central within educational research and as such call would appear warranted, not least in recognition of the complexity and range of relationships young people enter into in the school context. Practically they suggest the concept of emotional capital to be under developed by Bourdieu, equally so, the reasons why individuals embrace varying habitus. Toward expansion Holt et al (2013) suggest choices made 'emerge through beyond-conscious acts rather than strategic, rational agency' (pp2), driven by an innate need for positive affirmation (Maslow 1943). Notably the mapping of social engagement in this manner alters how one might address the problem of 'behaviour', not least it directs us to be mindful, of not only how conduct becomes viewed as trouble, but what functions the appearance of trouble serves for those implicated.

At this juncture it is important to balance the impression that troubled identities are imposed. Butler (1997) suggests identity to be the outcome of both external and internal processes and makes a case for a synthesis of Freudian and Foucauldian theory to explicate the processes underpinning subjection. Toward this, Butler highlights an important distinction between being profiled as trouble and internalising the role as an accurate representation of self; signalling processes which are further problematized when the subjection is of a child and that subjection leads by proxy to deficit identities of the wider family, which are found alternatively resisted or accepted (Holt 2008, 2010).

Holt's (2010) research amongst parents subject to compulsory parenting orders is illustrative, finding that although parents resisted locally the implication of deficit, the logic of the parenting order placed them in a double bind. Notably that if they co-operated with their orders and made changes, their initial deficit status was confirmed through progress, yet if they resisted, they were vulnerable to further scrutiny and additional sanctions, consolidating the original identification of deficit. Toward a reconciliation, Holt identified evidence of the internal and external processes that Butler suggested were intrinsic to subjection. Parents displayed private resistances to the negative identity their parenting order conferred, alongside informal collusion with other parents similarly placed, whilst publically complying with the demands of the order.

This camaraderie supports the notion of multiple habitus as well as the contention that emotional affirmation is a prime motivating factor toward how individuals respond to and resist difficult circumstances in their lives. Holt's findings are also important for

our understanding of how power is effected and resisted and are compatible with Butler's (1997) claim that power is bound up within a matrix of psychological and physical inter- dependency which is defining of the human condition. From this perspective, the exercise of power in varying guises, may be to extend from such dependency.

3.1.5 Accepting Accountability

Gillborn and Youdell (2000) suggest accountability is sanctioned particularly in education and the legal system, amidst wider implications of threat. Butler (1997) in contrast suggests interdependency predisposes us to a physical and psychological acceptance of regulatory norms; albeit channelled by an equal need for emotional recognition and social validation, which of itself predisposes persons to engage within habitus that are affirmational and regulatory. Youdell and Armstrong (2011) extend an emotional geography of education, focusing on the significance and workings of space, subjectivity and affectivity in everyday life in schools. Within which they found subjection to be a fluid rather than a linear oppression, negotiated in both the structures of the school day and the informal use of social spaces in terms of both physicality and emotion.

Gillborn and Youdell (2000) suggest there to be a rationing of educational success in schools, linked to the embrace of the institution's dominant value system. Power and control state Gillborn and Youdell is exercised in two forms. Firstly, through the establishment of internalised standards and values, which can take the guise of being fair and proportionate and thus appear incontestable. Secondly, through the metering of educational success and failure, which is itself conditional upon an embrace of the previously stated value system. These claims are further supported by Holt's (2016) finding of a disproportionate representation of white working class children identified with EBD. Thus if one accepts the intimation of middle class bias in schools (Ball 2013), these statistics supports Holt et al's (2013) contention that the appearance of difference may extend from transitional difficulties from one habitus to another, or indeed from one cultural value system to another.

Holt (2016) further suggests that the subject position 'EBD can act as a mechanism for the reproduction of socio-economic exclusion' (pp 155), as does the classed nature of 'good parenting' found accompanied by the vilification of working class parents (De Benedictus 2012, Jenson 2012). Additionally where behaviour is an

additional further burden, Runswick-Cole and Goodley (2016) find there to be a greater State resolve to absolve itself of responsibility. It is at this juncture that the functionality of accountability is most evident, as Runswick-Cole and Goodley explain, stating 'mothers of disabled children find themselves differentially precarious as their children have come to represent both a present and future danger to scarce state resources in a time of austerity' (pp 17). Thus the conferring of accountability, particularly its maternal internalisation, operates to deflect any governmental failings in respect of support as well destabilising entitlement to future support Barnes and Power (2012).

The determinism intimated above, contrasts markedly with Holt, Lea and Bowlby's (2012) finding from a research project conducted in an attached (to mainstream) unit for autistic pupils. Contrary to expectations, engagement between those identified as abnormal (autistic pupils) and those deemed normal (mainstream pupils) opened spaces for change that were transformative of the delineation of normal. The intersections of normal and 'abnormal' were also found acted upon by individual agency, as such were considered a key feature in the way subject positions were occupied and made available.

As a consequence, Holt, Lea and Bowlby (2013) suggested that 'normalisation reframes power, as positive generative and inclusive, rather than negative and exclusionary' (pp 2194). Indeed it was further found that 'normative power was bound up with nurturing relationships' (pp 2198), channelled through an innate tendency to seek affirmation, which in administration was found to generate disposition to self-regulate. Hence although the ASD Unit was found by Holt, Lea and Bowlby (2012) to perform contradictory purposes, simultaneously a site where difference was accepted, as well as a 'container for the abnormally behaving' (pp 2200). It was its impact on social norms and identities that was considered to offer greatest scope for change; as is stated, 'despite some critiques of special units, they can act as sites of specialist knowledge and safety for young people on the autistic spectrum, and as a launching pad to reproduce more inclusionary social and communicative norms' (pp 2003). The integration of pupils on the autistic spectrum was thus concluded as 'expand[ing] the norms of behaviour (re)produced in mainstream school spaces' and potentially beyond' (pp 2202).

One might conclude therefore that what is considered accountable is linked to wider considerations of what constitutes the norm, which is itself linked to the various

habitus intersecting in a given social context. Thus 'troublesome', is not only contextual, collaborative and unstable it is performative. 'Processes of abnormal are performed, dynamic and sociospatially shifting, and individuals can be more or less (dis)abled in different spatial contexts.' (Holt, Bowlby and Lea 2013, pp 2195).

As a consequence it is useful to employ the micro-political frame of questions (Francis (2013), which asks 'who are the relevant social actors, what are their sources of power? What are their vested interests? Whose definitions of trouble prevail, in which contexts and why' (pp 85). Such address leads me to an immediate conclusion that the actors comprise in the immediate, the child and his/her family as well as the range of school professionals commonly present in a mainstream school, teachers, teaching assistants and pastoral staff. Yet following a more nuanced assessment, leads to a broadening of this list to include both medical practitioners and government agents, entrusted with the monitoring of professional standards in schools. Equally the school as an organisation intersects with many wider institutions, not least future and higher educational institutions, potential employers, and community interests. This interplay of interests, resonates with Holt, Bowlby and Lea's (2013) claim of multiple habitus, it also suggests that the interests served, as well as definitions of what may be considered trouble are liable to be complex, directed by wider political and economic priorities and vision, at both national and global level (Tomlinson 2008, Youdell 2011, Robinson 2011; 2015). There is thus an interconnectedness to what constitutes trouble and thus forth, what is accountable. This review now considers more deeply the role of the school context toward delineations of disability and familial accountability, it concludes with a corresponding consideration of the family as an equally constitutive site.

3.1.6 Schools as active architects of disability and deficit identities

Schools may be seen to occupy a dual role in relation to childhood disability; on one side they are entrusted with its identification and appropriate response (Rothi 2008, DfE 2015a), on the other they are charged with being formative to its appearance, not least through the sanction led system of control common in contemporary schools (Baker 2002; Waterhouse 2004; Graham 2007 a; b, Graham 2008, Graham and Macartney 2012, Bailey 2006; 2008; 2010). Goodley and Runswick-Cole (2016) suggest institutional priorities led by escalating processes of governmentality are formative toward dispositions to categorise children, particularly those presenting as disruptive. Notably such disposition does not translate to equal impact in terms of

mitigation for actions, to the contrary Jimenez (2015) finds where behaviour is an issue, punitive intent supersedes the protections accorded through the European Convention on Human Rights. Caslin (2014) concurs; citing schools to be disabling institutions, particularly for pupils exhibiting behavioural challenges. Caslin also indicates concerns in relation to the impact of medical labels, suggesting that 'the labels attached to young people determine their educational trajectory' (pp 164). This concern has also been expressed by Ofsted (2010), claiming that a significant percentage of SEN identifications stem from school rather than pupil inefficiencies.

Challenging behaviour has posed both historic and contemporary problems for schools, linked to the core function schools have been considered to provide in regards to the socialisation and education of a future workforce. This role is also considered fundamental to the constitution of mass education systems in the UK, particularly in relation to disciplinary procedures (Tomlinson 1982; 2005, Robinson 2011; 2015). Tomlinson (1982) states, 'the preparation of a normal productive 'educated' workforce was seen after 1870 to be impeded by the presence of troublesome defectives' (pp 13). Robinson (2011) likewise suggests the former needs of an industrial work force have not only shaped the form of school systems, but contemporarily have failed to keep pace. As a result they are contributory to the appearance of many commonly diagnosed childhood disabilities. This contention is echoed by Youdell (2011), who states 'schooling is implicated in the making of particular sorts of people as well as the making of educational and social exclusions and inequalities (Youdell 2011 pp 1). Graham and Slee (2011) observe similarly finding 'troublesome' children are less welcome in their local schools than those with mild disabilities' (pp 951).

Graham (2008) addresses the role schooling plays in the rising rate of ADHD diagnosis; finding that schools rely on normalizing discourses, 'operate not only to define normal/abnormal ways of being,' but that the terms 'disabled' and 'learning disabled' inadvertently acts to stigmatize children whose particular difference does not quite fit within these parameters or might otherwise be described in deficit terms' (pp 591). Behavioural disabilities hold an inconsistent association with disability and are notably absent from benevolent popular discourses as the headlines penned by journalists Walker (2011) and Goldberg (2011) indicate. Although brief they are powerful, intimating a familial abuse of the diagnostic system for financial gain. At no point in the articles published is there any medical evidence offered to support or

refute the claims made, nor the opportunity for the accused to make a defence. Tellingly, although both banners allude to ADHD as a contested medical label open to abuse; it is parents rather than doctors or schools who are positioned as the architects of such abuse.

Graham (2008) draws upon Foucault's (1972) assertion that 'psychiatric discourses finds a way of limiting its domain, of defining what it is talking about, of giving it the status of an object—and therefore of making it manifest, nameable, and describable' (pp 41). This sentiment is most apparent when one considers conditions like ADHD, whereby diagnosis is highly subjective without the security of organic markers. It is doubly so in relation to the identification of pupils with EBD, as it is not only the actual presentation which is found to be directive of the sense made of challenging behaviour. Rather it is also the evaluation of parents by schools which contribute to school determinations and it is at this juncture that class factors are implicated in school judgements (Nind 2008; 2010). Harwood and Allen (2014) caution similarly, finding that minority groups and children from disadvantaged circumstances are over-represented in educational remediation and disciplinary programmes and additionally that boys are more likely to receive a diagnosis relating to behaviour than girls.

It is at this juncture that further consideration of the constitutive nature of schools is justified; not only in relation to the appearance of disability, but toward the types of pupil presentations which are considered to have a detrimental impact on the school organisation. Kauffman (2001) cautions that EBD is whatever a school or government determine is unacceptable, although at a later date, defends the maintenance of segregated educational provision for pupils whose differences have an impact on instruction (Kauffman 2015). These seemingly contrasting stances both suggest and deny the constitutive nature of schools. In contrast, Harwood and Allen (2014) indicate a need for research attention to be directed to psychopathology discourses in schools. They further suggest that the absence of such discourse projects the impression of medical labels as static and the young person in need of repair. Sentiment which may be said to bear a resemblance to Kauffman's (2015) stance on appropriate education and continuing need for specialist pedagogy.

Barr (2014) in contrast suggests that pupil heterogeneity, particularly in relation to class and culture can be divisive, where there is an incongruence of values and attitudes between school, family and the child, generating the perception of individualised difference. Deviating from direct discourses of oppression, Barr draws

upon the Integrated Threat Theory of Prejudice (ITTP) to make sense of negative responses to persons and groups which deviate from the collective norms. The theory, framed around the notion of in-group and out-groupings, suggests outgroup members will behave in a manner that compromises the security of the group. Barr's theory of ITTP, offers explanation for why pupils and families who deviate from the dominant norms and values of the school as an in-group are perceived as a threat and as such trigger exclusionary or punitive discourses. These pupils and families whether presenting low level disruptive behaviours (LLDB) or more severe behavioural challenges, generate impression of out-group status (which is itself an impetus to segregation, both 'challenging' pupils from their peers and the school body as a whole). Such impression also serves to support the reasonableness of accountability and as such mitigates against school inclusion and equality.

Equally constitutive are the attributions formed in the school context toward LLDBs. Ofsted (2014) found such behaviour to be a regular feature of school life, stimulating concerns towards discipline standards rather than triggering any association with behavioural disability. Undoubtedly some instances will reflect immature behaviour, but many will not and it is the absence or method to discern the difference that is a concern. Notably several disability charities highlight the injustices levelled against children and young persons with disabilities of impact on behaviour, these include CEREBRA (2013), the Ambitious about Autism Charity (2014) and Contact a Family (2013). A common concern stated is that schools appear undiscerning in their response to challenging behaviours, fostering a reactive response the infraction of school based behavioural codes, rather than one which is directed to cause.

Bailey (2010) cites interdisciplinary engagement as foundational to the increasing prevalence of behavioural disabilities in school and in doing so casts doubt on the integrity of the classificatory systems generally. 'The DSM, the influence of the 'med-psy-ped' alliance and the presence of risk anxiety in governmental rhetoric over 'safety' and 'welfare' (DfES 2004a) paves the way for the pathologising of children' (pp 588). Such position is worthy of merit as it reflects an inherent interconnectedness of discourses and demonstrates that there are unequal discourses operative. The various stances detailed intimate that schools are indeed active in the construction of explanations for behavioural challenges. Yet the attributions underpinning these constructions are less defined. Not least because

they are bound up with wider governmental and economic priorities, as well as the priorities indigenous to the school system.

Undeniably challenging behaviours serve to unsettle the authority of the school system; authority which is vital given the size and demands placed on schools from government and employers. The White Paper “Educational Excellence Everywhere” (DfE 2016b) alludes to the frenetic pace and ongoing governmental pressure on schools to evidence improvement. Which by its nature does not leave positive spaces for those identified as disruptive and as the quote below suggests serves to inhibit the conditions necessary to deliver any positivity:

‘Five years on, our schools system still has further to go. We need to extend and embed the last Parliament’s reforms so that pupils and families across the country benefit; and we must raise our game again to reflect higher expectations from employers and universities, and to keep up with other leading countries around the world. Other education systems – from Shanghai and Singapore to Poland and Germany – are improving even faster than we are’.

Inevitably and unfairly, for some young people, the demands for continued and sustained improvement are unrealistic through no fault of their own, yet attract accountability and sanction nevertheless (DfES 2005, Rogers 2007a, 2007b, OFSTED 2012, 2014a). The most recent indications of governmental aspirations for schools as shown in the quote above, not only suggest fluid global competitive pressure, they also point to the need for school systems to have structures in place to limit the effects of challenging behaviours irrespective of causation.

An underpinning need to maintain order as part of an institutions wider competitive engagement offers a reason for the continued (disproportionate) exclusion of pupils with both SEN and disability. Notably most often for behaviours that are described as persistent disruptive behaviour (DfE 2015b; 2016a). Tomlinson (2005; 2008) describes this exclusionary mind-set as an inevitable consequence of the spread of Neo-Liberal governmentality, predicated upon individual performance and accountability. McGregor (2015) echoes such sentiment stating, ‘contemporary global economic contexts are shaped by a Neoliberal paradigm of hyper individualism and meritocracy, strongly influencing national policies in welfare and education’ (pp 1). To this one might add they are also shaping of identities, namely deficit identities which justify exclusionary sanctions.

These processes have real life policy and identity implications, not only for the individual, but for the disabled population as a whole and their families (Garthwaite 2011, Hughes 2015, Roulstone 2015, Hirschmann 2016). For as Roulstone (2015)

emphasises, the political climate has directly resulted in a constricting of the disabled population as a whole, set amidst a climate of mistrust and attributions of exploitation.

Within this climate of mistrust, the social supports developed in schools and through the benefits systems become evidence of acquisitive exploitation, even for parents who have their claims validated through medical discourses. These discourses may however be seen as part of a wider determination to redact pupil/parent rights and status as is clearly shown by the withdrawal of the former statement of special educational needs. This assessment pathway although replaced by the Education, Health and Care (EHC) plan, signals the introduction of an assessment process which is a poor fit for children whose difficulties present only in the school system, whereas a dedicated educational needs assessment protocol enabled their educational needs to be highlighted. As a result pupils who exhibit mainly behavioural difficulties are not always considered suitable for the EHC pathway.

Equally so, changes to the appeals process and the intent to confer increased powers to head teachers (DfE 2012d) indicate a worrying trend away from educational right to educational accountability, as such acts to position both child and family unequally, signalling at first hand unequal relationships of power that are definitional. It is to a consideration of the processes of subjection that this review now turns.

3.1.7 Subjection – a symbiotic relationship of innate needs and external priorities

Butler (1997) problematizes the notion of a linear power bearing down (uncontested) on an individual or group, rather points to the role agency plays in the exercise and resistance of power. Butler addresses the implication of power being considered productive of subject hood in respect of individual agency, as logically the notion of power being constitutive, implies an innate dependency on the sources of power for existence as the following statement expresses. 'If following Foucault we understand power as forming the subject as well as providing the very condition of its existence and the trajectory of its desire, then power is not simply what we oppose, but also in a strong sense what we depend on for our existence' (pp2). In a real sense 'subjection signifies the process of becoming subordinated by power as well as the process of becoming a subject' (ibid).

Butler's argument indicates it to be an oversimplification to suggest that schools are solely constitutive, rather from a constructivist perspective, it is more apt to suggest that schools operate in conjunction with both pupils and parents to effect subject positions. Notably the extent of subject agency continues to pose an ongoing quandary in social theory, as does the notion of individual being, prior to subjection. In particular it raises questions in regards to the implications of multiple subject hoods and prior subject positions. These issues although beyond the scope of this research, have philosophical implications in relation to the essence of human being.

Although Butler (1997) charges Foucault with an inattention to the psychological processes implicated in the process of submission, this charge is equally levelled towards Freudian theories of the psyche, not least for a lack of address of the impact of external power on personal dispositions and capacity to resist. I suggest therefore that any theory of power necessitates a theory of the psyche as well as a theory of power. At this juncture it is useful to return to Bourdieu's notion of capital and indeed Holt's (2013) expansion of this in relation to emotional gratification to postulate what if any psychological functions are served by submission to externally imposed subject positions.

Toward a dynamic theory of subjection Butler suggests that subject hood is emerges from the consolidation of the effect of a prior power and the potential of a conditioned form of agency; such symbiosis may be seen to be generative of a tension which is mutually productive of subject hood. Returning to the problematic of medical labels and subject hood in schools, Butlers theory explicates why, despite a medical label being the outcome of an external judgement (diagnosis), its identity is owned and moulded by the identified. This process is most clearly exemplified by reference to the autistic community (Sinclair 2005, Thoreau 2007, Boundy 2008, Wrongplanet.net 2012), but equally disability specific support groups for parents and young people may be seen to fulfil a similar objective. Returning to the Holt Bowlby and Lea's (2013) notion of the drive to accrue emotional capital and Barr's (2014) Integrated Threat Theory of Prejudice, I suggest that a central motivation shaping the symbiosis detailed is the pursuit of affirmation.

Butlers call for a focus on the psyche of power is nevertheless complicated when directed to the subjection of children. Most specifically because the postulated interplay between the inner psyche and an external power source is distorted by wider familial input. This input may be seen as not only actively constitutive of the

child's identity as an extension of familial status, but also because the parenting role engenders a familial role as proxy for the child and is thus directive of external medical labels (identities) sought or resisted. Such endeavour has been termed emotional labour by Runswick- Cole (2013) and is also implicated in what Rogers (2013) terms the act of caring about and for. Indeed identity work may be seen to be heavily implicated in the act of 'caring about', not least in the drive to present the child as more than the sum of his/her disabilities (Berube 1996, McLaughlin, Goodley, Clavering and Fisher 2008b, McLaughlin, Phillimore and Richardson 2011). Consequently drawing upon Butler's (1997) call for a theory of the psyche, the multifarious ways that parents attempt to positively present their disabled children (Berube 1996, Jackson 2004, Gallagher 2010b, McLaughlin 2011; 2016) may be seen as the embodiment of the psyche by proxy, directed to the task of resisting negative subjection through medical labelling. This review now looks to the legislative contexts of inclusion and Equality legislation toward a consideration of the extent to which the promise of equality and inclusion has delivered egalitarian relations, both for children and for families.

3.2 Subsection 2: The legislative implications of Inclusion and Equality Protections

The policy of inclusion promises in principle an equitable educational system, it may also be considered a marker of how inclusive the wider society of which it is a part is. It is therefore a concern that despite inclusion being a well-established educational culture, exclusionary processes persist, perpetuating individualised accountability for the behavioural manifestations of a disability. Notably Edwards, Armstrong and Miller (2001) caution that 'the concept of inclusion only has meaning in relation to the concept of exclusion' (pp 474), signalling a symbiotic inter-dependency which has implications for the integrity of the policy of inclusion itself.

Markedly the history of Inclusion reveals an inconsistent identity, which has resulted in an equally obtuse definition. Nevertheless as a concept it has been hailed as the embodiment of educational right (UNESCO 1994a, Booth 2002, Powers 2002) and is a global initiative (UNESCO 1990; 1994a; b; 2008), attracting wide international commitment as evidenced by the number of signatures to the Convention of the Rights of Persons with Disabilities (UN 2007). Indeed Kanter (2015) records that by 2013, 156 countries had signed the treatise and was ratified by a further 137, signalling broad commitment.

Nevertheless Inclusion is also a qualified right (Parliament 1981, 2002, 2014) and has been depicted as a dogma (Party 2010), generative of unwelcome consequences (Warnock 2005, Cigman 2007, Leslie 2008, Rogers 2007b; c, Runswick-Cole 2011). The policy of Inclusion has thus stimulated questioning not only around a pupil's right not to be included, but also toward the efficacy and implications of its claims. Not least its relationship to normalising discourses which are cited to be an unstated pre-requisite to being included (Edwards, Armstrong and Miller 2001). There are also concerns expressed towards the extent to which Inclusion as an initiative can be seen to differ in form to that of its forerunner the policy of Integration. In answer it would appear that whilst both terms differ in regards to philosophy, there is less of a difference in practice, particularly in relation to their impact on the educational entitlements of pupils with behavioural disabilities, particularly in relation to a continued vulnerability to school exclusion (DfE 2015b, 2016a).

The UK has been foundational toward the wider interpretation of Inclusion internationally. Nevertheless it differs markedly to the system of inclusion implemented in Italy through law 517, ratified a year prior to the publishing of the Warnock report (1978). Notably Law 517 is attributed to have led not only to the eradication of school exclusion, through a prohibitive legal framework, it has also fostered a professional mind-set which views exclusion as unthinkable (Arnold 2009), nevertheless it remains understated in the literature surrounding the evolution and development of inclusion.

The experience of inclusion for parents is equally fluid as Runswick – Cole (2008) indicates, finding divided opinion amongst parents in relation to mainstream or special school placement. Runswick – Cole defines three typologies of parental response; commitment to mainstream; initial commitment to mainstream but later change of opinion and commitment to special school. These divisions may be seen to echo other accounts of negative experience in mainstream, which are punctuated repeatedly by the identification of an identified lack of resources, social integration and general acceptance. (Kauffman and Hallahan 1995; Cigman 2002, Warnock 2005, Humphrey's 2008a, 2008b). Inclusion has also generated academic tensions toward both its intent and purpose (Barton 1987, Slee 2001, (Clough and Corbett 2002), Pather 2007, Dunne 2008, Graham and Slee 2008, Acedo, Ferrer et al. 2009). These concerns in particular question what has changed. Indeed for some

academics, inclusion represents nothing other than special education in a differing guise. For example Slee and Allen (2001) suggested at the turn of the millennium the processes observed both in the UK and Australia constituted little more than a 'reforming project of submerging disabled students in the unreconstructed culture of regular schooling' (pp 177). When in contrast, philosophically, Inclusion was hailed as the embodiment of a paradigm shift, demanding radical change at the level of systems with the remit to commonly educate in mainstream all pupils. Inclusion as a philosophy has been described as the embodiment of the 'aspiration for a democratic education system' (Slee 2001, pp 168). Such vision suggests awareness of the disadvantaged and unequal treatment of disabled pupils, (Tomlinson 1982, Oliver 1990, Barnes 1991a; b, Armstrong 2003, Barton and Armstrong 2008) and has also been considered to have an impact across the life span (Winzer 2007).

The development of inclusion has however been piecemeal; the consolidation of domestic and international legislation (Parliament 1981, 2001, UNESCO 1990, UNESCO 1994a, UNESCO 1994b, UNESCO 2008). Although focus has been disproportionately on placement issues, one important distinction of inclusion as opposed to integration was the stated motivation to move away from the use of medical labels as the basis for placement entitlements (Warnock 1978). In the UK this resulted in a refocus on pupils difficulties in learning, which was an impetus to the introduction of the statement of educational need (Parliament 1981).

Although the abolition of segregation by medical labels was considered revolutionary, in implementation its efficacy is questioned as the following excerpt from Barton and Armstrong (2008) indicates:

'New notions of 'special educational needs' and 'integration' ushered in by the Act and the Warnock Report (1978), rather than abolishing 'categories of handicap', introduced a new super category 'SEN', and 'integration' only concerned a limited number of children – those who could 'fit in' to existing structures'(pp 5).

Such contention directs attention from the 'what' and 'whys' of educational policy, toward a wider questioning of the relations of resistance (Allen 2010) to such change. Armstrong and Barton (2016) state that 'the pursuit of an inclusive society involves a very difficult and demanding struggle against those cultural, ideological and material forces which combine to generate policies and practices of exclusion' (pp3). Such caution positions inclusion in education as only one institutional strand, embedded within a much broader inter-connected matrix of institutions. As a result, it is necessary to address whether it represents a wider momentum congruent with its

philosophy, or whether it is swimming against a metaphoric tide and as such being distorted by wider tensions.

Armstrong and Barton's (2016) depiction of inclusion above give the impression of inclusion as work in a state of perpetual progress and even if the indices for declaring inclusion achieved were stated, it would remain an ongoing process as the potential for exclusionary policies and practices are ever present within the matrix indicated. Armstrong and Barton (2016) state that 'the particular forms which discrimination and exclusion take and the degree to which various groups are subjected to them will change and vary according to the particular social and historical contexts in which they take place (pp 7). Markedly there is no indication of optimism that a resolution to the potential for inequality is imminent. This contention does however offer a start point from which to evaluate the current state of inclusion, focusing not on inclusion's mechanics or successes, but rather by the level of exclusion which co-exists alongside it.

In the United Kingdom, school systems are punctuated by both qualifications to mainstream educational entitlements and resource allocation barriers deterring special school placement. Contemporary statistics reveal an increase in school exclusions for the period 2014/15 (DfE 2016b), halting the celebrated decreases of previous years (DfE 2012a; 2013b; 2015b). Although the identified rise is small (0.13% - 0.15%), the actual increase in terms of children is significant. In total equating to 850 pupils, or visually speaking the population of an average sized primary school.

Overall there were an identified 5800 pupils subject to permanent exclusion for the period 2014/5. In addition the most recent statistics indicate that 302,980 pupils across all primary, state and special schools were subject to a fixed period exclusion. Although the term fixed period implies a limitation of disruption to the pupil, current guidance states that 'a pupil may be excluded for one or more fixed periods up to a maximum of 45 school days in a single academic year. This total includes exclusions from previous schools covered by the exclusion legislation' (DfE 2016c pp 3). It is therefore feasible that a child could be legally excluded on a fixed tariff from three separate schools in the space of one academic year. Such potential may seem unlikely, however is less so when one considers the practice of encouraging managed moves from one school to another.

The Child Law Advice Centre (CLA) describes the managed move as 'a voluntary agreement between schools, parents/carers and a pupil for that pupil to change school or educational programme under controlled circumstances'. It is further cautioned that 'managed moves are often used as an alternative to permanent exclusion; the result is that no exclusion is formally logged on the pupil's school record' (CLA 2015). The managed move therefore holds a manipulative potential; as such generates insecurities in relation to the accuracy of permanent statistics, most particularly that they may well exceed published figures.

Although Armstrong and Barton (2016) observe that disadvantaged groups are fluid, their constitution responsive to history and context; it is noteworthy that in the school context, education statistics indicate there to be continuities of inequality and exclusion in respect of pupils with SEN (DfE 2012a, b; 2013; 2014; 2015b). Most notably pupils with identified special educational needs (SEN), represent half of all permanent exclusions and fixed period exclusions (2016c). Thus despite the rhetoric of inclusion, the school system as currently configured, is far from inclusive Nor does there appear to be any political or social will for it to become so; for example the 2010 Equality Act, the Education Act 2011 and the Children and Families Act 2014, all host qualifications clauses which serve to legitimate an exclusionary response to pupil difficulties (Parliament 2010; 2011; 2014). Additionally looking within the populations embraced by the umbrella term SEN, statistics allude to the type of pupil vulnerable to exclusion. This is found to be children exhibiting persistent disruptive behaviour, who accounted for 1,900 (32.8 per cent) of all permanent exclusions in 2014/15, confirming that the pupil most vulnerable to exclusion is one who exhibits behavioural difficulties.

Swain (in Barton and Armstrong 2008) refers to the work of Finkelstein; most particularly how the problem of integration is found to be rooted in processes of segregation. In relation to contemporary school systems in the UK, Swain suggests two issues to be prominent. Firstly that the problems of schooling appear to now be being conducted outside of the discourse and priorities of inclusion. Such contention suggests there to have been a political shift, resulting in the marginalisation of Inclusion as a social or political priority. Conspicuously the recent White Paper "Educational Excellence Everywhere" (DfE 2016b), affirms governmental commitment to global competitiveness through pedagogical and summative output. Markedly as these priorities are echoed in previous pieces of governmental

legislation (DfEE 1997a, DfES 2001a; 2005b, DfE 2012c), it raises doubts as to whether there was ever a compatible social and economic structure able to support an evolving egalitarian education system.

The second issue raised surrounds the effects of undue attention focused on the failings of inclusion, particularly those raised in relation to the impact on pupils identified as vulnerable, (Warnock 1995, (Norwich 1999, Powers 2002, Hyde and Power 2004), Cigman 2007, Chamberlain, Kasari et al. 2006, Humphrey and Lewis 2008a, Humphrey and Lewis 2008b). Most specifically this can be seen to direct attention from underpinning social prejudices which foster disadvantage (Tomlinson 1982, 2012, 2014, Dyson 2008, Tomlinson 2014, Goodley, Runswick-Cole, Liddiard 2015).

In combination, misdirected attentiveness and inattentiveness to inequality has served to foster a climate, where education is metered through exclusionary concepts of entitlement and disentanglement. Signalling discourses which directly conflict with the notion of Inclusion as an educational (or social) right. Equally as the secondary data shared in subsection 1.4.4 indicates, this has served to position Inclusion as the problem, not the solution. Henceforth, following Finkelstein's contention that segregation is the locus of exclusion, I suggest that the identified problems attributed to inclusion, lead at core from the segregationally inevitable implications of maintaining a special sector and the legislative sanctioning of exclusionary sanctions. From this perspective, alternative educational pathways (including pupil referral units, internal mainstream units and special schools) do not expand educational access, they perpetuate discourses around placement appropriateness and indeed entitlement to a mainstream education.

Conspicuously the legal framework ratified to enforce inclusion in the UK has consistently factored in qualifications which sanction exclusion. Thus the continued diversity of educational providers and the maintaining of a specialist sector, in tandem with a contemporary Neoliberal political culture, founded upon individualism and competition, foster determinations of placement appropriateness and worthiness, not least because far from pupils being educational consumers, they may be more appropriately considered educational and workforce capital (Tomlinson 2005). As Youdell (2010) cautions, 'there is little incentive, resource or conceptual space for mainstream education to pursue inclusive education' against a continuing back- drop of national testing, league tables and climate of consumer driven competition'

(Youdell 2010 pp. 315). Thus it may be suggested that political drive to increase institutional accountability through a standards and inspection agenda, also heightens vulnerability to individual pupil accountability. Thus setting in motion the conditions whereby institutions have an investment in promoting success and reducing impediments to such success. As a consequence the value of high and consistent school achievers, serves to position less able peers at the opposite end of a value continuum (Benjamin 2002, Tomlinson 2005), necessitating a framework of explanation that does not implicate the individual institution. To emphasise this contention, it is useful to refer to a differing interpretation and implementation of Inclusion, enacted in Italy, which although equally imperfect, has resulted in fostering a pedagogical and legal climate where school exclusion is not permitted.

3.2.1 Integrazione Scolastica

The Italian policy of *Integrazione Scolastica* demonstrates that pupil differences including behaviour difference, need not be an axiomatic impediment to an inclusive system of education as is implied by some critiques (see for example Warnock 2005 and Cigman 2007). Nor that it is an inevitable feature of contemporary education systems linked to historic employment or economic systems (Young 1999, Tomlinson 2005, Robinson 2011; 2015). To the contrary its efficacy may be seen as determined by the strength of political commitment to the abolition of exclusionary educational structures.

Ratified in 1977, rule 517 acted to close all Italian special schools, units and segregated provisions. In doing so set the conditions for inclusivity (in terms of placement) in the Italian mainstream. In direct contrast although the Committee of Inquiry in the UK (Warnock 1978), was indicating a similar commitment in regards to the education of disabled children, itself a main impetus to the policy of inclusion. In enactment, the policy of Inclusion was piecemeal, set amidst wider educational and political discourses which were inhibitive of such a vision. In particular there was divided opinion toward the establishment of a comprehensive school system and the abolition of alternative provisions (Gilliard 2011). In enactment therefore, Inclusion was neither final, nor radical; differing markedly in its political finality to that ratified in Italy. Rule 517

Notably whilst exclusion as a disciplinary sanction was abolished by rule 517 and markedly remains both illegal and in pedagogical terms, unthinkable; UK education

policy was founded upon exclusionary discourses (Parliament 1981), which served to not only define the qualifications to mainstream entitlements, but also to err from the abolition of special or private sectors of education, as such perpetuated the existence of exclusionary pathways in contemporary educational systems.

The finality of the policy of *Integrazione Scolastica* (rule 517) stands in stark comparison, yet is as D'Alessio (2008) asserts, inexplicably absent from many wider debates on inclusion. Looking for wider explanations for the differing approaches adopted, Arnold (2009) suggests that it was Italy's differing social and economic circumstances which fostered the environment for such dramatic and final change. Set amidst a growing discontent towards educational inequalities and a collective call to move beyond the social and political restrictions left following the war years, 'education was seen as a powerful agent for change' Arnold (2009, pp 1).

Looking comparatively, Arnold (2009) concluded that there are significant differences between the Italian system and that in the UK, most specifically of the educational and legislative frameworks that support both school systems. Nevertheless a comparison of actual pupil behaviour led Arnold (2009) to concede there were stark commonalities. This may be seen as a significant test of the Italian systems resolve, for Italy has no formal provision for alternative placement, nor the option for exclusion. As an alternative the Italian sanction system relies upon demand to repeat an academic year where deemed necessary which serves to retain pupils in the system, reinforcing for teachers a pupil's unquestioned tenure. Notably the Italian system continues to attract positive opinion as Kanter (2015) states, 'Italy's national policy of *Integrazione Scolastica* continues to provide a robust example of best practice that is not typical in other countries' (pp 27).

Arnold (2009) notably found that although Italian teachers felt the option to exclude unthinkable, they also conceded that the pressures on teachers in the UK, combined to reinforce the need for and indeed reasonableness of, exclusion. Unsurprisingly the tensions identified included official practices of accountability, linked to wider responsibilities to maintain and improve standards and output in the form of grade referenced successes. Reviewing the contemporary impact of *Integrazione Scolastica*, Kanter (2015) found one of the most notable features has been its consistency, which as previously noted, contrasts markedly with the successive educational and priority shifts witnessed in the UK (Parliament 1970; 1981; 1995; 1998; 2001; 2003b; 2006; 2010a; 2010b, 2011; 2014). Shifts which Kanter asserts

have maintained a role for provision differentiation, based upon the notion of the educational consumer.

Equally political thinking can be seen to have led to a shift in focus away from disability equity or even social equality, to standards and accountability, underpinned by notions of individual responsibility (Gillborn and Youdell 2000, Reay 2008). In contrast the Italian government has remained firm in its decision to abolish segregated educational provisions and has not only removed the option to exclude or segregate, its consistent prohibition, has resulted in new entrées to the teaching profession to consider such action untenable. In contrast currently the UK government retains a commitment to expanding independent schools, through both academies and free schools (Parliament 2010a, Party 2015a, Party 2015b). There has also been a sustained determination to address issues of behaviour through the conferring of greater disciplinary rights to teachers and school heads (Party 201a). Notably however there is no address of how such direction is reconciled when the causes of behaviour are derived from a disability and are thus warranting (legally) of accommodations.

The problems faced in the UK context are found to represent a broader global trend. Hardy and Woodcock (2015) state 'the extent to which inclusion is a substantive concern within educational policies in specific nations, states and schooling systems in the context of more Neoliberal conditions is highly variable' (pp 141). Such caution resonates even in the context of the Italian system of inclusion. For although Kanter (2015) finds that the principles of *Integrazione Scolastica* to be embedded in the teaching professions mind-set, D'Alessio (2012) suggests that the Italian system still reproduces forms of micro exclusion. Finding in particular that the 'use of space and place has an impact upon the learning of disabled students and represents a barrier for the development of inclusion' (pp 520). Equally processes of micro exclusion are found by D'Alessio to extend from the Italian system's reliance on internal withdrawal to deliver educational interventions to pupils displaying additional needs. Thus albeit in a more subtle way, the Italian system also reinforces difference, despite communal education. Interestingly similar processes of exclusion and inclusion in the mainstream at a micro level have been observed by Benjamin (2002) and similarly by Black – Hawkins and Rouse (2008). Such finding emphasises the need for attention to the detail of education at every level of its delivery and structure. This need also

strengthens Edwards et al (2001) assertion that exclusion is the essential marker of inclusion.

Anastasiou (2015) also expresses concerns towards the efficacy of the Italian system and notes an increasing move by parents to place their children in private 'special' schools. Does this indicate an innate need or suggest that needs are not being met in the mainstream? Certainly the impetus to segregate mirrors parental impetuses found by Runswick-Cole (2008) and also echoes those of Baroness Warnock (2005). It is thus illuminating that concerns are expressed in relation to the role and availability of support staff, who are found by Anastasiou to be key to the support of disabled pupils in Italian public schools. Anastasiou (2015) further suggests the level of dependency on support staff is productive of a two tier system, whereupon the classroom teacher is focused on able pupils, whilst support staff retain jurisdiction for teaching children with disabilities. It is notable that similar concerns have been expressed by Ofsted (2010) and like Gibbs and Elliott (2010) and Gibbs (2012) may intimate that the core difficulties faced pedagogically, surround perceived efficacy in the face of medicalised difference, which predisposes to a deferring of responsibility to expert support staff.

The nature of these concerns might reasonably be taken to suggest the Italian system offers only the illusion of inclusivity: yet this is challenged by Norwich (2015), who suggests that Anastasiou (2015) is operating from a distortive position which equates inclusivity with placement. Whereas wider interpretations tend toward a stance that references the emotive aspects of school life such as acceptance and belonging, which the Italian system has achieved. Notably Norwich takes the position that Inclusion should be viewed as an ongoing venture, which may have no end point, but operates as both a philosophy and a legislative force directed to a vigilance against discrimination. On this basis Norwich finds that superfluous evaluations of Inclusion flawed where levelled against the assumption of a finished product. Both the Italian and UK provisions support the contention that the retention and expansion of 'special' or separate provision either within or without the mainstream, erects barriers to any real possibility for pupil equity (Arnold 2009). As such supports Armstrong and Barton's (2016) contention that any review of inclusion as an educational policy, must extend its vista to the wider social, political and economic terrain, toward an explication of both its form and its efficacy.

Problematically, Edwards et al (2001) suggest that the practice of Inclusion where exclusion is an option, is to deny, rather than embrace the practical realities of difference; as to be included implies an acceptance of the host group/institution's core's values and conducts as a prerequisite for being included. Thus looking at Anastasiou's (2015) concerns, they speak to the need for an appreciation and acceptance of the reality of 'difficult differences' (Rogers 2013, pp 132) and a realistic appreciation of how they can be responded to efficiently. Such difficulty may at times necessitate choices that may be disavowing of the philosophy of Inclusion, but may speak to its practical exigencies.

Equally so, despite the concerns raised D'Alessio (2012) and Anastasiou (2015), the absolute nature of the Italian system supports Finkelstein's (2001) assertion that processes of segregation are primary to the perpetuation of barriers to inclusion. As Kanter (2015) found; the absolute nature of *Integrazione Scolastica* has effected change, both in systems and mind-set, reinforcing claim that abolition of potential for segregation is essential if the foundations of inclusion are to be laid. Notably the Italian system remains 'work in progress, as such I suggest that the existence of pockets of exclusion, does not diminish the role model claims made by Kanter (2015). It does however reinforce the need to be both mindful of the relational processes underpinning prejudice (Barr 2015), at both individual and structural levels.

3.2.2 Abolishing exclusion in the UK – Searle's (1996) experiment

Arnold's (2009) comment on the absence of the Italian policy from texts and discussions dedicated to the issue of Inclusion is equally applicable in relation to an educational trial conducted by Searle (1996). Searle (1996) finding similarities between excluded children in developing and developed worlds, spearheaded a longitudinal educational approach during his term as a head teacher, whereby exclusion was not an option, except in the most extreme of cases. Staff were thus advised to 'resist the idea and practice of expulsion' (pp 41). In conjunction Searle addressed teachers attitudes, particularly those that implied a cultural superiority, which was considered a further element predisposing to exclusionary discourses. To support a no permanent exclusion policy, several approaches were implemented, including a creative interpretation of the curriculum, in-school counselling services and a greater forging of links with the local community.

Initially the approach was met with disquiet, fuelled by concerns that the policy would undermine teachers authority and lead to an escalation of disruption and out of control pupils. Nevertheless these were proven unfounded and after four years, exam results were found to be consistently improved, as were admission numbers, particularly amongst post 16 enrolment entrants. Not only were these outcomes contrary to collegial expectations, they were found to have fostered a different professional mind-set, similar in nature to that observed in Italy by Arnold (2009).

What conclusions can be drawn from this approach? Firstly although contemporary schools now offer counselling services (DfE 2015c) and are increasingly confident that the establishment of local trusts is an educative benefit (DfE 2015d), Segal's (1996) trial has failed to be considered a model to emulate. To the contrary, there appears a lesser tolerance and a greater reliance on medicalised explanations for school problems (DfE 2012d). Notably the existence of an anti-exclusionary mind-set established by Segal was found to reinforce amongst staff that the welfare of the pupil population was a collective responsibility that could not be negated when pupils were challenging. Such sentiment stands in stark contrast to that of the teaching profession contemporarily (Smithers 2003, NASUWT 2012a; b, NFER 2012) and of government (Parliament 2011, OFSTED 2012), as such speaks to issues of accountability identified in my research.

So why has Searle's approach not been highlighted as a model of inclusivity? Searle (1996) tellingly alludes to a possible explanation, suggesting that an increasing marketization of education, by its constitution of competitiveness serves to make exclusion an attractive (and one suggests a functional) option. For the establishment of a prescriptive curriculum has necessitated schools adherence to its narrow scope, in order that they can engage competitively in league table results. Yet by default the lack of curricular scope, renders education irrelevant for the pupils who cannot, or see no purpose to engaging in the competition (Robinson 2011; 2015). Hence in a market system which commodifies pupils for their output, these pupils present as the least valuable and in terms of summative output, represent a liability.

Likewise Dunn (2015) notes that prior to the early 1990s, permanent exclusion was uncommon, yet escalated between the years 1990 to 1997, a period associated with increasing marketization of education and attention to standards (Tomlinson 2005). Subsequently despite a dramatic decrease in exclusions following New Labours return to power, sustained for a three year period, the incidence of exclusion steadily

increased, peaking in 2006 (DfE 2012b). These statistics are interesting as they coincided with a period in education history where the rhetoric (if not the practice) of inclusion was at its peak. Hence although Webb and Vulliamy (2004) refer to the multifarious initiatives to support pupils vulnerable to exclusion, there has been no political determination, despite successive governmental changes to render exclusion unlawful as the Italian government did.

The previously identified priorities of schools intimate there to be a vested interest in retaining the right to exclude (Carlile 2013, Slee 2001; 2013b). As such may further explain why the positive outcomes that Segal witnessed alongside the Italian enactment of Inclusion remain understated. Thus despite the continuance of debate on how to enact full inclusion (Clarke, Dyson, Milward, and Robinson 1999, Booth and Ainscow 2002, Rogers 2007 a, b, 2012, Norwich 2008, Singal 2008) and corresponding debate as to why it has not occurred (Carrington 1999, Powers 2002, Warnock 2005, Cigman 2007, Connor 2007, Dunne 2008), at systems level the option to exclude may be led by governmental priorities. Thus it may be that the option to exclude is retained because it is juxtaposed by the responsibility to include; hence holding pupils accountable for their own exclusion acts as a skilful deflection, enabling schools to legitimately remove hard to retain pupils, without compromising their identity as an inclusive institution.

When looking at both inclusion and exclusion in terms of educational experience, it is easy to be swayed by the emotive significance both states holds for young people and their families. Nevertheless outside of the emotive zone, these practices reflect government policy, which in enactment appear to embody what Veit-Wilson (1998) defined as a 'weak' interpretation of inclusion. Veit Wilson differentiates between discourses framed around humanistic assumptions (viewing individuals as both motivated and agentic) and those he terms 'asocial (abstracted from the human), focused on discourses of social exclusion. Notably Veit-Wilson defines tendency to place the onus of change onto the individual a weak approach to the problem of social exclusion. In contrast stronger approaches are defined as those which focus on the sources driving exclusion, directed toward a regulation of their powers.

Legislative history alludes to a 'weak' interpretation to inclusion, consequent upon the legislative qualifications which restrict the right to mainstream inclusion, and which are discussed more fully at point 3.2.5. This contention is reinforced by a continued commitment to retaining exclusion as an educational option. Equally the legislative

qualifications which have restricted inclusion, (not least the retention of a special sector), are fundamental to the disadvantages identified earlier by particular pupils. Typically those whose behaviour or ability does not meet the expectations or needs of contemporary school institutions. Such disadvantage has been described by Carlile (2013) as institutional prejudice, whose form remains obscured by the ever present priorities imposed upon schools, which are stated by Carlile to disinhibit the tendency to objective reflection. As a consequence Carlile also calls for a legislative end to the possibility of exclusion.

Toward this it is worthy of note that the 2016 government white paper 'Educational Excellence Everywhere', offers promise of a move away from the use of exclusion as a means of abrogating responsibility for troublesome pupils. The government states commitment to 'change accountability arrangements so that a pupil's mainstream school will retain accountability for their education outcomes and will take a lead role in commissioning their provision' (DfE 2016b, para 6.76, pp 103). This is an ambitious statement which in implementation would signal a move toward Veit-Wilson's definition of a strong approach to inclusion. It is however notable that in the same document although it is critical of current provision, particularly of PRUs, it is also intimated that future provision is likely to remain what is termed 'alternative provision'. It is therefore a concern that the white paper is less open in regards as to whether this provision is likely to be provided within the mainstream or outside of it, despite call for a school to retain jurisdiction over the pupil. If it is to be outside of the school, one must question, what if anything is likely to change for the child or family. This review now looks more closely at the political periods that have defined the enactment of Inclusion and which can also be shown to have consolidated qualifications to inclusion and educational equity.

3.2.3 The 'illusion' of the era of inclusion

Looking at the history of educational provision in the UK, it is possible to see how the retention of special (and to an extent private) schools has both directly and indirectly fostered exclusion. Not least through the implied message effected by their retention that one size does not fit all and that it is reasonable that some children should be channelled into different types of schools. Such division if based solely on parental/pupil choice would not be problematic; it becomes problematic, when the criteria for channelling is predicated upon normalised discourses which act to evaluate ability and disposition for dividing purposes, not only between the sectors,

but within them. Equally, a parallel system of education, diminishes the responsibility on schools to manage the full range of pupil diversity, including presentations of disability. In essence the option of a dual system rationalises selection, based on the notion of need and ability to meet that need.

In contrast a single system would uncompromisingly necessitate a pedagogically flexible response directing the onus of adjustment onto the level of system not pupil. It may as a result serve to inhibit individualising discourses of accountability, which in the UK underpin many school exclusions (Kanter 2015). On that basis I suggest that the legitimisation of a parallel system has inhibited the possibility for inclusion to be an effective vehicle of social equity.

The origins of segregation (outside of ability to pay) can be traced to the 1944 Education Act which despite extending universal (free) education to all pupils, also laid the foundation for a range of school types based on ability and disability (Parliament 1944). Although the Act was revolutionary in its historical context and extended means of education to all irrespective of income, it was underpinned by pedagogical assumptions in regards of ability and aptitude which led logically to the segregation of children into different educational pathways (Parliament 1944). Batteson (1999) argues this direction to be a direct result of civic pressure and commitment at an administration level to maintain a selective system of education. Thus whilst the act in principle extended equality of opportunity to all pupils, in practice its enactment and structure was imbued with processes of segregation.

These processes have attracted longstanding critique and are charged with bias in relation to issues of class, gender and cultural (Young 1958, Little 1964, Tomlinson 1982, Dene 1995, Young 2001, Jones 2003a; Jones 2016, Spencer 2005), yet notably less so in relation to disability. It is further suggested that contemporary protocols for separating and excluding pupils, stem from the origins of compulsory mass education (Robinson 2011; 2015). The implication that the channelling of pupils is underpinned by a self-serving agenda is emphasised by Conner (2007) who impresses that we, 'remember the terms of exclusion that put 'special' into motion' (pp74). These terms as suggested have their roots in the 1944 Education Act and although subject to significant amendments (Parliament 1970; 1981; 2001) which have been directed to a fairer educational system for pupils with disabilities, for pupils with behavioural disabilities, segregation remain as conspicuous (DfE 2015b; 2016a, c).

Hence although the initial impression generated by the 1944 Act was the pursuit of educational equality through the extension of universal free education; closer inspection reveals that it also acted as an impetus to additional child surveillance protocols, which legitimated the channelling of children based on pedagogical and medical assumptions. Pedagogically this was underpinned by the notion that children's abilities were fixed and could be revealed at the age of eleven through the 11+ exam. Notably the 11+ acted as a filter directing children into future educational provisions of three distinct school types, grammar, secondary technical and secondary modern. In a sense these schools acted as a glass ceiling as they were determining of what a child could achieve (Tomlinson 2005). What is less stated in regards to this policy are the sorting implications for pupils who were unable to satisfy the requirements of the test. It is thus at this juncture that medical assumptions become equally directive of educational pathways.

Medical assumptions may be seen to channel not only children with immediate physical/medical disabilities, but also those who failed to satisfy the standards of the 11+. These assumptions were based upon eleven categories of disability and were comprehensive in their coverage, embracing not only physical/medical difference, but equally so learning, behavioural and emotional differences. It is also notable that medical jurisdictions exceeded those of both parents and the teaching profession. Colloquially entitled 'Special Educational Treatment, medical authority was formalised through statutory obligation, requiring parents/guardians make a child aged over 2 available upon request for medical examination if disability was suspected (Borsay 2005). Thus identification was a professional, not a parental right.

The 1944 Act also founded educational relationships for disabled and non-disabled pupils alike and although medical jurisdiction abated when the Education Act (Handicapped Pupils) of 1970, passed educational responsibility for all children to the Local Authority (Parliament 1970), there remains traits of its logic in contemporary educational systems, most specifically in the system currently known as special education. Special education may be seen as the synthesis of medical and pedagogical assumption; founded on the belief that at for some children, their ability or being necessitates separate educational provision which can be most usefully revealed through pedagogical and medical markers.

Barnes (1991a) in particular draws attention to shortcomings identified in both the Committee of Enquiry Report (Warnock 1978) and in its enactment in the 1981

Education Act (Parliament 1981). Barnes states that 'whilst reiterating the notion of integration the Warnock Report (1978) and the 1981 Education Act both emphasised the importance of the concept of Special Educational Needs (SEN) in relation to the education system as a whole thus leaving the door open for the continued separation of large numbers of disabled children with SEN from ordinary schools and colleges' (Barnes 1991a, pp 6).

As a result, pupils exhibiting identified differences were rebranded through the pseudo-medical field known as special education, which I suggest is illustrative of the alliances Rafalovich (2001a; b) alluded to. Quicke (1986) likewise states, 'it is no exaggeration that the development of special education, in the broadest sense of the term, was not only assisted by, but in a large part made possible by, the educational psychologist's technology'(in Barton 1986, pp 144). Nevertheless I would argue that although Quicke's claim is credible, it does not automatically equate to separation, rather, may be seen to act as rationalisation for separate educational provisions and professional specialities. Rather the logic of separation extends from broader alliances, most notably between the law, education and the medical profession, centred on issues of risk and responsibility as discussed at section 2.6.10.

Avramidis and Norwich (2002) point to an important distinction between integration and inclusion and in so doing destabilises the contention that Inclusion has ever been instituted in the UK in accordance with its core philosophical principles. Thus whilst educational placement from an integrational position is determined by its appropriateness in relation to a pupils particular needs and circumstance; the Inclusion movement (in principle) called for the education of all children communally (or at least a move towards), facilitated by structural and pedagogical accommodations at an institutional level to cater to a child's needs and circumstances. Consequently whilst the principles behind Integration rested upon a pupil 'fitting in', those of inclusion spoke to change at the level of systems and pedagogy (Booth and Ainscow 2002).

It is nonetheless fair to suggest that the Integration movement was a game changing lobby; which in its historical context, debunked belief that the separation of disabled children from the mainstream was inevitable. In so doing, it may be seen to have impressed unintentionally the notion of sameness in regards to childhood as a developmental phase. This implication may be viewed as foresight, given the rapidly expanding research interest that has developed within disability research (Curran

and Runswick-Cole 2014). Nevertheless the Integration movement in implementation attracted concern, not least because it relied upon the interventional capacities of what is termed 'special education' which served to divide and stigmatise (Barnes 1991a, Tomlinson 1982, Barton 1986, 2005, Slee 1993).

Special education is a term formerly associated with the education of children with disabilities, which was broadened on the recommendations of the Committee of Enquiry into the Education of Handicapped Children and Young People (Warnock 1978). The Warnock Report urged for emphasis to be directed from the medical impairments a child may hold, to emphasis on the difficulties children had in learning. Nevertheless despite the intimation of compensatory pedagogical strategy, special education was beset by concern, notably in regards to an over and under representation of discrete populations (Dyson 2008, Tomlinson 1982; 2012). Of specific concern was the difficulty of defining a special educational need, which Armstrong (2005) states 'led inexorably to a growth in statementing and special school placements as this meaning was negotiated in practice by powerful pressure groups' (pp, 140). Croll and Moses (2012) contribute to the stock of concerns, finding teachers remit to identify special educational need at the level of classroom learning to be subjective, hence inconsistent and incomparable.

Thus although the enquiry become synonymous with the eventual Inclusion movement, a responsibility Baroness Warnock appears to maintain (Warnock 1995), the extent to which Inclusion differs from Integration remains subject to debate. Not least because despite changing terminology and an incentivised political hype; practically little appeared to change in the educative lives of children, as there remained two sectors of education (special and normal) both within and without the mainstream. It is therefore unsurprising that Inclusion, like its predecessor Integration retains an association with the educational placement into the mainstream of children with disabilities. Such association has resulted in a rapid expansion of learning support assistants and aligned tertiary roles, which has served to heighten the appearance of difference and to stigmatise pupil identities further (Beardon 2008).

Inclusion is also heavily associated with the challenges 'included' pupils bring to the mainstream, opening up discourses of entitlement and mainstream educability. These discourses act to legitimate exclusionary responses, framed around culpability and the needs of the child exceeding the capacity of the mainstream to deliver.

These attitudes are reflected in the concerns teachers express, including forced placement on account of inclusion being a legal responsibility) and limited classroom support, due to funding restrictions (Evans 2002, NASUWT 2008, 2012a; b, NFER 2012, Neill 2013). Parents similarly indicate negative associations, typified by a perceived lack of support and importantly, understanding of need (Rogers 2007c; 2012, Lamb 2009, CAF 2013).

Conspicuously as previously discussed earlier in this subsection, although the 1981 Education Act enforced many of the committee of enquiries recommendations, there was an unwillingness to close special and dedicated units of educational provision. Thus although the Committee of Enquiry (Warnock 1978) laid the foundations for what is now termed Inclusion, the formal stating of inclusive intent and the role of special schools within it, has been directed by at times conflicting political will (Tomlinson 2005, Ball 2013). The enactment of Inclusion has as a consequence been responsive to changing political interpretations and in particular was harnessed as a concept and rebranded as a New Labour initiative (Hodkinson 2010). Nevertheless, Hodkinson cautions that New Labour equally failed to enforce a single unilateral provision of education for all pupils, rather, their predecessors, chose to retain a special sector.

During the final years of the Labour administration, the consensus around Inclusion was beginning to wane, this was most openly expressed by Baroness Warnock (2005), who cited ongoing concerns towards the impact of mainstream schooling on certain groups of pupils, in particular those on the autistic spectrum. Such concern has been echoed and remains an unresolved debate (Lloyd 2003, Cigman 2007, Dunne 2008, Graham and Slee 2008; 2011, Humphrey and Lewis 2008a; b, Leslie and Skidmore 2008, Rogers 2012, Kauffman, Ward and Badar 2015)

The future direction of Inclusion was brought into further question by an expressed commitment of the Conservative Party (2010) to end the monopoly of Inclusion. This may be said to have shepherded in a post inclusive era, punctuated by the exclusion of Inclusion from the political playing field. Notably during the campaign period of the 2015 UK general election, Inclusion was absent from campaign rhetoric. Not only in terminology, but in ethos. Markedly all three main parties indicated continued commitment to ongoing school improvements as can be measured by exam success and pupil progress (Party 2015a, Party 2015b, Party 2015c). Thus referring to the contention made by Sikes, Lawson et (2007) that 'Inclusion has been on the English

agenda since 1997 – although the rhetoric and discourse by which it has been promoted and articulated in Government policy and publications could be described as somewhat vague’ (pp 357), I suggest that by 2015, Inclusion was off the English agenda.

What does this mean in relation to the educational security of pupils with challenging disabilities and for accountability generally? In answer I suggest that Inclusion as originally envisaged and as implemented in Italy remains an ambition, not a realisation. Nor can it be realised as long as there is commitment to the retention of a special sector, able to cater for the extremes of pupil difference, fostering not only segregation, but an impression of the rightness of segregation. I further suggest that the priorities of contemporary mainstream schooling across the political terrain, as previously indicated, serve to foster a culture of competitiveness. A culture which serves to result in schools being measured disproportionately in terms of academic output, on the premise of raising standards. This culture by the logic of its terms is affirming of winners, not losers and inevitably for some pupils, losing within the priorities outlined is inevitable, as Benjamin’s (2002) ethnographic observations attest.

Given the concerns revealed through professional membership surveys such the one conducted by NASUWT (2008; 2012a; b), it is necessary to ask whether separate provision is inevitable? Toward this Sauer and Jorgensen (2016) consideration of the implications of the principle of ‘least restrictive environment’ is useful. For although in the UK it is a term which holds association with the Integration movement, in the USA it remains embedded within the Individuals with Disabilities Education Act (IDEA 2004). Its relevance in respect of this research is that whilst it is not formally stated in law, in working practice its sentiment can be observed through the principle of meeting a student’s educational needs, questioning the extent to which Inclusion as visualised philosophically has ever been enacted. Thus just as Sauer and Jorgensen find the principle flawed in relation to the American context, the same charge may be levelled against the practices and premises which extend from its sentiment in the UK context. Overall the idea of least restrictive environment may be seen to perpetuate the idea that some children are unsuited to a common education alongside their peers.

Unpacking the concept of least restrictive practice, it is necessary to probe the logic behind the term ‘least restrictive’. This leads to a deeper address of in whose interest

is it least restrictive and whose interests are catered to first if the interests of the individual and others are irreconcilable. Conspicuously, although the term is openly stated in the American context, enabling open critique to emerge, in the UK context, it is inconsistently recognised as a central principle underpinning the practical enactment of Inclusion. This may be said to have enabled its premises to influence educative decisions, including segregation and exclusion, irrespective of disability rights.

A useful example of this premise in UK legislation is offered through reference to the Equality Act (Parliament 2010b). As is shown, the outline of duties are prefaced by their qualification as stated at subsection (3):

Those concerned with making special educational provision for the child must secure that the child engages in the activities of the school together with children who do not have special educational needs, subject to subsection (3).

These exceptions listed as points a-c, embody the principle of least restrictive environment, not however in the interests of the implicated child, but more specifically in the interests of the majority as points b and c demonstrate:

- a) Where the child is already subject to differentiated provision, led by presenting educational need.
- (b) Where to commonly educate would jeopardise 'the provision of efficient education for the children with whom he or she will be educated'.
- (c) Where to commonly educate would jeopardise the 'efficient use of resources'.

Thus although points a-c can be interpreted as the attempt to temper accommodation with fairness, they can equally be seen to embody the considerations which define 'least restrictive practice'. Thus in terms of implementation and working practice, Inclusion would appear to exist and be enshrined legislatively in name only, not as was initially envisaged at the level of organisation (Carrington 1999, Booth and Ainscow 2002, Carrington and Robinson 2006), but rather can be viewed as based upon ability to 'fit in', which ironically was the rationale of Integration.

Paradoxically similar contention is stated in the Bow Report and suggests that 'segregated (mainstream) provisions [are] acting as 'surrogate special schools to maintain illusion of effective inclusion' (Leslie 2008, pp14). Such critique although extended to undermine the policy of Inclusion, acts to reinforce contention that Inclusion as originally envisaged has yet to be implemented.

This raises the question of why there has been such resistance to the abolition of special schools despite an expansion of special provisions in the mainstream. Barton (2016) suggests distorted perceptions may explain why the specialist sector is not only retained, but insulated from critique; stating that ‘the strong tradition that special needs professionals are caring, patient and loving, makes it hard to raise questions about low expectations, patronising and overprotective practices and stigmatizing labels’ (pp 64). Thus forth, the specialist sector is viewed from the perspective of benevolence and nurture rather than as the embodiment of oppression, setting the scene for not only an unequal relationship, but one which holds potential for abuse on multiple levels (Oakes 2012).

3.2.4 Delivering Inclusion within the UK

Looking at the legislation which has been pivotal to the enactment of Inclusion, it is possible to identify that not only have qualifications to Inclusion been embedded within educational legislation; but that the guise of Inclusion has been shaped inconsistently on the basis of wider political and economic priorities, many of which were contrary to ethos of Inclusion and the practical realities of a single education system. Three major periods have moulded the shape of Inclusion, these are the Conservative administration post Warnock [1979 – 1997], the era known as New Labour [1997 – 2010] and the former Coalition period [2010 - 2015]. The legislative output of these periods although directed to the common term Inclusion, represent disparate implementations of inclusive intent, which in practice have been buttressed by often incompatible wider priorities.

The Conservative era 1979 – 1997: although not formally linked with the term Inclusion, may be seen to have laid the foundations for what was eventually termed Inclusion. Of greatest significance was the passing of the 1981 Education Act (Parliament 1981), enacting many of the recommendations extended through the 1978 Committee of Inquiry Report (Warnock 1978). The Act was radical in its intent as it demanded movement from educational provision guided by medical categorisation to that based on assessment of educational need. For those identified to need the greatest support, this was to be legally stated (and enforceable), through an official statement of educational need. Irrespective of integrity, these directives were in practice complex and ambiguous to deliver (Armstrong 2005), leading to an uncontrolled expansion of SEN identification (Tomlinson 2012) as well as an escalation of the newly introduced statements of educational need. The scope of

demand engendered unanticipated financial and staffing burdens for both local authorities and schools. It is at this juncture that one can detect an incompatibility between the State invested vision of common (but supported) education and a parallel political commitment to free market forces becomes apparent (Tomlinson 2005).

The ensuing tensions resulted in a formalising of identification processes and requirement to appoint specialist special educational needs co-ordinators (SENCOs) in all schools (Parliament 1993), to input specialist knowledge and lead a consistent system of identification and response. Problematically in parallel the agency of the teaching role was being eroded, principally through centralised consolidation of curriculum content (Parliament 1988, Carlile 2012), monitoring of teaching standards (Parliament 1992) and formal school inspection protocols (Parliament 1993). Changes which may be considered to signal the beginning of an accountability culture.

An escalating culture of accountability is suggested by Gillborn and Youdell (2000) to have directly inhibited the development of Inclusion, offering explanation for why Inclusion as enacted in the UK, differs so markedly in its approach to that of the Italian system. It is also notable that the formalisation of teacher accountability is suggested to have been underpinned by concerns about teaching standards (Youdell 2005), triggering a professional culture of defence, inhibiting of the institutional embrace of all pupils (Youdell 2011). Equally the intimation that financial supports were to be performance linked, with poor performing schools incurring financial penalties, further compounded the disadvantaged position of pupils presenting with difficult differences (Rogers 2013). As such re-positioned pupils with SEN or disability as a liability, rather than the asset Kanter's (2015) Italian respondents suggest such pupils to be. It may be thus suggested that the emergent changes pursued by the Conservative Party were incompatible with an educational rights agenda. As Tomlinson (2005) asserts, 'in the regressive Conservative vision of the 1980s, fairness and vision were not visible attributes' (Tomlinson 2005, pp 32). I suggest that this signalled a shift toward a culture of self-help and an intolerance of need, compounding a change of emphasis, from right to Inclusion, to earning the right to Inclusion.

New Labour 1997 – 2010: the incoming Labour administration (1997) renewed commitment to promote Inclusion, a commitment encapsulated in the Green Paper

'Excellence for all Children' (DfEE 1997). Notably such momentum appeared to critique endeavours laid down in the 1981 Education Act, leading to a rebranding of Inclusion as an educational vision. This rebranding was nevertheless embedded within competing priorities, many of which had their legacies in the outgoing Conservative administration. Of particular significance was the Labour administration's commitment to the raising of school standards, which signalled further professional accountability and the aligning of the curriculum to the needs of a global knowledge driven economy (Parliament 1998, 2006, DfES 2001a, 2005b).

New Labour has also been charged with furthering the commodification of education, promoting educational gains as individualised responsibility and personal investment (Armstrong 1995, Tomlinson 2005; 2008, Reay 2008). As a result the terminology of Inclusion as harnessed by New Labour, is charged with perpetuating an industry of special needs, albeit subtly obscured by a rights rhetoric (Graham and Slee 2007, Armstrong 2005), procuring of an inevitable deficit position for disabled pupils.

This era also witnessed expansion of State involvement in child rearing (DfES 2003), disempowering the agency of the family through the extension of school and allied agency jurisdictions, consolidated through the centrality of the Every Child Matters (ECM) agenda (Parliament 2003b). The ECM strategy stated commitment to interagency collaboration and observance of five key factors, as such was prescriptive of the parameters of personal growth and well-being. It also by extension served to delineate the parameters of difference and deficit. Consequently New Labour's educative and social vision, not only re-defined Inclusion, but by fostering dependency on experts, framed around the notion of self-help and personal responsibility to seek such help, they may be seen to have laid the relational conditions necessary to expand an included population.

These relations were nevertheless flawed by the actual realities of embodied disability; for although New Labour's vision intimated all to be potentially economically productive, 'the great majority of children with SEN will, as adults contribute economically, all will contribute as members of society' (Employment 1997 pp. 5), such expectations have not only been dismissed as unrealistic (Benjamin 2002, Armstrong 2005), they may also be seen to have set in motion the conditions of accountability for failing to deliver the expectations of this vision. It is therefore unsurprising that the generation of a marginalised population, is suggested to extend

from wider structural inequalities, not least the economic relations which underpin it (Young 1999, Bauman 2004, Girox 2009; 2011).

The practical mechanics and selectivity of these processes are summed by Tomlinson (2005) who states, 'while New Labour was preaching inclusiveness and developing palliatives to mitigate disadvantage, market and selective forces were demonstrably excluding large sections of the working and non-working class, plus many ethnic minority children' (Tomlinson 2005, pp 91).

As a consequence, the promise of full Inclusion may always have been untenable, not only on account of the ambient economic and political climate, but as a direct result of the emphasis placed by New Labour on individual responsibility and accountability. This direction, enacted by the quantification of standards through school inspections, served to make a system of Inclusive common education unrealistic, stimulating very specific concerns from within the teaching profession (Evans 2002, NASUWT 2008, 2012a; b). Notably these concerns reflect disproportionately the impact of pupils with behavioural disabilities on teachers (Cook 2000, 2001, 2004, Klehm 2014). Such concerns are equally evident at government level and have been used to justify an increasing regulation of teaching, demand for improved school standards and an increase in teaching staffs powers of discipline (Parliament 2006, DfE 2012d, Carlile 2012, Ofsted 2012). This call for improvement at professional and organisational levels, has nevertheless been swiftly deflected onto pupils and families, through sanction led responses that have exclusionary effects (Austin and Carpenter 2008, Carpenter and Emerald 2009, Gallagher 2010b, CAF 2013, AA 2014). It is thus unsurprising that within these discourses of accountability there is little room for disability accommodations, nor is there incentive to pursue the possibility of any (Youdell 2006; 2011).

Stepping back from the seemingly incontrovertible drive to increase standards (Robinson 2011), Kauffman (2015) calls for an expansion of what a high standard is; suggesting that it is not an arbitrary line, but rather represents an unfair subjectivity, against which schools and pupils are judged, irrespective of their ability to compete. There is much written about standards in the UK education system, generally in relation to outcomes as measured against the A-C GCSE standard. Yet it may be suggested that marking is itself a subjective exercise and there are mixed opinions as to whether exam grades are sufficiently precise as to be a measurable index of a standard (Baird 2004, Fowles 2009, Bloxham 2009). Additionally it is suggested that

the craft of raising standards involves more complex pedagogical skills than governmental demands imply, rendering illogical their pursuit to be directed at, not driven by the teaching profession (Black and William 2006).

Coalition era 2010 -2015: pre-election the Conservative manifesto declared commitment to end the bias toward Inclusion (Party 2010). Seemingly no longer a bastion of equality and entitlement for children with additional needs, Inclusion was now framed as part of 'the problem'. Indeed the outgoing Labour administration was charged with the deliberate marginalisation of the specialist sector, led by rhetoric, rather than practical need or parental will. In address, the Conservative manifesto stated commitment to provide alternative provisions within the private sector, to which the free school initiative, as ratified within the Academies Act 2010 was central (Parliament 2010a).

In light of a seemingly changing climate, Barton (2010) has questioned whether the various strands of discontent constitute evidence of a paradigmatic shift, which is incompatible with inclusive educational commitments. Thus jeopardising the position of disabled students, particularly those who have difficulties with behaviour. Certainly the tone of the 2011 Education Act suggests so, as the Act extended disciplinary powers to teaching staff and reconfigured the formal SENDIST appeals process to Single Tier Appeals Panels (Parliament 2011). Thus signalling a new era of reduced parental and child rights. Markedly the convened coalition government appeared driven from an inclusive system of education to one mirroring the Dutch model, based on universal entitlement to 'appropriate education'. Notably 'appropriate' education in the Netherlands is negotiated between professionals and families, essentially privileging need as opposed to right. Nevertheless it is a system which in order to maintain an equality, relies upon equal partnership between families and professionals, which by virtue of the role and status of medical and pedagogical knowledge in the UK is unlikely to be achieved (Rogers 2007b; c; 2011).

The ongoing emulation of the Dutch system is further indicated by Barton (2013), finding evidence of government proposal to replace full inclusion. Notably this proposal is predicated upon the idea of 'reasonable inclusion' (pp6), founded upon a continuum of provision. This shift of commitment holds important ramifications for the rights of pupils irrespective of disability, signalling a move from the right to placement, to the right of schools to evaluate the most suitable placement. Similarly such sentiment may also be seen to reshape inclusion from the status of a moral

imperative, to that of a professional and governmental judgement. Thus forth, it may be seen that closer consideration of the periods delineated, demonstrates that what has been labelled Inclusion, has been shaped, not solely by adherence to its original philosophical tenets, but by wider governmental priorities, which times are incongruent with the premises of Inclusion as a moral or indeed egalitarian imperative.

Going forward Thomas (2013) argues for new conceptualisations of Inclusion, moving from former critiques and barriers which have legitimated the retention of the specialist sector. Toward this Thomas calls for a 'new kind of thinking and policy about inclusion', based around a greater appreciation of the mind-sets which have underpinned its critique, as well as engagement with contemporary thinking around teaching and learning (pp 474). Four areas of address are cited and emphasise need to embed inclusive education within a wider frame of social equity; in a manner which resonates with the embeddedness of Inclusion within the Italian system, in relation to both thinking and action.

Firstly Thomas calls for a move from 'the kinds of thinking that still construct and define failure at school' (pp474). Secondly, Thomas calls for progress to be founded upon an appreciation of the negative implications of inequality in its varying guises across the life span. In particular Thomas references processes which construct educational winners and losers through systems of contrastive appraisal, setting pupils and schools in competition with each other. Thirdly it is suggested that any continued progression toward inclusion needs to highlight its collective benefits, both in and out of the school context. Such action Thomas suggests will move Inclusion from the position of an enforced right, to a mind-set which sees it as right.

Finally Thomas urges that future progression be informed by reference to international experiences, particularly at the level of policy. Indeed it is this final area of address which resonates with the findings of this review. It is therefore suggested that any future drive toward Inclusion should be mindful of past mistakes and be open to new, untried ways of driving forward an inclusive system of education. This necessitates serious reflection in regards to past endeavours; posing difficult questions, not to critique, but to openly address the extent to which Inclusion has been implemented in the UK. This I suggest requires an honest evaluation of not only the practices which legitimate segregation and exclusion, but also the mind-set which has led to their retention.

Looking back to the impetus for inclusion in the UK, it is reasonable to state that the original Committee of Inquiry stopped short of calling for the abolition of the specialist sector. Instead the retention of a special sector may be seen to have acted as pseudo insurance policy, enabling Inclusion to extend to most not all pupils. It is also telling that those not included hold common characteristics, not least those for being seen as difficult to include, either from a management or control perspective (Croll and Moses 2000; 2002). Thus due to the retention of a special sector, Inclusion in the UK may be seen to have been implemented only partially and although many pupils with disabilities now are educated in the mainstream, those that pose greatest challenge are not. Thus in reality, there remains two systems of education, one a fall back to cater to 'difficult difference' (Rogers 2013, pp 132), which is confirmatory of Holt's (2016) assertion that 'young people with socio-emotional differences experience entrenched disablism' (pp 159).

Such duality has fostered the illusion of inclusion for some, whilst placing the onus of blame onto those it cannot accommodate. In so doing it extends an explanation for segregation which does not jeopardise the core tenets of Inclusion, nor does it demand that teachers develop the additional pedagogical skills necessary to meet the needs of an increasingly complex pupil diversity. Thus an unchallenged adherence to a sanction led system of pupil management in schools, underpinned by the right to exclude has extended a practical and damage limiting means of combating the difficulties faced by pupil diversity. This frame also enhances the notion of individual and familial accountability. Indeed it is suggested that without the safeguards of a parallel system of education and the right to exclude, the emphasis for change and accommodation would through circumstance move from the level of the individual, to that of the school system (Arnold 2009) a such focus which has notably been cited to be central to the tenets of inclusion as initially envisaged, as well as being stated to be the key differentiation of Inclusion from Integration (Carrington 1999; 2006, Booth 2002).

I therefore suggested that far from a post Inclusive era, the literature would suggest that the UK has yet to enter a truly inclusive era. I also suggested that if such entry is to happen, it must be accompanied by the disbanding of a spill over special sector, in conjunction with an end to the placement qualifications which legitimate school exclusion. Conspicuously the qualifications which are seen to inhibit Inclusion are also apparent in the context of equality legislation (Perlin 2000; 2008, Karpin and

O'Connell 2015, O'Connell 2016). It is to such issues, that this review now turns, illustrating how they mirror and build upon the qualifications to inclusion found in education. This section also illustrates how these negate the possibility of disability equity for persons whose disability impacts behaviourally.

3.2.5 Legislative qualifications to inclusion and Equality

Looking at the research focus, it is possible to map how the protections of inclusion as it is domestically defined (within the UK), parallel in important respects those accorded by the Equality Act (2010). Not however in social equity, or avoidance of discrimination, but by the qualifications and denials that are embedded within both forms of legislation (O'Connell 2016). The protections conferred in both contexts are found to concede their status on the grounds of wider impact: in education in relation to personal/peer impact and expense, in wider society, to impact as determined under penal law and judgements around risk (both to self and others). This conjures questioning around why at system level, processes of separation are so embedded.

Arnold, Yeomans and Simpson (2009) suggest the disposition to segregation in the social context, extends historically from efforts at disease control and population protection. Equally the latter rationalisation appears also to underpin wider contemporary practices of segregation (not least as enforced through school exclusion and involuntary incarceration), but also aligned (caring) services such as learning support. These services on the one hand intimate levelling, yet have also been found to effect separation (Armstrong 2003, Borsay 2005, Beardon 2008). Segregation whether used as a form of social control or support, fosters impression that it is the individual which is locus of the problem. Thus confirming the need for individual, rather than social solutions. Individualising discourses may also be seen to stimulate perceptions of threat (Barr 2014), disinclining further inclination to assimilation.

Notably, dividing processes are implicit toward how education policy has developed since its universal extension and despite changes in detail and in rhetoric, there has been consistent commitment to the retention of separate educational provisions, for those posing the greatest challenges (both medically and socially). This commitment contrasts markedly with that of the Italian system, which from the inception of *Integrazione Scolastica*, through rule 517, dismantled the apparatus of segregation and in doing so laid the conditions for a more inclusive mind-set, particularly at a

pedagogical level. As Arnold (2009) observed, exclusion is not an option under the Italian system, which negates discourses of entitlement and indeed inclusion, as all are included.

Equally controversial is the argument put forward by Kauffman (2015), who suggests that whilst full Inclusion may in principle be laudable and compatible with the aims of social justice, as a pedagogical practice it is flawed. 'The idea of full inclusion may be described as delusional because it is so clearly disconnected from logical thinking from education and from the realities of teaching and learning particularly the actualities of statistical variability and disabilities in the context of education' (pp 72). Indeed this is also an argument extended by Baroness Warnock (2005), who suggests that one size could never cater for the entire range of pupil diversity, not without compromise that is prejudicial to the pupils concerned.

Kaufmann also defends the ideal that special education is imbued with specialist pedagogy and suggests it misguided to dismiss these skills on the premise that all teaching should be special. Equally, Kauffman (2015) does not consider differentiated education to be discriminatory in the same manner, negative differentiation towards attributes such as race or gender is, as pedagogical differentiation is professionally defensible. Kauffman thus calls appropriate education based upon a policy of qualified inclusion, responsive not to medical labels per se, but to the differences (irrespective of diagnosis) that impact on instruction. Indeed Kauffman's vision of qualified Inclusion mirrors very closely the working practice of *Integrazione Scolastica*. Nevertheless these contentions do not explicitly or address the very real discrimination found levelled to particular populations of disabled students and adults alike (Tomlinson 2014).

Thus forth, although Kauffman's (2015) call for qualified inclusion may hold pedagogical merit, it is partial in its concerns. The last section in this review, considers the continued discrimination against disabled persons, despite the status of disability as a protected characteristic (Parliament 2010) and draws parallels between the concerns identified in education and those in the wider social domain.

3.2.6 Equality legislation

O'Connell (2016) asks "at a time when brain-based explanations of behaviour are proliferating, how will the law respond to the badly behaved child? In answer it would appear in a harsher manner, than that shown toward the child who has no

neurological explanations for his/her conduct (Loucks 2007, Bishop 2008, Hughes 2012), as indeed the Prison Reform Trust (2013) report:

'Most youth offending team staff believe that children who offend with learning disabilities, communication difficulties, mental health problems, ADHD, and low levels of literacy are more likely than children without such impairments to receive a custodial sentence' (pp.50).

O'Connell suggests that neurological explanations for disorder introduce dilemmas in respect of how disability as a factor of mitigation, can be reconciled with the principles of justice. These considerations are according to (O'Connell 2016) founded upon issues of neurological malleability (in respect of rehabilitative potential), juxtaposed against the risks perceived posed to self and others. Similar tendencies are paralleled in the school system, punctuated, not by incarceration, but exclusion. Nevertheless they reflect a similar mind-set which determines the capacity for change to be less than the risks posed.

Thus in the current context; although disability is deemed a protected characteristic according to the terms of the 2010 Equality Act, its protective capacities are counterbalanced by wider considerations of collective impact. Signalling limitations which are similar in nature and logic, to those found in relation to Inclusion. Indeed impact may be seen to be the juncture where considerations of right, concede to considerations of public and personal protection. This contention can be most clearly evidenced in the wider domain through reference to the delineation and management of mental illness. Most particularly the Mental Health Act (Parliament 2007) which in terms of accountability can be seen to overlap with the criminal justice system.

The treatment of mental illness has a controversial history (Foucault 1967, Szasz 1974; 1987; 1988; 2007; 2012 Laing 1985, Rissmiller 2006), founded upon concerns in relation to professional practice and the misidentification and treatment of mental illness as a form of social control. These concerns persist, not least due through contention that some of what is termed mental illness, reflects wider problems in living, not individualised disorder (Conrad 2007). This mind set is paralleled in the school context by writers such as Youdell (2006, 2011), Graham (2008) and (Graham and Macartney 2012); all of which assert it to be environmental structures that drive the appearance of disorder, rather than within person organic factors.

Equally despite the impact of academics such as Szasz (1974; 1987) and Goffman (1968a; b) towards understanding of the durability and constructiveness of mental health labels, it is notable that concerns persist in relation to treatment, stigma and response to mental illness(Perlin 2000, 2008; 2016), particularly where issues of

mental health coincide with issues of the law. Prins (2015) draws our attention to how the legal and psychiatric professions have evolved through successive changes in legislation, which has served to alter not only what is considered illegal, but also what is considered evidence of mental instability. Prins also cautions that law breaking is in itself an unstable indicator of mental illness, as 'crime is merely that form of behaviour society defines at various times as illegal and punishable by the criminal law' (pp27). These contentions resonate with the sentiment expressed by Kauffman (2001) in relation to the determination of what constitutes an EBD.

By far the most contentious issue in both the realm of mental health and that of the criminal justice system is the loss of liberty and it is significant that Prins (2015) emphasises the role that changing societal dispositions have had on the likelihood or not of a custodial disposal in court or in the psychiatric domain, signalling a subjectivity that is also evident in the school context and is inconsistently metered (Dyson and Kozlesk 2008). Court directed treatment, refers to therapeutic interventions that are court directed and generally conditional upon court leniency. Introduced by the Criminal Justice Act 1948 upon the notion of court directed correctional treatment and preventative treatment (Parliament 1948), it is notable that such distinction remains evident in both the legal and medical domains, relating to perceptions of accountability and capacity to change. Interestingly its sentiment has parallel within the school system, through the expectation that parents and children will concede to the authority of child experts. Expectation that Goodley and Runswick – Cole (2012) describe as the reading of the child and Singh (2004) defines as the obligation to avert maternal accountability.

Notably, despite the policy of deinstitutionalisation, involuntary incarceration remains an option under the Mental Health Act (Sections 2, 3 & 4), particularly where reasonable concern of harm to either self or others can be established (Parliament 2007). This mirrors very closely the sentiment that exclusion from the school community is a reasonable option where a pupil is found to extend a negative impact on others, as incarceration may be visualised as exclusion from society. It is also the juncture where the legal system and the medical profession are most closely engaged, a professional alliance which can be traced back to the 1957 Homicide Act (Parliament 1957, section one).

I suggest further that this signals the juncture where the rights surrounding physical and psychological illness divide. In example it is useful to consider the discriminatory

difference between response to mental and physical illness, which in its extreme can be exemplified by reference to the practice of detaining vulnerable adults and children in police custody under place of safety orders (Beckford 2014). As this response would be unthinkable in the case of a medical emergency involving physical symptoms, it is pertinent to question why it is common practice in relation to psychological illnesses. It is also telling that the Quality Care Commission (QCC) found that over a five year period, there was a 12% increase in persons subject to mental health orders, and that during the period 2012/13, over 50,000 people were detained or treated under the act. The test of the legitimacy of this practice is revealed by the statistics collated in terms of outcomes, for the QCC indicate that only 17% of these detentions warranted further detention. Thus raises question as to the need for detention (as a medical response) of the 83% who were found not to management and response to psychological difference, it does not demonstrate an equal health system that is undifferentiating.

It is notable is that such differentiation is paralleled throughout the school system. Hence although the response may differ, the differentiation between physical and psychological difference in terms of accountability and response as discussed in Chapter two is marked, in both guise and underpinning rationale of impact on others. School exclusion and 'special educational' interventions, may thus be viewed as the educational alternative to custody or detention under mental health law. Both serve to separate; to deter assimilation within the main population, based on individual, rather than social understanding of the locus of the problem. It is therefore unlikely given the identified alignment of approach between the institutions of law, education and psychiatric medicine, that the school context could ever be a vanguard for social change (Booth 2002, UNESCO 1994a; 2008), rather it is reflective of wider inequalities and it is to these that this review now turns.

3.2.7 Accountability

Instances of disability discrimination not only highlight vulnerabilities and bad practice, they also allude to who is recognised as disabled and importantly through absence, who is not. Thus punitive response to behaviours known to be associated with disability in both the criminal justice sector and the educational context, indicates that 'behaviour does not maintain automatic association with discrimination, or acceptance of behaviour as a symptom, not a deliberate act. Parsons (2005) refers to the will to punish, noting that the mind-set underpinning response to pupils

exhibiting challenging behaviour, is about 'confronting and diverting the unwanted behaviour and not, for the most part, about meeting unmet needs' (pp 188). This signals a disposition which according to Parsons, underwrites response at both policy and school levels, mirroring closely O'Connell's (2016) observations of a disjuncture between criminal law and that of disability protections, led in essence from a duality of responsibility to both the individual and those impacted upon by that individual.

O'Connell (2015) addresses this issue and notes the tensions incurred when behaviour is identified as disability, but impacts negatively on others. Towards a deeper resolution O'Connell directs attention to the impact of context and relations to the appearance of behavioural disorder. O'Connell (2015) thus calls for multifaceted model of disability which recognises holistically the interplay between genetic/neurological factors, context and impact on others, stating there is a need to acknowledge organic factors 'without ignoring the social context in which disability is constructed' (pp 15). O'Connell thus calls for the brain to be viewed 'as inseparable from its functioning within the body and embedded in overlapping biological, social, and environmental systems' (ibid).

O'Connell's (2015) stance calls for change toward how disability is viewed, not only in law, but at all levels of the social as the imputed constructed nature of disability calls for an appreciation that difference is a normal feature of human diversity and it is the sense made of difference which defines disability. Neurological discourses inform this sense, but not in any absolutist sense. Rather the identification of disability is stated by O'Connell (2015) in the first instance to reflect the norms and conduct expectations of context and in so doing define the boundaries of many commonly diagnosed neurodevelopmental disorders, such as ADHD and Autism.

This has important implications for individualised accountability. For if context and individualised behaviour are seen as symbiotically intertwined, accountability logically is too. As such, confers an equal responsibility onto organisations to be mindful of their role in the appearance of difference or challenge. This one might suggest informs the idea of reasonable adjustments, but how does this logic inform the position of children and adolescents with behavioural disabilities in relation to their right to be included, yet pose risk to others? O'Connell suggests that a legal approach is needed that would allow for the possibility of vulnerability alongside aggression, and see 'bad' behaviour as embedded in a particular set of relationships' (pp 14). Such view indicates the need for change, which if logically cannot be

attained (at that point in a child's life) individually, then calls for a change in the relationships that underpin the behaviour. As such suggests that for a small minority of pupils, the expectations of a mainstream school are unattainable.

This perspective calls for a different address of the problems associated with Inclusion and indeed policies of exclusion. Not least address of the assumptions underpinning current responses to disability which, where behaviour is involved legitimates the conceding of disability protections to criminal and education sanction (BIBIC 2005; 2009, Parsons 2005, Jull 2008, CEREBEBA 2013, O'Connell 2016).

Karpin and O'Connell (2015) address this issue in law, identifying a unique area of vulnerability which marks behavioural disabilities as distinct from disabilities with stable organic markers. It is suggested that although founded upon the certainty of science in the first instance, their delineation as disability labels not normal child variation is socially constructed. As such they are vulnerable to being 'intertwined with social and cultural assumptions, including stereotypes about certain types of people' (pp 1467). Karpin and O'Connell (2015) offer example of such practice by underscoring the gendered assumptions that underpin conditions such as ASD and ADHD. It is of additional concern that the authors finds such assumption to feed back into what may be termed the scientific 'natural attitude' (Schutz 1973), as such is definitional of the knowledge base (evidence) which underpins diagnostic criteria; which O'Connell suggest is the means by which 'the gravitas of science are given the status of 'fact' (ibid).

The finding that genetic and neurological explanations for behaviour can tend toward deterministic response (Karpin and O'Connell 2015, O'Connell 2015; 2016) based upon the interpretation of neurological knowledge is heightened by attribution of environmental triggers as an additional causational aspect. This interplay is stated by Karpin and O'Connell (2015) to extend from the lack of tangible biological markers to substantiate the existence of a discrete medical disorder. Thus neurodevelopmental diagnosis have depended upon non organic markers, in particular behaviour and social interaction, which are determined through social convention, not objective markers. As Karpin and O'Connell (2015) state 'there are few if any reliable genetic or neurological biomarkers. Instead, the conviction that these biomarkers exist, and are simply waiting for proper scientific measurement and full revelation, means that these disorders are, in the meantime, treated as biologically meaningful, and their future scope and consequences imagined in concrete detail' (pp 1465).

Nevertheless the reliance on behavioural markers introduces scope for not only subjective assessment but also accountability for lifestyles and cultures which can be identified as contributory. It is at this point that Holt's (2013) notion of multiple (and at times incompatible) habitus resonates as a contributory factor to accountability, equally so Barr's (2014) Integrated Threat Theory of Prejudice. In combination these complex social interactions lay the foundations for accountability to coalesce around medical labels, and present the impression that some lifestyles, parenting standards and indeed attitudes are as contributory to the symptoms of defined medical labels as the imputed organic factors are stated to be. As such these dual attributions serve to effect a disconnection between the identities of such labels as de jure medical conditions and the symptomatic indicators as the consequence of a medical disorder. Rather they introduce the intimation that environmental triggers are equally contributory, which serves to rationalise their accountability.

Equally the observations made by O'Connell (2016) that there are mixed opinions in relation to the malleability of the brain and particularly that children's brains demonstrate greatest plasticity, open further spaces for the accordance of accountability. Most particularly it introduces spaces for familial blame; for where conventional opinion asserts capacity to change and change does not occur, the logical line of accountability is environmental and for the child, the primary environment of influence is the family and most specifically the mother. Thus where change is impeded it speaks to the need for greater control, rather than as O'Connell (2015) suggests an integrated relational assessment of the child and the environment, looking to necessary contextual changes.

These processes may be seen as mirrored in the school system, through the retention and expansion of units for children with 'behavioural' problems. Notably Fein (2012) suggests some medical labels attract greater forgiveness in relation to behavioural symptomatic effects than others, reducing the accountability liable to be levelled. Notably there is a correspondence between how pervasive a neurological disorder is viewed and the level of control or accountability metered in childhood. Most specifically Fein cites the condition Asperger's disorder as an example of a medical label which attracts the expectation of permanency. Nevertheless in adulthood, or indeed childhood I would argue this does not render the person identified as any less accountable in law or in the education system if one takes the actual outcome implications as a measure of accountability. Thus as is discussed at

points 3.2.8 through to 3.2.10, childhood disability is no protection against discrimination, responsibility in law or school exclusion.

3.2.8 Disability Discrimination

Conspicuously the Disability Discrimination Act (Parliament 1995) lagged behind other legislation prohibiting discrimination based on the attributes of race and gender (Parliament 1975; 1976). It is equally conspicuous that although protections against discrimination were consolidated by the Equality Act (Parliament 2010), its protective scope in the case of disability has been considered restricted by the terms that underwrite its protective scope. As Lockwood (2012) observes, the detail of the Act places the onus of disability disclosure onto the disabled person, it is the crux of proving an act of discrimination, as it rests upon whether disability was known or could have 'reasonably been expected to be known'. Thus in the case of disabilities without physically obvious features, the burden of proof is a grey area, particularly in contexts where disability may not have been formally disclosed or identified.

Shakespeare's (2014) contention that the Social Model of Disability acts as 'obstacle to the further development of the disability movement and disability studies' (pp 20) resonates in regards to this issue. Not least as a main contention is that the concept of disablement has served to deflect attention from the practical realities of embodiment. Undeniably, lack of empathetic awareness of the challenges faced by pupils with disabilities of impact on behaviour is a factor underpinning exclusionary response, it is also a leading factor implicated in relation to accountability as has been discussed in the previous section.

Borsay (2005) accuses the 1995 Disability Discrimination Act of partiality, suggesting that the prerequisite for disability recognition demand by both the Disability Discrimination Act (Parliament 1995) and the Equality Act (Parliament 2010b) served to disadvantage persons who lacked physical features or who had fluctuating or inconsistent symptoms (Borsay 2005). Boyd (2012) concurs finding such contention to remain an issue.

The precise wording of the Equality Act results in disability rights and protections being conditional upon ability to demonstrate 'substantial and long term adverse effect on ability to conduct normal daily activities' (Parliament 2010, Chapter 1, para 6 (1b)). What remains notably unstated are the parameters of normal, or what constitutes substantial? Campbell (2009) suggests that the delineation of normal is

directly resultant from unequal relationships of power which are define not only what is normal, but also the severities of response, through their capacity to delineate the boundaries of tolerable and intolerable difference. In education Billington (2000) suggests that exclusion 'constitutes punitive acts of authority in which children's differences are identified, prior to an imposition upon them of a social exclusion' (pp 2). Interestingly exclusion in this respect, exceeds external exclusion, but is equally pertinent to other acts of segregation, justified in the name of difference, for example special education classroom support, special units and special schools.

Looking specifically at the issue of emotional and behavioural difficulties (EBD) Golubtchik (in Bursztyn 2011) highlights the implications of subjectivity in relation to this highly fluid classification. Pertinently he asks 'when does a behaviour problem become an emotional disorder' (pp 107); and in answer it would appear that there is inconsistency and variation across which reflects varied organisational protocols. Markedly the rates of pupils identified as having behavioural difficulties are unequally distributed across social groupings. This Dyson (2008) suggests mirror wider social inequalities, thus in relation to 'behaviour' and what constitutes 'behaviour', 'public issues' become framed as 'private troubles' (pp 43). A tendency which I suggest is compounded by the rhetoric of educational equality on the basis of what are perceived as the levelling effects of Inclusion and meritocracy. This impression of equality of educational opportunity in conjunction with an increased medicalisation of 'behaviour' (Conrad 2000; 2007) I suggest acts to deflect the locus of accountability from systems and structure to the level of the individual and the family.

In the school context disability recognition takes place across multiple contexts, punctuated by complex interactions, both in and out of the classroom. These involve not only the child, parents and school, but also engagement between peers, subject staff and inputting agencies (Benjamin 2002, Black-Hawkins 2008, Nind 2008, Holt 2013). Disability is thus both private and public, the recognition of which (in the absence of obvious features) necessitates identity work to procure the recognitions previously referred to in relation to the Equality Act (Parliament 2010). In respect of child disability, parental competencies are a key factor influencing disability recognition and identities (Gallagher 2010b). It is thus unsurprising that disability disadvantage (even in regards to initial identification) appears to intersect with other social variables associated with disadvantage in education (Collins 2000, Nind 2008, Bursztyn 2011, Gurian 2013, Tomlinson 2014).

Race (2007) states that disability legislation is not specifically tailored to meet the needs of individuals with learning disabilities and to this I add that neither is it tailored towards the needs of persons with disabilities of impact on behaviour. Looking for explanation for these omissions, Rogers (2016) alerts us to the possibility that such omissions may reflect a more pervasive devaluing of particular types of disabled persons. Certainly in the school context, devaluation is evidenced by reference to the disproportionate population of pupils with heightened vulnerability to exclusion (Parsons 2005, Jull 2008, O'Regan 2010). Graham and Slee (2011) describe these processes as 'segregation within the mainstream [impacting] particularly on children with emotional or behavioural difficulties' (pp 949). Disability protections may thus be seen to be tailored to those with a physical impairment; yet such partiality cannot be justified numerically as out of the 9.4 million disabled people in England, only 2% are wheelchair users (EFDS 2015). In parallel a further 2% are considered to have a learning disability, but do not engender disability association as readily as their mobility impaired peers.

Paradoxically Race (2007) following a comparison of governmental white papers thirty years apart (DHSS 1971, DH 2001), that there was growing recognition that the needs and vulnerabilities of persons with psychological disabilities differ radically from those with physical difficulties. Thus whilst the publication of 'Better Services' (DHSS 1971) was conducted amidst a low status accorded to mental health, politically and significantly within the field of medicine. In comparison the 2001 white paper 'Valuing People' (DH 2001), expressed greater commitment to support this populations specific needs. Nevertheless it is notable that such recognition is not reflected as discussed in the detail of the Equality Act (Parliament 2010) in respect of the varying protections needed.

The continuing lack of appreciation that the varying presentations of disability require dedicated legislative protections, operates to facilitate the perpetuation and ratification of discriminatory practices. Not least in education, where the conditions for Inclusion, mitigate against those who cannot fit in (as previously discussed in this subchapter). Allen (2006) notes that sociology has failed to retain an influence in the area of disability discrimination in education and suggests the need for a sociological presence which could elucidate the contradictory imperatives in the school domain. These imperatives are according to Allen 'often resolved by privileging one imperative over another, in a way that the obligation to the 'other', – the disabled

person or the individual with learning difficulties – is denied’ (pp 607). Indeed this contention appears evident when one considers the main reasons given to substantiate exclusion from schools is on the basis of impact on the wider school community.

As has been discussed, the tensions generated by the competing demands of ‘Inclusion’ and ‘the standards agenda’, serve to illustrate the dynamics Allen refers to in relation to the educational rights (and needs) of pupils with behavioural disabilities. Most specifically it may be said that the positioning of this population as individually accountable (thus excludable), permits the illusion that the school is both inclusive and able to deliver the desired output in terms of summative results. Freire’s (1996) notion of the silence of the dispossessed may be seen pertinent in this respect, as the positioning effected for both pupil and family through discourses of accountability deny the potential for recognition that such action is discriminatory.

The existence of disability discrimination in education is internationally recognised by the World Health Organisation (2011), finding that in education, those with a physical impairment experience fewer barriers than pupils with cognitive impairments. It is further found that disability reception within the employment sector appears similarly preferential as the following statement indicates:

‘Beliefs and prejudices constitute barriers to education, employment, health care, and social participation. For example, the attitudes of teachers, school administrators, other children, and even family members affect the inclusion of children with disabilities in mainstream schools’ (WHO 2011 pp 9).

Covert discriminatory practices embedded within wider institutional protocols is a term described as ‘institutionally ratified discrimination’ (Watson 2013). The term refers to practices that deliberately or inadvertently construct barriers which prevent the equal engagement of persons in that institution, on account of a known or suspected disability. Furthermore the limitations to equality identified in relation to educational and the criminal justice system are considered to further inhibit the identification of disability and act to confirm the reasonableness of individual accountability.

Quarmby (2008) refers to the systemic nature of disability discrimination, in particular the issue of hate crime, concluding that ‘Britain had a serious and pernicious problem with disability hate crime and with its attitude toward disabled people’ (pp 2). This contention extends to the level of legal protections, as disability hate crime was not recognised until the 2005 Criminal Justice Act (Parliament 2005), notably decades

later than those pertaining to race and gender (Parliament 1975; 1976). In addition Quarmby emphasises that disability hate crime is unequal in comparison to other attributes of difference, for it is defined in law as a 'demonstration of hostility', which is of a lesser legal status to that of other forms of discrimination.

Quarmby (2011) concludes that the origins of disability hate crime are aligned to historic fears and prejudice toward difference, a tendency reflected in the nomenclature common of the period (Corbett 1996). Prejudice may be said to persist and can be illustrated by reference to campaigns that insinuate abuse of the system for personal gain (Garthwaite 2011, Quarmby 2011, Hughes 2015, Roulstone 2015) such implication is also levelled at schools in respect of the additional funding special needs pupils attract (Levy 2013). Quarmby further suggests that hate crime crosses geographical and social barriers and is bound up with negative attitudes to perceived imperfection. In this instance I suggest that the concept of imperfection crosses the physical/psychological divide and speaks to dispositions and imputed integrity.

These contentions resonate with Rogers (2016) discussion of humanness, not least the implications that coalesce around the image others hold toward difference. In particular this may be said to affect young people with behavioural challenges, as they present as different in conduct, but not appearance, thus attract inconsistent understandings for their difference. Equally so the autistic child, whose engagement with others both separates and defines, notably in contemporary society sentimentally (Murray 2006; 2008). Rogers suggests that 'in thinking about disgust as an emotion and then imagining those who are deemed less than human, we are lured into a belief that certain types of people are contaminated' (pp 10). Disgust is a highly emotive word that at first glance may be considered to belong to a former period (Armstrong 2003), yet if one probes deeply responses to challenging behaviour, the undertones of disgust amidst threat to the status quo are apparent and act as an impetus to not only separate (Arnold, Yeoman's and Simpson 2009), but to legitimate response.

Barr (2015) asserts there is a functional purpose effected by the segregation and stigmatising of those presenting as different. In particular it acts to strengthen the bond between those considered same and consolidates group cohesion and complicity. In schools for example the rejection of pupils exhibiting challenge, may be seen to diffuse any dissonance faced by teachers in respect of the authority expectations of the teaching role. Equally, punitive responses to pupils exhibiting

behavioural challenges reaffirms to the majority their identity as 'good' students. Holt (2012) expands on the dynamics of this process, stating that 'it is only by a practical sense of the abnormal, that the normal emerges, as a sociospatially set of practices, rather than as a pre-existing dictate' (pp 2202). Holt (2012) further maintains that Inclusion (socially and educationally) operates to effect processes of assimilation into the norm. Segregation and accountability are thus purposeful responses to difference, they are at once affirmational (for the majority) and discriminatory to those set apart.

3.2.9 Recognising discrimination

A primary objective of my research was to address why there is limited recognition, resistance or outrage to the disadvantaging responses found levelled toward children and young people affected by behavioural disabilities, despite the protections accorded by virtue of formal disability status. Deal (2007) suggests that as societies become more intolerant to discrimination, the nature of discrimination and prejudice changes and may be unrecognisable to both protagonist and recipient, as the following comment explains:

'Blatant forms of prejudice towards disabled people appear to be disappearing in the UK. However subtle forms of prejudice remain and may be highly damaging to the achievement of the vision of disabled people being respected and included as equal members of society...Aversive disablism recognise disablism is bad but do not recognise that they themselves are prejudiced' (Deal 2007 pp.1).

The discourses underpinning 'aversive disablism' and prejudice can be seen to be couched in an authoritative professional tone, detached from emotions such as disgust, they are therefore less visible and often rationalised through professional argument. Perlin's (2000; 2008; 2016) delineation of 'sanism' offers an example, whereby the boundaries of 'normal' (saneness), act to legitimate the continued oppression of persons who deviate from the norms of cognition. As such oppression is typically metered under the guise of rehabilitation and adjustment, it is discrete, but on closer inspection, reveals limitations and restrictions infrequently extended to other forms of difference.

Perlin (2000; 2008; 2016) suggests mental illness is one of the most stigmatised of social conditions and in respect of prejudice hosts the 'same quality and character of other irrational prejudices that cause and are reflected in prevailing social attitudes of racism, sexism, homophobia and ethnical bigotry' (pp. 590). Nevertheless sanism is seen to differ from other forms of prejudice because 'sanist' 'decisions are frequently

justified as therapeutically based', yet as Perlin (2016) further observes, 'customarily result in anti-therapeutic outcomes' (pp12). Perlin further suggests that the prejudice underpinning 'sanism' is embedded in the cultural presuppositions that engulf us all (pp 17), leading to what is termed pretextuality. Pretextuality refers to (either formal or psychological) processes whereby the facts presented, are rationalised either knowingly or unknowingly on the basis of pre-held assumptions, described by Perlin as heuristic knowledge. Heuristic knowledge is stated to be the output of cognitive processes which facilitate the simplification of complex knowledge, which in use 'frequently leads to distorted and systematically erroneous decisions and causes decision makers to ignore or misuse items of rationally useful information' (pp20).

It is reasonable again to point out the similarities between heuristic knowledge and the notion of natural attitude as typified by Schultz (1972; 1973). Looking toward the educational arena it would appear that ableism, acts to segregate difference in the same manner as sanism. As such effects distance and justifies unequal response (Campbell 2008). The processes underpinning ableism are nevertheless not static, but emerge as the product of relational processes and are the output of subjective and political opinion which operates to devalue disability (Hehir 2002, Hehir 2005). Ableism may thus be seen primarily as a positioning tool in the same manner as 'sanism', serves to position in the legal context and in both spheres acts to legitimate and perpetuate inequalities.

Associations of cause and effect conjure impression of linearity and inevitability which holds important implications in relation to the capacity for resistance. The work of Anderson (2009) is therefore significant as it adds to our understanding of the dynamics of positioning in education. Most specifically it impresses upon us not only that resistance and change are possible, but also offers expansion on the areas where change and resistance need to be occur. Anderson finds that acts of positioning are cumulative in nature (the past influencing the present) and contribute to wider matrixes of knowing, 'through their intersection with different layers of interaction, authority, ideology, and time' (pp 294). Through review of processes of 'positioning' on both the micro and macro levels, Anderson (2009) shows how cumulative knowledge across both domains are primary to both positioning and identity construction. They thus impact on vulnerabilities to deficit identification and also discrimination. Anderson's profiling of these relational processes also highlights the interrelatedness of knowing and its vulnerability to wider overlapping influences.

This contention is further supported by Nind's (2008) finding that the role of socio-economic position is an important factor determining how a child's difference is defined. It also points to ways that such discrimination can be openly revealed and guarded against.

3.2.10 Illegal exclusions

The notion of aversive disablism (Deal 2007) is a useful concept to explicate the unwarranted (and unrecognised) effects of some school practices. Most specifically because it is suggested by Deal that both protagonist and affected party may be unaware that their actions serve to disable. The practice of 'illegal exclusion' illustrates how an institution can appear benevolent, despite operating in a discriminative manner. The Office of the Children's Commissioner's [OCC] inquiry into school exclusion is illustrative of this. The inquiry was a direct response to a growing awareness that particular pupil populations were disproportionately vulnerable to what is termed 'illegal exclusion' (OCC 2012; 2013). The term 'illegal exclusion' represents the practice of informally withdrawing a pupil from either school or a selected aspect of the school curriculum, often with the awareness and agreement of parents. Although anecdotal parental evidence suggests that illegal exclusions are common (CAF 2013, AA 2014), the OCC cautions that because of their nature, formal data to support prevalence is difficult to obtain. Nevertheless trends have been detected and the OCC report 'many of those illegally excluded also come from the groups suffering inequality, coming from particular ethnic backgrounds, or having special educational, behavioural or other needs. They are amongst the most vulnerable, and being made more so' (pp 4). The intersection of wider indices of disadvantage suggests that discriminatory practices are not random or isolated acts, rather are part of a wider more systemic culture of disadvantage.

Within education, exclusionary practices are ratified through two dissimilar but intertwined discourses. Firstly they are rationalised as a reasonable and reluctant response driven by a pupil perpetrator, irrespective of an identified disability or SEN. Secondly as a reasonable but reluctant response subsequent upon inability of the school to meet the pupils identified needs. Whilst both of these sentiments are pivotal to the rationalisations offered for an illegal exclusion, the identification of which children/young people meet the criteria appears selective as the OCC state:

'This illegal activity appears to impact disproportionately on those groups which are also most likely to be formally excluded, particularly children with SEN. It appears to happen most to

those children who are least likely to know their rights, or to have adults in their lives who know the law, or who can and will support these rights on their children's behalf' (OCC 2013, pp 6).

The OCC's findings confirm that parents felt 'let down by the education system...and have lost faith that it will treat them fairly' (pp8), whilst others stated they felt 'like a problem that has to be dealt with, and that therefore their right to an education is neither respected nor assured' (pp 8). The sentiments parents expressed to the Inquiry, offer impression suggest that some pupils encounter school response that intimates they are less valued than other their peers.

At institutional level, the justifications offered to explain illegal exclusions suggest that they are led the pressures metered through governmental accountability and cross school competition, rather than innate pupil challenge or need (CAF 2013, AA 2014). The OCC also note that financial restrictions are of impact, particularly on a schools ability to hire in (effective) specialist support in schools. Collectively these problems notably mirror the findings of the Lamb report (2009) and suggest the lessons of the report were ineffective.

The concerns stated in the Lamb report were wide ranging and extended from professionals and parents. These included perceived school incompetence and ignorance of the rights of the child' (Specialist Teacher/SENCO, pp103) and concerns over funding, particularly that 'schools were not using dedicated funding' (Parent of a child with ASD, pp103). Others alluded to concerns around being dismissed as 'over anxious' and for 'blaming' parents for their child's difficulties, especially for impairments like ADHD and Asperger's (Parent Partnership Officer, pp 109). It is at this juncture that Rogers (2016) delineation of careless spaces can be charted against specific practice. Most specifically it offers description of the attitudes that lead to the negation of educational rights for certain populations. Rogers (2016) call for the humanising of education relates directly to the situation faced by these young people and children. It calls for mindfulness that the life chances of these pupils are as important as those pupils who do not display difficulties.

Notably the range of issues raised by parents and professionals in the educational arena firmly indicate that the nature of complaints are impacted upon by wider systemic pressures that have become a consistent feature of schooling in the UK. It is however of concern that the OCC research clearly showed that illegal exclusions were often framed in a benevolent tone and stated to be of pupil benefit. This

introduces into the communication field, the implication of manipulation and overt self-serving discriminatory practice. The nature of this communication however, if unchecked, holds potential to be internalised by both parents and professionals as right and just practice. For example CAF (2013) record that '70% of illegal exclusions are because the school suggests it is for the child's 'own good' as he or she is having a bad day. Of these, 45% indicate it to happen every day, or every week' (pp 3). It is of greater concern that the AA charity found exclusionary practices were being justified to parents in a conspiratorial manner, intimated to be means of preventing 'punitive exclusion'. In these instances exclusion was framed around the notion of being included, of offering 'respite', for school, not as one might anticipate for the pupil (Autism 2014).

3.2.11 Rights, responsibilities and discrimination

Participation in education is a legal requirement (Parliament 2008) and mainstream schools are currently the main provider of compulsory education for school age children. As such are directly responsive to the direction of government, in relation to the authority to exclude, as well as the demand to include. It is therefore significant that the current government maintains an increasingly intolerant stance (Mills and Pini 2015). Predictably Courtney (2016) finds that the detail of intolerance to be unstable, yet responsive to the expectations upon which institutional success and failure is judged. In this way both surveillance and power are metered indirectly through an interlocking chain of command and accountability, a process described by Courtney as post-panopticism. From this perspective the boundaries of achievement (learning ability) and conduct (behaviour) reflect political not medical determinations, which is congruent with the assertions previously discussed that suggested both behavioural disabilities and their response are the product of subjectivity. Notably by revealing the political nature of success and failure, it is then possible to postulate as to the origins of and functions served by individualised accountability.

Courtney (2016) talks of 'fuzzy norms masquerading as stable' (pp 631), signalling an instability which is said to be a defining feature of the post-panoptic period. I thus suggest that in relation to educational rights and accountability, such instability is in part both caused and a consequence of, the ambiguous detail surrounding a child's right to an education. Particularly as at classroom level what constitutes normal child behaviour is found to be not only subjective in relation to wider social and institutional norms, it is also found to be localised through individual

interpretations. Thus although the right to an education is formally stated in the Convention on the Rights of the Child (UNICEF 1989), it remains unstated as to how such education and what quantity, should be delivered when a child's 'needs exceed the norm. For as has been shown, this too is directly responsive to political, economic and popular vision. This leverage places the disabled child/young person in a vulnerable position, as claims of discrimination can be rendered impotent by the various priorities stated within a multi-layered chain of command and surveillance. Indeed it may be said it is the fluidity of priorities which directly impacts on the 'who' and 'what' is accountable; and by extension discretions in relation to rights and responsibilities.

How schools interpret their duties under the Equality Act (Parliament 2010) is illustrative and suggests many practices in direct contravention of its stated demands go unchallenged (Commissioner 2013, Family 2013, Autism 2014, Sellgren 2014). It would therefore appear that the recurrent inclusion of qualifications to educational and legal rights, extended through exclusionary clauses which extend covert permission to discriminate, disadvantage disproportionately disabilities and SEN that may be considered 'difficult' (Rogers 2012; 2013) and incompatible with the priorities of the dominant institutions which constitute what is termed euphemistically structure (Giddens 1984).

Medical labels may be said to consolidate collective anticipations of difference (Hobbs 1975, Florian 2008a), within a bounded classification or spectrum of conditions. However some medical labels attract stigma and act to define a person as dangerous on the basis of a diagnosis, not observed or intimated disposition. Schizophrenia offers example of a cognitive imbalance that has engendered such mistrust. Equally the common condition depression, is found to attract both internalised and public stigma (Ferriman 2000, Angermeyer 2005). Such observation is found by Thane (2005) to be historically consistent, for as Thane states, 'some disabilities – generally, physical disabilities such as being blind, deaf or dumb - have always been more sympathetically treated than others, such as mental disabilities'(pp.3).

BIBIC (2005) equally observe a limited tolerance toward families whose children display antisocial behaviours. Even where consequent upon a disability, BIBIC found many parents subjected to the assertion of poor parenting, leading to court directed attendance at compulsory parenting classes, which Thane describes as 'picking up

the label bad parent' whilst opposite their children are stated to be 'naughty' again' (pp. 2). Troublingly research indicates that lay public ability to differentiate between discrete categorisations of mental illness is limited (Angermeyer 2006). It is thus reasonable to infer that similar limitations are likely in relation to other medical labels.

A complication identified by Waterhouse (2004), is that concepts of normal or deviant in the school context, reflect the social boundaries of that context, which as Courtney (2016) found were also reflective of the wider tensions aligned to the previously intimated multi-layered chain of authority. In practice, teachers ways of seeing involves categorizing each child in relation to a socially imposed social boundary within the school or classroom, which fundamentally amounts to an arbitrary identification of 'normal' and 'deviant' pupils' (pp 73). The implications of Waterhouse's assertion is to deliver responsibility for attributions of accountability into the local immediate domain. However in essence the chain of responsibility envisaged is reminiscent of a hall of mirrors, each layer reflective of the last, which problematizes its revealing. It also raises wider implications, as such thinking may not necessarily be congruent with the exigencies directive of the medical boundaries of normal and it is at this point that professional tensions ensue. It therefore prudent to suggest that professional 'knowing' is multiple, reflective of the professional priorities and tensions in the moment. Notably therefore it must be defined as partial.

Chapter three has looked at the social contexts of the family and school, finding these to be instrumental to the types of knowing generated and pursued. In this respect it is reasonable to suggest that both contexts are constitutive in terms of the identities both 'familial' and 'formal knowing' produce. Where childhood presentations include behavioural difficulties it has also been shown to trigger the impetus to blame, not least to pre-emptively deflect any organisational accordances of accountability. Chapter three has also found the current political and pedagogical climate to heighten these dispositions. In particular, looking at the legislative contexts of equality legislation and the educational doctrine of Inclusion, has led to the conclusion that all disabilities are not equally protected by such legislation. To the contrary there is evidence of historic and contemporary qualifications to both legal and educative entitlements, compounding disadvantages found. On this basis it was concluded that all disabilities are not equal and that status disparities were led in the first instance by the type of disability presenting, dividing between physical and psychological presentations of disability. Chapter three concluded with a

consideration of how discriminatory practices emerged in varying guises, not least that they took on the guise of benevolence. It was concluded that the practices identified were by nature fluctuating and responsive to complex layers of structural and organisational priorities and tension, which at times were not always congruent. Overall the literature reviewed in Chapters two and three, confirmed both the existence of disproportionate disadvantage and discrimination toward behavioural challenged pupils and their families. The literature also pointed to discrete sites that were fostering of challenge in respect of medical labels. On that basis it was concluded that the literature reviewed supported the need for a wider interrogation of the guise of disability challenge and discrimination. This thesis now turns to the methods and philosophy I engaged to conduct my research.

Chapter 4 Methods and philosophy

Introduction

This chapter is divided into four sections, section one commences with an outline of the philosophy which underpins the research undertaken, drawing upon social theorists who have influenced its form. I then consider methodological issues and ongoing debates in relation to the status of qualitative social research as a valid approach and how such approach is able to explicate relations of power. Section one concludes with a consideration of how the traditional markers of reliability and validity can be assessed from a qualitative position. Section two narrows the philosophical focus and offers the reader a philosophical frame to account for the mechanics of social action and communicative engagement. This section proceeds to an address of the wider issues which coalesce around what is termed 'insider research'. I then introduce and defend the employment of an autoethnographic approach; acknowledging the different styles of autoethnography currently employed and offering an expansion on why the choice of an analytical autoethnographic approach was considered a better fit for the purposes of this research.

Section three looks to ethical implications and is subdivided into two discrete parts; part one is concerned with issues specific to the varied respondent groupings, whilst part two focuses upon ethical issues pertinent to insider research and the autoethnographic method. In particular this section addresses issues of direct impact on myself and my immediate family. Section four outlines the detail of the research, introducing the reader to the research process, justification for choices made (through reference to issues highlighted in section two) and the research design chronology. This section proceeds to an overview of the methods of data collection employed, noting both strengths and weaknesses, followed by a comprehensive introduction to the different respondent groupings, and where applicable an anonymised biographical and geographical outline. This is followed by an overview of the stages of analysis, including the processes of consolidation and elimination which resulted in the identification of two broad Meta-themes which were fundamental to the conclusions drawn. The chapter concludes with a consideration of issues of validity and reliability and in particular the confidence that can be accorded to the findings of my study.

4.1 Philosophical underpinnings

4.1.1 *Underpinning Ontology*

This research is underpinned by what I term a qualified social constructivist ontology. I suggest it to be qualified because although the constructivist ontology rejects deterministic theories which claim to be directive of social relations (Marx 1904; 1967), individual psyche (Freud and Strachey 1964) and general social laws as envisaged by Comte (1868), Spencer (1892) and Durkheim (1952; 1982), I maintain that there is a tangible authority evident in society which is directive of the capacity for self-determination. I thus maintain that individuals are born into a pre-existing social world, ordered upon unequal economic and social relations, which both shape and are shaped, by individual agency (Berger and Luckman 1966, Giddens 1984; 1987, Bourdieu 1986; 1989, Bourdieu and Wacquant 1996). Hence although the social world may be ordered through negotiation and social construction, this does not inevitably imply equal negotiation. Rather it is more apt to suggest, the output of negotiation resides upon the logic of a pre-existing interlocking network of claims to truth, brokered through social and professional capacity to realise those claims (Foucault 1981).

Despite this acceptance there is also adherence to the position that human beings are at core, meaning making (Winch 2008); and it is meanings conferred (themselves the output of collaboration and negotiation), that underlie not only the appearance of solidity and order in the social world, but the social positions available to individuals across multifarious contexts (Harre 1999). This stance has been extended further through both the feminist movement (Hanisch 1969, Collins 2000, Yu 2011) and disability lobbyists (Oliver 1990, 2013, Shakespeare 2006; 2014, Ramanathan 2010), who through ongoing campaign have raised awareness of latent inequalities founded upon issues of gender and disability.

In education, similar concerns are expressed; Freire (1996) in particular cites the education system to be a prime institution fostering inequality through the notion of meritocracy and an individualising of success and failure. Notably the timing of Freire's contentions coincided with a growing momentum to establish 'Inclusion', which in practice has led to mainstream placement for the majority of pupils. Thus the ideals of meritocracy have wider implications and may be seen to disadvantage disproportionately those who cannot compete with the standards set. Indeed the logic of meritocracy inevitably benefits those who can, leaving those who can't

marginalised, practice that Mijs (2016) describes as 'unfulfillable promise'. It is reasonable therefore to assert that pupils with disabilities of a behavioural nature, particularly those with additional learning difficulties are by the very nature of the school system immediately placed at a disadvantage (Tomlinson 2015).

Practically, ongoing tendency to evaluate school performance on the basis of summative pupil progress scores and formal examination results, positions less able pupils as an educational liability, necessitating formal (recognised) systems of explanation to deflect accountability from the individual school (Youdell 2010). Tomlinson (2005) has applied human capital theory to the situation faced by pupils in contemporary UK schools and in doing so offers a stark visualisation of organisational priorities and the potential social positions available to pupils within it.

In recognition of these and similar issues, the underpinning philosophy of this research engaged with philosophical works that were able to explicate the nature of social positioning and unequal relationships of power. In particular I sought theory that was able to elucidate the finer nuances of power, which through its guise is concealing of its form and function. For example Freire (1996) points to pedagogical practices which perpetuate disadvantage and serve to internalise disadvantage and inequality as personal failing (pp 12), setting in motion a culture of silence which can only be broken by the realisation of the populous as to the core locus of inequalities.

Indeed it is at the juncture of recognition and consciousness that one can usefully refer to the concept of hegemony (Gramsci 1973, Reay 2008) and the role it plays within what Schutz (1973) terms 'the natural attitude' (pp6). The natural attitude can be defined as the common consciousness or collective schema that underpins the appearance of what is taken for granted in society as natural and inevitable in the form it presents. The idea of their being a natural attitude to both disability and mothering is particularly apt in the frame of this thesis. Most specifically it offers means to explicate how the ideals and expectations of 'motherhood' (Rogers 2007a; 2011; 2013; 2016, Landsman 2009, McLaughlin 2016, Runswick-Cole 2016) and ability (Heir 2002, 2005, Gabel 2005, Goodley 2011), produce the illusion of a norm, which is central to the delineation of 'good' mothering. In employment these norms serve not only to define a standard, but when interrogated they can also be seen to individualise shortcomings, offering a rationale for the accordance of individualised accountability. Furthermore it may be said that the establishment of norms in relation to role expectations and ability, define by default the boundaries of what is outside of

that norm; as such serves to position that so defined as an abnormality, requiring of address.

Notably it is through processes inherent to consciousness raising, that it is possible to observe how taken for granted (negotiated) meanings, do not always reflect the material reality of a situation. As Stanley (1992) emphasises, consciousness raising represents a means of “encouraging a reflexive understanding of the relationship between individual consciousness and social structure, not only relating social selves to social collectivities, but also recognising the part that selves play in constructing structures as well as being mediated by them” (pp 44). Social Constructionism thus offers the potential to reconcile the idea of human agency with both inequality and structural constraint.

At this point it is useful to distinguish between interpretivist and constructivist approaches as the distinction holds implications for usage and applicability. Schwandt (1998) asserts constructivists hold different concerns to those of their interpretivist peers. Where interpretivism addresses method and the constitution of social science subject matter, constructivists extend this focus to include the constitution of truths and the basis of knowledge. As this thesis focuses upon disability accountability it inevitably encroaches on the understandings held toward not only disability but also the medical labels which define in contemporary society disability. I place emphasis on the historic context asserting that what counts in contemporary terms to be disability is historically referenced. As a result the certainty around medical labels is contentious and I determined that a constructivist approach could help explicate both their status and influence in working usage. This approach was also compatible with my belief that medical labels do not necessarily represent *de jure* truth, but rather represent ‘negotiated truths’, bound to time and context rather than discovered phenomenon (Schwandt 1998, pp 237).

This research sought understanding, indeed understanding of understandings, which I felt could be likened in ambition to the tenets of *Verstehen*. The concept of *Verstehen* has had a discrete impact on both interpretivist and constructivist philosophy and is most notably attributed to the work of Max Weber (1948). It has nevertheless been usefully refined by Schutz (1972) and bridges the personal and public domains. Schutz likens the concept of *Verstehen* to his delineation of ‘common sense thinking’ (pp 56), citing it to be the central mechanism of understanding within the social (both individual and collective) domain, founded upon processes of

'acculturation' (ibid). Nevertheless it is the concept of 'Visceral Verstehen' which emerges as most closely resembling the research focus of this study and is stated by Glass (2005, pp 12) to represent an approach which focuses on both meaning and the socio-historic context within which it is embedded. Thus returning to the example of autism, its meaning and the differences it represents may be seen as tied to the contemporary context, not the medical label itself. Thus forth, it is congruent to suggest that the challenges raised pertain to contemporary understandings and contexts also, which renders it vital that both label and context are interrogated to inform the research foci.

4.1.2 The Objectification of thought

At its core constructivist philosophy claims knowledge and 'truth' originate as matters of cognition and that it is the transference of such cognition into tangible entities which creates the appearance of a stable and tangible pre-set world. The disposition to such objectification stated to be itself founded upon the social nature of human existence and 'shared systems of intelligibility' (Gergen and Gergen 1991, pp 78). Blumer (1969) intimates there to be three spheres of reality, the physical the social and the unique and it is interesting that these spheres broadly parallel the parameters of the Social, Medical and Embodiment Models of disability as discussed in Chapter two, subsection three.

Nonetheless in everyday engagement, objects and concepts present as tangible, which is problematic when one tries to defend an ontology from the position of social constructionism. Fuss's (1989) contention that essentialism links logically with Social Constructionism through systems of linguistic representation is therefore notable. For it is suggested that it is such representations (linguistic tags) which 'establishes their (that which is referenced) existence in the mind' (pp 5). Looking closely at the nature and form of medical labels, such contention appears timely, for although medical labels such as Autism and even ADHD are hailed as having an historic consistency; it is equally pertinent to suggest that they do not necessarily represent the same phenomena. Rather, through their linguistic tags, the appearance of continuity stands as testament to their truth. Equally the expansion of prevalence is interpreted as greater incidence, not shift in classificatory meaning.

The example of Autism and ADHD reveals how a concept can evolve from the abstract to the concrete and not only retain, but expand upon its jurisdiction, losing all semblance of its once intangible guise. Autism and ADHD are thus concrete 'things',

as it may be suggested is challenging behaviour now, through the introduction of Disruptive Mood Dysregulation Disorder into the DSM 5 (APA 2013, pp 156). Although in its embryonic stages, this new medical classification (label) offers an opportunity to observe a conceptual construct progress from thought to tangible object and in doing so offers a practical demonstration of Fuss's analysis.

Schwandt (1998) has claimed that the 'meanings given to terms are shaped by the intent of their users' (pp 221); and one can argue that the changing diagnostic criteria for autistic spectrum disorders (which has expanded diagnostic entitlements to persons who previously would not have met the criteria) is illustrative of Schwandt's point (APA 2013, pp 50), as is the controversy that has been equally stimulated. For example this rapid expansion of prevalence has been likened to an epidemic, triggering various research initiatives to account for a perceived increase in the general population (Russell, Collishaw, Golding, Kelly and Ford 2015). In particular the now discredited link between MMR Vaccine and Autism (Wakefield 1998) had a fundamental impact on public and practitioner understanding of the nature of autism as a condition that was caused, rather than innate. Equally the same phenomenon has also been attributed more generally to the processes of medicalisation discussed in Chapter two (subsection four), which has had a major impact on autism's status as a discrete neurodevelopmental condition.

In contrast Eyal (2010) puts forward a social explanation for this expansion, concluding that expansion can be traced to the policy of de-institutionalisation, in particular need to categorise persons formally have been absent from the community. From this perspective, rather than medical advance leading diagnostic change and re-classification, it has been the need to explain the presence of persons formerly outside of public view, whose visibility has been generated through the policy of de-institutionalisation. Thus Eyal suggests that the implications this has had for resource distribution and support needs has led to a (socially necessary) widening of the criteria for diagnosis. These differing interpretations of the same phenomena illustrate how differing lenses can forge very different, but equally plausible explanations. This open up a very basic question, which asks how confident can we be that what passes now as autism, is the same as what was understood to be autism historically (Bleuler 1908, Kanner 1943). From these examples it is evident that the naming of phenomena is relative to the historic period within which it is

situated. Thus comparisons historically are vulnerable to distortion and may not even represent the same phenomenon.

4.1.3 Social Constructionism

Social Constructionism is stated to be a distinct philosophy that extends across a spectrum of approaches which share distinct, but common features, stated to be foundational to the Social Constructivist method. (Burr 1995). It is thus useful to outline these features to demonstrate their compatibility with the philosophy I have detailed previously, my proposed methods and the nature of the research focus undertaken.

1. Social Constructionism takes a critical stance toward taken for granted knowledge; directing the research process toward an interrogation of taken for granted and ill-defined inequalities, which serves to destabilise social as well as individual truth claims. Given the educational inequalities identified and experienced, in conjunction with the claims to truth medical labels command, this particular aspect of the approach was considered particularly suited to an address of disability accountably. In particular it offered a firm philosophical rationale from which to interrogate teachers views towards the status of medical labels. As Burr states, Social Constructionism 'invites us to be critical of the idea that our observations of the world unproblematically yield its nature to us' (pp3). Thus given that the foci of my thesis surrounds disability challenge and disadvantage; and that one of the identified explanations is that all medical labels may not axiomatically be accepted equally outside of the medical profession, this feature was considered particularly significant.
2. The Social Constructionism philosophy maintains knowledge and experience to be historically and culturally specific, and directs analysis to detail the particulars of each period. In the context of my research, this position enables attention to be directed to the incongruence of disability accountability without entering into protracted debates in relation to truth claims. It is hence sufficient for the purposes of this research to acknowledge the role of medical labels, in terms of educational provisions and understandings of difference and to accept such labels are contemporarily embedded in everyday consciousness and working practice.
3. The Social constructionist philosophy maintains that the nature of the world is not given, rather extends from 'the social processes and interactions in which people are engaged with each other' (Burr 1995, pp 4). Nevertheless practically these structures

appear permanent and tangibly unyielding, except during periods of crisis where their tangibility is less certain. Periods of war or terrorism are extreme examples of social ruptures that distort the synchronicity of social engagement; but equally significant are more subtle social insecurities, for example shifts in economic policy following governmental changes or indeed the unknown impact of the recent European Union Referendum. It is at these junctures that the tone of interaction is vulnerable to shifts, which impact on both social relationships and codes of conduct. Jensen's (2013) review of the emergence of what is termed 'poverty porn' (pp1) is a useful example, as it shows how subtly entitlement and disentanglement can change without any formal statement. Such subtleties are similarly relevant to my research as the idea of disability disadvantage, speaks to wider notions of educational entitlement and disentanglement, which itself can be charted historically. Of equal significance are the contemporary and historical profiles the roles of parenting, mothering and pupil have conjured and their relevance to educational entitlement and attributions for difference. As I discuss in Chapter five, the expectations of 'normal' parenting and parent/child relations are unattainable for some parents amidst the crises which can accompany what are termed behavioural disabilities. At these junctures, circumstance reveals most acutely, the unnaturalness of assumed instinctive roles (Carpenter and Emerald 2009, Gallagher 2010b, Rogers 2013; 2016).

4. Social Constructionism is stated to privilege the inherent connection between knowledge (social constructs) and social action; stating action to be meaningful, based on prior held conceptual schema, as equally are the understandings and attributions accorded to the action of others. Barr also maintains that multifarious constructs are operative within a community, as such are able to accommodate and account for the presence of conceptual incongruences. Such stance was directive of my research foci and prompted me to consider more closely the constructs held by individuals and institutions in relation to childhood disability. Most particular the sense made, and validation of medical labels by teachers and parents, as well as that made of challenging behaviours and the role of parenting and teaching toward such presentations.

4.1.4 Methodological issues and debates

Bryman (2008) asserts qualitative methods are particularly amenable to an interpretivist epistemology. They also purport to the notion of 'truths, rather than any singular 'truth', amenable to scientific discovery. This logic extends to the research

relationship and notably a qualitative approach commonly embraces researcher reflexivity. This approach views the research relationship as collaborate and the knowledge output, co-produced. Thus as my intention was to use personal experience to further a wider research project, this stance was of specific relevance. Rose (2007a) states, 'collaborative research means doing research with your respondents or informants, rather than on them. It means acknowledging a respondents own skills and understandings' (pp, 251-252). My chosen methods of data collection reflected this position as I aimed to encourage through narrative a spontaneous dialogue, which, although guided by me, was directed by my respondents. This however does not conclude the research process, as the conclusions drawn in my final analysis, extended from the meaning wrought by me toward my respondents data. This was made in conjunction with an embrace of wider academic theory and research, using skills developed during my doctoral programme. Overall it was determined that the qualitative approach was philosophically congruent with a research project that sought to interrogate the interplay of meaning making and experience with organisational and legislative structures.

It is nevertheless prudent to look more closely at the qualitative method and juxtapose its utility against that of a quantitative approach in respect of my research. By doing so it became evident that the use of quantified means to record and analyse my ranking data was the most time effective way to collate a large volume of responses. It also offered means of cross referencing the rankings against the medical labels listed, allowing me to see if any patterns were evident, similarly my final closed 'quick questionnaire' with teachers was also amenable to such management. I did not feel this detracted from the depth of data received, to the contrary, the data managed quantitatively was expanded upon through textual annotations which were transcribed and subject to a thematic content analysis, hence in practice this duality of approach was complementary. Qualitative and quantitative approaches may thus be seen to represent fundamentally different tools, which when used in combination appropriately, can complement the explanatory capacity of each other. Therefore on a practical basis, the perennial dilemma of qualitative versus quantitative methods, can be seen to be reconciled on the basis that each holds capacity to inform (differently) social research.

Problematically nevertheless this methodological divide extends practicality and speaks to the very core of the nature of society and how it can be known. Hence has implications not only for the philosophical congruency of the approach adopted, but also the type of knowledge and knowledge claims that emerge from the research process. Looking at my own research ambitions, I wanted to understand the reasoning behind disability challenges, as their existence appeared to contradict the general premise of disability being a physical or psychological difference whose impact was beyond the immediate control of its host. I thus needed to employ an approach that would enable me to engage with how challenge was both rationalised and experienced. As this pursuit was also liable to result in multiple accounts, which may not hold logical congruence with each other, there were further dilemmas conjured in relation to the validity of each respondent's data and how it could be determined. Notably these dilemmas and their resolution speak to historic (and ongoing) debates surrounding philosophical and methodological persuasions, particularly in respect of methodological validity and utility within the field of social research (Sale 2002, Lund 2005, Onwuegbuzie 2005, Kelle 2006, Greene 2008, Sandelowski 2009, Fielding 2010, Symmonds 2010, Lund 2012).

It is thus notable that the claim of social science to scientific status on the basis of qualitative methodology as an equally valid scientific approach has been challenged (Smith 1983, Eisner 2003, Adams St. Pierre 2006) and in response defended by assertion that the innate differences between the subject matter of the social sciences and that of the natural sciences necessitates a differing approach. Central to these arguments is the issue of subjectivities and meaning production (Berger and Luckman 1966, Burr 1995, Winch 2008, Gergen 2009). This too is disavowing of any arbitrary notion of truth and as such offered means to reconcile the challenges I identified in respect to my own data. The origin of this position may be attributed to Max Weber (1947), who through the development of the notion of *Verstehen*, was fundamental to claiming distinction between the phenomenon of the social sciences and that of the natural sciences. The methodological impetus which followed led to an expansion of qualitative approaches, including autoethnography and insider research (Reay 1996, Rogers 2003, Anderson 2006, Ellis 2004, Delamont 2007, Cooper and Rogers 2015). Nevertheless understanding, or its lack, remains a key issue in the social sciences, particularly in the field of disability studies, where there remains debate about the ability of non-disabled researchers to appreciate the

embodied situation of disability (Barnes and Mercer 1997, Kitchin 2002, Sinclair 2005).

4.1.5 Qualitative approaches – a force for subversion or liberation?

The evolution of qualitative methodology was driven in the main through expansion of humanist social theory and in particular the embrace of constructivist ontologies toward understanding of the social world and social interaction (Berger 1967, Schutz 1973, Goffman 1990a, b, Searle 1995, Schwandt 1998, Winch 2008) and it is throughout such time frame, prior to their general acceptance as the mainstay of social research methods that their utility and radical potential is evident. Qualitative methods, underpinned by focus on meanings and emotion (Clough 2007) might imply a science suited to individual experience, rather than grand theory. To the contrary, qualitative approaches have been considered illuminative toward 'the pervasive nature of power in people's everyday lives' (Rogers 1977, pp 88). Qualitative methods are thus suited to a research project that is directed toward the exercise of power in the lives of disabled children and their families. Focused not only the attributions made toward behavioural difference, but how those attributions serve to objectify and hold accountable, despite their being centrally placed within a medical model of disability. This approach has also been stated to be suited to research directed to the macro level; and it is telling that its input remains resisted and at times challenged. Not overtly, but subtly, for example it is notable that the humanities and social sciences command a lesser status in education, lesser government funding and is actively denied access to the natural curriculum. Such resistance appears to reflect the threats perceived as Kincheloe (2002) states, finding that qualitative research is associated with the production of 'undeniably dangerous knowledge, the kind of information and insight that upsets institutions and threatens to overturn sovereign regimes of truth' (pp 87). The emergence of post structuralism has also strengthened and elevated analytical capacity; not least through attention to the relations of power at both the structural and individual levels. This has served to highlight its pervasiveness into the ordinary spaces of peoples lives. Central to this has been attention to the role of discourse and the production of knowledge in respect of the social relations produced and reproduced. See for example Bourdieu 1977; 1980, Derrida 1978 and Foucault 1972; 1980 and 1981)

As the data sought within this research invited both qualitative methods and quantitative analysis (qualitative as a means of understanding complex opinions and

attributions, quantitative to unpick and present diamond ranking data) it was important to be familiar with debates that argue for and against the mixing of methods. The mixed methods approach emerged within the field of psychology and has developed in status and technique within social science (Creswell 2003). Although its utility was initially based upon the principle of triangulation towards a means of data validation, this approach has evolved and is now considered a distinct approach.

The emergence of mixed methods may also be seen as evidence of a philosophical reconciliation, the bridging of the historical gulf between qualitative and quantitative methods. Although practically it may simply reflect a growing recognition that each opposing stance holds methodological utility. For example the transposition of quantitative data into a qualitative format offers scope to expand the 'why' surrounding associations and patterns, in contrast converting qualitative data into numerical formats extends means to review large data sets in a manner amenable to simple statistical analysis, thus holding potential to highlight patterns and associations. This certainly was the allure of employing a base level of quantitative data management and analysis into one discrete area of my research. It was therefore reassuring that there is a substantial body of opinion which supports the position that it is plausible to employ a mixed methods approach without compromising ontological integrity (Greene, Caracelli et al. 1989, Greene 2008a, Sandelowski 2009).

It is nevertheless significant that Greene (2008) moves beyond the issue of compatibility and philosophical integrity and claims that a mixed methods approach is transcendent; rapidly emerging within the social science field as an entirely separate research approach which 'embraces multiple paradigmatic traditions and has or will have distinctive methodological components and distinctive markers of practice', (pp 20). This argument introduces many dilemmas for what may be seen to have been the bedrock of the social science discipline (the philosophical binary between quantitative and qualitative approaches) and its implications are beyond the remit of this research. They in my final judgement also determined to be irrelevant, as a quantitative approach was employed for specific purposes and it was my judgement that it met those purposes as previously stated. Thus as I did not make any claims to the nature of knowledge, beyond a stance that maintained that responses to the diamond ranking exercises were sufficiently similar in nature (if not content), that they

were amenable to non-parametric quantification for reporting purposes, the issues raised by Greene were noted, but considered of no direct relevance to the research integrity of this thesis.

4.1.6 Objectivity - fact or fiction?

Embarking on a lengthy study which is founded upon problems not only perceived but experienced, begs address ethically of personal motivations as well as the risks/benefits to respondents. The goals of the research process has been extensively debated in relation to educational research and are too voluminous to cover in depth. Nevertheless at face value there is an impression of opposing positions, centred on the role of the researcher in the research process and the ambition for the research generally.

Two main positions emerge, the first calling for researcher neutrality, a stance which is fundamental to Mills (2001) visualisation of the sociological imagination and the ideal that the researcher can operate with a detached neutrality, divorced from his own social embeddedness. Hammersley's (2008) contention that the impact of values must be minimised to guard against research bias. This position may be seen to echo methodological principles inherent to the natural scientific method and is juxtaposed against stance which denies the practicality and desirability of such neutrality (Gewirtz and Cribb 2006). Consequently the researcher is directed both ethically and professionally, to be open about the value assumptions underpinning the research focus and direct them toward [stated] political and social outcomes (Gewirtz and Cribb 2006).

In this manner social research may be seen to be purposeful, and indeed the disability movement are illustrative of this stance, not least in respect of the impetus behind the research and political underpinnings of both the Social and Embodiment Models of Disability (Oliver 1990, 2013, Shakespeare 2006; 2008; 2014). Goals directed research is equally evident within the Feminist movement, not least through the contention that the personal is political (Hanisch 1969). Drawing on Hanisch's logic, one might deduct that any study founded upon the personal will be inevitably political. Although I would concur with this claim, I also considered it important to strive for balance, avoiding the all or nothing stances implicated. Indeed it is the arbitrariness of the positions that are unhelpful, particularly as they do not meet either the professional realities of the research context, or the ethical obligations which are rigidly enforced (Abraham 2008).

Greenbank (2003) and Abrahams (2008) offer a third perspective which is considered helpful toward a resolution of the dilemmas posed. Claiming it to be an oversimplification that research be value neutral, or indeed a political tool, as the researcher is equally embedded in the social context and holds latent opinions and positions. Indeed such awareness is central to the ability of the researcher's ability to define areas worthy of research. As a consequence there is a call for researchers to be aware of their values, to be value committed, but to strive to produce quality research output to inform contemporary issues. Looking reflexively, I asked whether I simply seeking understanding and if so for what? Or would it be more truthful to suggest there was a wider agenda and that my research was integral to it? These considerations in essence were nonetheless unanswerable in advance, as I could not know prior to the research was concluded what if any relevance it would indicate. I thus decided that this particular issue would be determined by the conclusions drawn from my research, although I remained open to the potential of my research to be employed toward the address of disability disadvantage.

Equally the approach pursued, by its nature naturally implied this stance as it necessitated the sharing of personal experience and the reasons to share. From the outset this was stated to be responsive to my own experiences of disability challenge and disadvantage, which I felt warranted wider interrogation to unpick the processes that sustained their practices and the functions served by them. Can this be seen to be goal orientated? I feel certainly it was objectives orientated, however I did not seek to find data that would further specific ends, my starting point was to test my own experiences against those of other parents, teachers and SENCOs. I would therefore conclude that whilst I had no outright political agenda, I was mindful of the potential of my research and was willing to employ any research output to the objectives as stated.

In regards to the former implications of using both quantitative and qualitative methods, I remained observant to the potential of any oversimplification of my data through my limited employment of a numerical approach. I employed strategically quantitative data management and analytical methods, preferring where practical to elicit first hand narrative in a sequential order that was relevant to my individual respondents. This approach was also maintained by the extending of an invitation to teachers to annotate alongside their ranking choices and at the end of the final quick questionnaire distributed. My overall approach thus remained embedded in and was

led by, the opinions and experiences of both the researcher and respondent groupings. This study did not aspire to the production of any de jure truth, rather was sensitive to the ideal that there are multiple truths and that these truths are directional of social action. Notably the distinction between 'truth' and 'truths' holds important ramifications in relation to issues of research validity and hence has a relevance to the confidence that can be accorded to my research conclusions and is discussed in subsection 4.4.11.

My choice of an analytical autoethnographic approach reflects a commitment to the principles of Social Constructivism, as it is a method which requires both social and institutional reflexivity, directed to address not only the 'what' of social experience and opinion, but the 'why', at both individual and collective levels. I determined that such reflexivity is essential to support the quality research that Hammersley (2008) and Greenbank (2003) consider the gold standard. Overall my role may be best summed as co-producer of knowledge. This role acknowledges the collaborative nature of the research relationship, as well as the uniqueness of each respondent's data. A central part of this role is the art of facilitation, of offering space and time for respondents to process and present their story and opinions. It is only when complete that the research role invites the implementation of professional research skills to analyse the data and to situate its relevance in the wider disciplinary field.

4.1.7 Considerations of power

Relationships of power were intrinsically implicated in my research foci, not least because the notion of inequality and disadvantage implies such imbalance. Nevertheless although heavily implicated, the locus of power is not easily located and this was a final consideration during the design of my research. Harre (1999) finds relations of power to be implicated at every level of social engagement, both micro and macro. The nature of relationships of power at a local and macro level based on specific indices of disadvantage has been extended by feminist theorists from the perspective of standpoint (Fuss 1989, Jones 1993, Yu 2011) and similarly in respect of disability (Sinclair 1993, Cousner 1997, Shakespeare 2006, 2008, Curran 2013, Shakespeare 2014) and in education, race and class (Collins 2000, Tomlinson 1982; 1985; 2013, Nind 2008, Holt 2012). These contributions are eclectically relevant as in combination they highlight the constitutive nature of social and in particular educational relationships.

There is nevertheless a more general question in respect of how can relations of power be recognised and who are the powerful? A preliminary answer was to determine that relations of power can be defined as the ability to effect influence. However Butler (1997) reminds us, that all individuals may be seen to hold capacity (albeit differently) to effect power. Thus I considered that this definition could be usefully extended by a further qualification which states that, whilst relations of power may be seen in working practice to embody the principle of being able to effect influence; power by extension may be seen as the ability to sustain that influence and legitimate its potential as appropriate and proportionate. Within the field of disability in education, this capacity is both relational and definitional, linked to wider processes of identity construction and built around pre-existing representations and expectations of medical labels.

Power may therefore be said to reside not only with those purporting to truth, but is also embedded in the dynamics of interlocking systems of discourse that legitimate its exercise. In that vein, by far the most influential text identified in respect of this thesis is Foucault's (1981) paper, "the order of discourse", in which Foucault asserts the pervasive nature of discourse and its embeddedness within the fabric of society as both source and defender of power. In the order of discourse Foucault lays bare how dominant discourses, subordinate challenge and in doing so manifest and wield power. 'In every society the production of discourse is at once controlled, selected, organised and redistributed by a certain number of procedures whose role it is to ward off its powers and dangers, to gain mastery over its chance events, to evade its formidable materiality' (pp 52). These mechanisms are considered of primary significance in regards to what is known and what can be known and are considered directly implicated in not only how children are categorised, but in the very definition of both physical and mental health.

It is at this juncture that Derrida's (1978) rejection of discourse as a means to truth is most pertinent, and by its tenets, invites challenge to the certainties of medical and pedagogical knowing. Equally the principles of deconstruction invite an inversion of the binaries of difference and sameness; which in its enacting opens important considerations for a thesis focused on disability accountability and challenging behaviour. For example it is pertinent to question not only why complicity is coveted, but also what determines the guise of what is deemed to be compliant or challenging. This stance thus demands the destabilising of truths that underpin medical labels, as

such directs one to question their potency and implications. Thus asking teachers to indicate their personal opinion toward the validity of specific medical labels, loses the semblance of ludicrous; rather it is congruent with the position that discourses are comprised of competing truth claims, which, following Derrida's caution can never amount to de jure truth, but are part of an inevitably unstable system of meaning, which contains within itself inherent contradictions.

Foucault's statement in the opening to this sub section may be seen to sum not only the reach of medicine in contemporary society, but also the tensions between medical and judicial explanations and response to difference. For although Lupton (2012) defines medicine as a pervading culture, O'Connell (2016) shows how in explanation it concedes to judicial process where there is a blurring of explanatory jurisdictions. Thus offering a contemporary example of not only what Foucault describes as discourse, but also an active defending of the jurisdictions of difference. It is also indicative of the temporality of meaning Derrida (1966) refers to, as such illustrates how within a system or systems of meaning, the seeds of deconstruction are already embedded within and inevitably give rise to a future truth system, hence unlike Kuhn (1962) who envisaged paradigmatic shifts and the superseding of one knowledge system for another, Derrida (1966) maintained such systems to be infinite as the following statement taken from Derrida's lecture 'Structure Sign and Play' indicates 'If one calls bricolage the necessity of borrowing one's concepts from the text of a heritage which is more or less coherent or ruined, it must be said that every discourse is bricoleur' (pp 6). On this basis it is suggested that the research process is usefully directed to seek, not the truth of phenomena, but their explanation, connectedness and implication.

This review of philosophical underpinnings confirms that my research approach is suitably situated within a social constructionist camp and as such reflects the methods I have chosen to conduct my research. Toward the management and analysis of data I have considered the acceptability of combining qualitative and quantitative methods of data analysis and found this to be congruent with the overall philosophical stance maintained. In particular I have indicated that I maintain there to be no singular truth to identify; rather maintain that here are multiple truths, bounded by personal circumstance, wider belief and ability to influence. My research subsequently aimed to produce a snapshot of the educational terrain, influenced by the philosophy of action I expand upon in subsection 4.2. Toward this I designed a

'layered' approach, which aimed to reflect the interlocking complexity of the social world and importantly, each layers impact on the other. The role of the researcher is identified as being crucial to this process, visualised in the first instance to be facilitative, whilst actively directive of analysis and research conclusions following data collection and analysis. This review now directs attention to a philosophy of social action and its compatibility with an 'insider' approach.

4.2 Detailing a philosophy of action and exploring 'insider' research approaches

4.2.1 A philosophy of human action

Whilst the first section of this Chapter (4.1) alluded to the overall ontology of the researcher, this section breaks down that ontology, illustrating how the processes of human action are bracketed to several distinct (but considered individually to be insufficient) philosophies of human action. These begin at the level of the individual and that of the collective, looking at the mechanisms behind meaning making and conceptual schemas (Personal Construct Theory and Symbolic Interactionism). These are found to reflect and be directed to the presentations and identities of persons and objects in the world (Social Representations Theory). Direction is then turned to understanding and the understandings that are formed towards the actions of others (Attributions Theory). It is found that these understandings link to perceived motivation, generated through past experience and anticipated action; framed around general collective scripts which circulate in the social context Underpinning this frame of social action are the mechanisms of social exchange. Two philosophies in particular contribute to the understanding of this. Firstly symbolic interactionism, which impresses that social exchange is based in mutual meanings which are both pre-existing and emergent during exchange. Secondly Positioning Theory, which offers a means to understand the negotiated nature of social exchange and unequal relations of power which are stated to be inherent to all social exchange. These philosophies are detailed briefly below.

Personal Construct Theory (PCT) was developed by George Kelly (1963) and reflected a growing rejection of the deterministic tenets of both behaviourist and psychodynamic models of human action. PCT may be seen to have resituated agency to human action. Kelly likened the individual to a scientist, stating 'when we speak of man the scientist, we are speaking of all mankind' (pp 4). Underpinning this sentiment is the implication that sense making was a prime motivational factor

underpinning human action. Personal constructs may be seen as the cumulative blocks of understanding a person develops and are generated through and of impact on social engagement. Toward a synthesis of working practice, Kelly states that 'man looks at his world through transparent patterns or templates which he creates and then attempts to fit over the realities of which the world is composed' (pp 8).

PCT is a dynamic theory of human cognition, not least because constructs are stated to be fluid, through their continuous generation and testing. The foundation of PCT resides upon the notion of Constructive Alternativism (CA) which refers to an innate tendency to develop schema through the generation of oppositions which give meaning to the construct. Such oppositions may be seen to be pervasive in the school contexts and foundational toward the typical measures of school success and failure.

PCT it is highly pertinent toward this research focus as medical labels may be seen to represent collective (medical) constructs, whose meanings are shaped at the level of the individual, mediated through a number of personal factors such as exposure, experience and professional training. It may also be suggested that the disposition to predict and anticipate human action is equally pertinent as schools are required to act in an anticipatory manner (DfE 2015a). Medical labels may be considered to facilitate this process as they offer guidance in relation to the anticipated effects of medical conditions; as such they may be seen able to guide the resources necessary to support pupils needs.

Nevertheless as Winch (2008) has argued, the social world is punctuated by collective meaning making. Social Representations Theory (SRT) was coined by Moscovici (2000) and extends means of explicating how the social world moves beyond the personal to be collectively understood. Potter (1987) states, 'social representations provide the means for people to understand and evaluate their world' (pp, 139). Moscovici maintained social representations were central toward all thought and understanding and were comprised of both abstract and concrete elements, which underpin the attributions and causal explanations people adopt. Two main premises detailed by Moscovici (2000) persuaded me that SRT was a significant philosophy to underpin a not only a view of social action, but the scope of the research project. In brief it is maintained by Moscovici that social representations 'conventionalize the persons, objects and events we encounter [and] give them a definite form' (pp23). Secondly social representation are held to be prescriptive and

pre-existing, 'their force a combination of structure which is present before we have even begun to think and of a tradition which decrees what we should think' (ibid pp 23). In brief social representations embody the tangible manifestations of cognition, generated by and generative of ideas.

SRT thus offers elucidation of how disability and discrete categorisations of disability can take present as tangible entities which appear to belie any imputed constructiveness implicated in their form (Conrad 2000; 2007; Timimi and Taylor 2004b, Timimi and McCabe 2010). Indeed it is the nature of social representations to impute a solidity to configurations of conceptual schema; and in the case of medical labels, the constitution of social representations may thus be seen to be restrictive, generating expectations, rather than a responsiveness to any contrary physical or psychological manifestations which may expand the bounds of the representation.

The guise of social representations was considered to mirror at the level of the collective the personal constructs Kelly (1963) defined in relation to the individual; as such offers a conceptual linkage from the level of the individual to that of the social collective. Indeed it may be said that such linkage is essential for any communal social communication. As Potter (1987) has suggested, it is only through the sharing of social schema that the appearance of a stable external version of the world is possible, and as such acts as a unifying homogenizing force in society (pp 40). Disability per se and the medical labels which are given to legitimate disability status, may aptly be seen as social representations; particularly in regards to medical labels which lack a definitive organic base, but also to Meta notions of particular social roles, in particular, the role of a mother, pupil and disabled child.

Symbolic Interactionism (SI) may be said to represent a theory of social engagement, as such I considered it to offer particular utility to elucidate interactive processes of meaning making and the sharing of such meaning amongst the collective. SI derives from the work of George Mead (1934) and Charles Cooley (2010), although formalised as SI by Herbert Blumer (1969). Although the approach has been defined as a theoretical framework, not theory (Stryker 2006), it provides a structure from within which to visualise the interplay of structure, collective and individual agency, hence is a particularly appropriate frame of reference to guide the interrogation of disability understandings and emergent truths surrounding disability categorisations.

SI rejects the claim that 'things' hold intrinsic properties, which in terms of this research supports a conceptualisation of medical labels as flexible and constructed concepts, which may differ between individuals and collectives. SI is also holds at its core the primacy of individual agency and the impact of that agency on the other, as Blumer (1969) emphasises, 'the meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing' (pp 4). Such visualisation opens spaces for the impact of unequal relationships of power and the potential for negative representations to impact on social interaction.

In this respect SI echoes Cooley's (2010) 'Looking Glass Self' theory, which holds that a person's sense of self develops from the reflected perceptions of others and is considered to offer an important means to understand how social processes can stimulate both internalisation and acceptance of deficit identities. It is also significant that SI does not imply that meanings are produced afresh during each interaction. To the contrary Blumer (1969) states that during social engagement each party will 'have in advance a firm understanding of how to act and of how others will act. They share common and pre-established meanings of what is expected in the action of the participants and accordingly each participant is able to guide his own behaviour by such meanings' (pp 17). As such SI offers explanation as to why medical labels may at times conjure expectations which are incongruent with the actual symptoms presented. Indeed a constructivist perspective proffers there to be a regulatory capacity which is indigenous to the collective. 'It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life' (Blumer, 1969, pp19). In this SI parallels Barr's (2014) Integrated Threat Theory of Prejudice. Essentially SI was considered to represent a 'collective construct theory', effecting a bridge between the personal and the public domains.

The penultimate component I identified as necessary to complete my study's philosophy of human action is Attribution theory, which may usefully be described as a philosophy of human motivation. It has been described by Wiley (2012) as a 'longstanding model of motivation that provides a framework for understanding how people perceive and respond to the behaviour and experiences of others and as appropriate oneself' (pp 282). Theories of attribution are directed to the motivational factors underpinning the formation of conceptual understandings, they therefore may be said to link logically within the other philosophies of action that I have detailed. Theories of Attribution are also considered particular applicability to the field of

education as it is found that teachers causal attributions for problematic behaviours have implications for school based behavioural interventions and research, not least the sense made of and causations attributed to presentations of difference in the school context (Miller 1995, Cook 2001, 2004, Klehm 2014). Equally as was illustrated in Chapter two, schools emerge as having a predisposition to hold pupils accountable where behaviour is an issue. This disposition appears historically consistent as Miller (1995), Parsons (2005) O'Regan (2009; 2010) and O'Connell (2016) have found.

Weiner (2001), similar to Kelly (1963) references the analogy of scientific practice in respect of human understanding and distinguishes between the motivational impact of intrapersonal and interpersonal attributions. This is an important distinction which explicates whether phenomenon generates internal (personal) or external (system or others) causal attribution. In education such distinction resonates with the sense teachers make of behavioural and learning difference. Equally it is pertinent towards how difference is rationalised within the wider network of legislative responsibilities, particularly Inclusion and Equality legislation.

In working practice nevertheless, the factors impacting on attribution are found to be complex as Roig's study indicates (2011), finding expectation as much as attribution impacted on reception and response to children with mental health issues. Notably this was also interlinked with conceptions of professional efficacy, belief in coping ability and length of service. It is however worthy of note that Roig's study assessed expectation along the indices of self-control and co-operation and found that expectations were lower in relation to children considered to hold EBD.

It would be improbable to suggest that all human exchange occurred within an equal relationship, indeed it may be said that all human exchange is not only concerned with meaning, but with positioning. A vying for the most prominent position to enable your own perspective or needs to be recognised and acted upon. Notably the miniature of human exchange is often lost within grand theory, or understated, an essential pawn to structure and structural forces. Positioning theory is suggested to accommodate both the macro and the micro, as such was embraced as an important way to understand the complex dynamics that accompany the interrelations inherent in and out of the school context.

Positioning theory (PT) was primarily developed within social psychology by Davies and Harre (1990) to explicate the dynamics of human relationships within a social constructivist paradigm. It acts as a pertinent guide to the exploration of everyday social interaction particularly in respect of dominance or subordination. PT is also mindful of the influence of pre-existing positions and structure within engagement, not least the (social) positions available to an individual, as such it is considered to build on the previous relational philosophies outlined. The notion of human agency is primary as Tirado (2007) emphasises, stating 'the individual is considered an 'active hermeneutic being with agency and implicated in each one of his social acts is the destruction, reproduction and creation of social order' (Tirado 2007 pp.2). Positioning theory thus frames a discursive impression of the social world, extending across contexts but equally constitutive in all domains.

Notably Harre (1999) acknowledges social and individual multiplicity, stating 'the concepts of positioning and rhetorical reconstruction can be used to understand the creation of different social worlds as well as of the selves that inhabit them (Harre 1999 pp.11)'. Looking within the school context, it is suggested that Positioning Theory extends a philosophy which can respond to the many differing sub contexts operate within any bounded social context (Benjamin 2002, Black-Hawkins 2008). Such contention does nevertheless infer that any notion of contextual or social communality is undermined. Notably Harre defines this contention stating that the idea of social worlds can be summed as 'a network of interactions framed within a relatively stable repertoire of rules and meanings' (Harre 1999 pp 11). It thus resonates with Bourdieu's (1980) concept of 'habitus' (pp 53-56), although it may be suggested that Positioning theory is perhaps less developed than that of Bourdieu, as it lacks sufficient explanation of the mechanics of status, nor does it fully engage with the notion of capital. Positioning Theory does however offer a frame from which to explicate social relations at both the macro and micro levels of engagement.

In working practice Positioning Theory is also a useful template to visualising why certain knowledge enters into the popular and professional consciousness and others does not as Jasanoff (2004) illustrates, stating that 'science and technology account for many of the signature characteristics of modern society [and represent]... the reduction of individuals to standard categorisations that demarcate the normal from the deviant and authorise varieties of social control' (Jasanoff, 2004 pp 13).

Unpicking this statement it appears implicit that the ownership of knowledge exceeds

the concept of intellectual property, but is harnessed for unstated gain, as such resonates with Foucault's (1981) exposition on the nature of discourse.

Looking at the nature of my research foci, Positioning Theory offered means to explain the interactional dynamics that are implicated in school engagement. In particular Positioning Theory may be considered a theory of motivation, which posits that human engagement is by nature competitive, directed to the attainment of the most favourable position. This visualisation offers a generic frame of human motivation and in particular offers an alternative motivation for parental decision to seek medical explanations for a child's differences. Such a visualisation urges honest reflection of the reasoning behind a parental embrace of a medical model, which by its nature raises uncomfortable questions. Equally looking at the relationships fostered between teachers and families, Positioning Theory invites a deeper interrogation of the motivations which underpin exclusionary discourses between schools/teachers and pupils. Equally it invites address of the motivations which lend toward accountability discourses for some presentations of disability and not others.

Finally it is necessary to rotate this line of questioning inwards to my own motivations for conducting this research, not least because the process of research is itself stated to be a primary means of knowledge production, one which aspires to objectivity, or at the very least reflexivity, but which from a Positioning Theory stance is also motivational and directed to personal/professional advantage. It was therefore important to consider such motivation and to consider what if any distortion this may have for the research findings. Positionality is said by Gregory (2009) to be embedded within the research process, from inception to conclusion. 'The fact is that a researcher's social, cultural and subject positions (and other psychological processes) affect, the questions they ask, how they frame them...their relations with those they research in the field or through interviews, interpretations they place on empirical evidence, access to data, institutions and outlets for research dissemination, and the likelihood that they will be listened to and heard' (pp 556). Gregory's caution also emphasises that even though the researcher may hold an affinity with his/her respondents through social group membership or common experience, the role of being a researcher changes this dynamic and introduces wider motivations and positioning intent, which may not necessarily be compatible with those pursued as a member of the community being researched. The employment of Positioning Theory within this thesis was therefore considered to hold

a wide application to inform the research foci addressed, impacting not only at an explanatory level in terms of analysis, but also guiding the integrity of the researcher role as well.

4.2.2 Insider research – seeking a definition

Looking more closely at the notion of insider research, certain issues emerge which at face value appear uncomplicated, yet when unpicked gather a complexity which is not always easily resolved. These surround the definition of insider research, as well as the methods strengths, weaknesses and aligned ethical implications which are implicated in its usage. McNess, Arthur and Crossley (2015) suggest 'being inside or outside is often part of everyday language and consciousness' (pp 300), nevertheless in the research field, the notion of being either an 'insider' or an 'outsider is problematized. These issues have attracted significant debate, resulting in a body of thought which asserts that the practice of conducting research makes either categorical position untenable. As such has prompted a stance which maintains 'insider researchers' occupy a liminal position between the two poles, which makes any absolute distinction untenable (Kanuha 2000, Narayan 2000, Mercer 2007, Kerstetter 2012, Pollack and Eldridge 2015).

Indeed as one continues to probe this issue toward my own position, I find any resolution hard to achieve. For example how close do you have to be to make claims to being an 'insider'? Costley, Elliot and Gibbs (2010) looking toward the work context, suggest insider researchers draw upon the shared understandings and trust of their immediate and more removed colleagues with whom normal social interactions of working communities have been developed (pp 1). However this implies a very level and equal working context which is unlikely to be realised in working practice. Similarly as a parent, can I really have confidence that I share sufficient commonality to claim insider status?

It is thus important to ask to what extent familiarity can confer insider status, or whether there needs to be a deep experiential empathy to claim such status. At a base level Narayan (1993) challenges the binary of native versus non-native and whilst acknowledging the role of anthropology towards the formation of ethnographic research, states that the days where there was an assumed unchallenged native and an objective researcher are gone. It is thus as problematic to claim to be an open minded outsider (objective status) as it is to be an insider. The issue of insider status

continues to allude any definitive answer, although at a philosophical level, it may be said to link most closely to ontological assumptions (as addressed in section one) about the nature of being and the nature of the collective. Its resolution therefore may reflect ontological assumption as much as actual positioning.

The dichotomy of insider – outsider is further problematized by McNess, Arthur and Crossley (2015) who state that in an age of rapidly expanding technologies, the old divisions between group membership are less defined, as such it is necessary to explore the possibility of a third liminal space that resides on the boundaries of between ‘worlds’ (pp 295), where group memberships meet. For as McNess et al argue, technological developments are resulting in ‘increasing access to real-time communication technologies, new understandings of identity and community, changing modalities for collaborative work and increasing global mobility for researchers and students all call for a more complex understanding of the relationship between the researcher and the researched and the ways in which all involved might situate themselves as ‘insiders’ or ‘outsiders’—or both’ (pp 297).

This position contrasts most markedly to the stance of Merton (1972) who proclaimed the divide between approaches represented distinctly separate doctrines, predicated upon objectivity of outsider researcher and deep empathetic knowledge of the insider researcher. The heritage of ‘insider’ research may be traced to the field of anthropology and in particular to the work of Malinowski (1922). Malinowski maintained that it was insufficient to observe a culture, rather in order to ‘know’ a culture it was imperative to view it from the inside, to see it as insiders do, a practice which he referred to as going native. Narayan (1993) makes distinction between anthropologists and native anthropologists and in doing so, frames inadvertently an important distinction between insider and outsider research as is illustrated below.

‘Those who are anthropologists in the usual sense of the word are thought to study others whose alien cultural worlds they must painstakingly come to know. Those who diverge as ‘native’, ‘indigenous’, or ‘insider’ anthropologists are believed to write about their own cultures from a position of intimate affinity’ (pp 671).

Indeed it is the notion of ‘others’ which is key to the insider/outsider quandary, not least in respect of considerations and the degrees of distance that determines membership or outsider status. Notably the ideal of the objective social researcher, decoupled from any historical or contemporary social situatedness has been formative to the establishment of a social science (Mills 2001) and retains a contemporary significance (Hamersley 2008), although its certainties are destabilised

(Greenbank 2003, Abrahams 2008, Gewirtz and Cribb 2006). It would however appear that the insider/outsider debate personifies historic social science debates about the nature of social science and the research role within it.

As this research is underpinned by an analytical autoethnographic approach, it is also useful to question the extent to which insider research is it the same as autoethnography. Or whether subtle nuances demarcate one from the other. It is indeed a division that lacks a clear definition and this served to perplex me during my research for this section. I was (and in a sense remain) unclear as to any exact distinction, particularly as insider research is stated to take on various stances. For example standpoint research, which Pollack and Eldridge (2016) describe as 'research which claims that one of us has a more accurate, legitimate, or "objective" view' (pp133) and may be suggested illustrative of Foucault's (1981) observation of how discourse acts to make claims to truth.

Insider research is also associated with work based research and again may be seen to infer a commonality which may not be entirely realistic in practice. For example, Costley, Elliot and Gibbs (2010) state 'when researchers are insiders, they draw upon the shared understandings and trust of their immediate and more removed colleagues with whom normal social interactions of working communities have been developed' (pp 1).

Kerstetter (2012) adds to this debate and suggests that the degree of insider status resists simple definition; rather it alludes to a grey area between the status of insider and outsider. Notably it is further stated that this continuum attracts commonly both strengths and weaknesses, intimating that their commonalities may be greater than the differences which are said to demarcate them. In conclusion I determined it most practical to visualise insider research as a broad research approach: within which autoethnography can be visualised as a particular derivative of it, in the same way participant observation (Jorgensen 1989, Atkinson and Hammersley 1994, Spradley 2016), or action research in education may also be seen to be (Baumfield, Hall and Wall 2012, Vincent et al 2016).

The ongoing debates which pertain to this genre of research cast doubt about the ability to ever fully achieve insider status, even when that research is conducted amidst family. I reached this conclusion whilst thinking reflexively about my parenting experiences and the extent to which my adult eye may interpret events differently to

that of my children. Equally I wondered whether the passing of time might also alter both mine and my children's perspectives, again intimating claims to being an 'insider' contextually situated in the present. Looking at my status in regards to the respondent families, I was also undecided as to whether I could claim insider status in regards to all my respondents, or whether it was more realistic that I would hold commonality with some respondents more than others, as Reay (1996) herself observed. I now intend to explore in more depth research dilemmas which are known to problematize the insider approach, although many of the finer nuances of issues pertinent to this research, are considered in greater depth in my discussion of autoethnography as a discrete method.

4.2.3 Insider research dilemmas and commonalities

Outsider research is considered the gold standard for researcher objectivity, nevertheless the capacity for objectivity is problematized within social research generally and aligned with the philosophical premises adopted by the researcher (Duberley, Johnson and Cassell 2012). Dwyer and Buckle (2009) suggest the role of the researcher and the need for a reflexive stance is primary, irrespective of insider/outsider status and is a central safeguard to assess the integrity of the research process. The need for reflexivity links to debates around researcher objectivity and the visible situating of the researcher in the research process. There are longstanding concerns that assert objectivity is unrealisable; as such call for a transparent appraisal of biases held (Rose 1985). These concerns remain contemporarily significant as Berger (2015) cautions:

'Familiarity may enable better in-depth understanding of participants perception and interpretation of their lived experience in a way that is impossible in the absence of having been through it. However, at the same time, the researcher must remain constantly alert to avoid projecting own experience and using it as the lens to view and understand participants experience' (pp 230).

Berger demonstrates practically following an unanticipated shift in personal circumstance, how nearness or distance from the research context impacts on what is asked (research foci), recorded (data received) and deduced (analysis). In doing so Berger illustrates the necessity for ongoing reflexive awareness, particularly when conducting research over time. The idea of shifts in insider/outsider status held particular relevance for my research, not least because at the time of data collection I had faced many crisis with my sons, but not the worst crises I was (unknowingly) to face. Additionally during analysis, during the process of looking back I was again

differently situated, yet the combined points of proximity impacted on the observations and deductions made. Hence throughout the process of my doctoral research I held various proximities to what might be termed by my research participants to be an insider. It is therefore pertinent to heed Berger's caution that 'the researcher's position may be fluid rather than static, and it inevitably affects the emic-etic balance in the research project' (pp 231).

Kahuna (2000) offers a distinction between emic and etic positioning; describing the former as a 'subjective, informed and influential standpoint', contrasted against an emic standpoint which is typified as 'more objective, distant, logical, and removed from one's project' (pp 441). Developing the implications of this distinction further Kahuna suggests that whilst proximity might be key factor in the decision to engage in a project, it cannot shield from the wider challenges innate to insider research, not least the need to retain an awareness of how one's own knowledge may direct or distort that of the respondents.

Pollack and Eldridge (2016) assert that 'participatory models of research require a willingness to critically examine power within research and scholarship, led by the contention that academic knowing is only one way of knowing, not the way of knowing' (pp144). Polack and Eldridge's comments conjure uncertainties as to the extent a researcher, from the inside or not can really claim to know 'how' anyone else understands a given phenomenon or person. Drake (2010) suggests that closeness can impede ability to see the bigger picture, recommending therefore the necessity of stepping back from the insider role and viewing the data from a greater distance.

Dwyer and Buckle (2009) recommend stepping outside of the dichotomy of insider/outsider to explore the space between that allows researchers to occupy the position of both insider and outsider, rather than insider or outsider. It is also suggested that that irrespective of researcher role (insider or outsider) 'the personhood of the researcher, including her or his membership status in relation to those participating in the research, is an essential and ever-present aspect of the investigation' (pp 55) due to the researcher's centrality in respect of design and analysis. Such position was considered highly pertinent as it is necessary to consider the extent to which being a researcher reduces the bonifide claim to insider status. Equally it emphasises that group membership is liable to be founded upon multiple membership criteria which intersect to produce a communal commonality. Therefore

the assumption of insider status, may be more in the mind of the researcher than the eye of the respondent.

These concerns reinforce Burrs (1995) contention that constructionist philosophy viewed research as collaboratively produced, rather than claiming any pure correspondence to what is. Alverson's (2008) guide to reflexivity thus presented a useful strategy to address some of the concerns toward reflexivity and bias. Although Alverson offers four strategies to guide reflexive practice, it is the concept of multi voicing which is of greatest utility to the issues at hand. Multi voicing practices affirm the centrality of the researcher within the production of the research, stating influence and laying bare the negotiation process inherent between researchers and researched, irrespective of insider/outsider status.

4.2.4 Insider research - swings and roundabouts

From a pragmatic perspective Kerstetter (2012) finds insider knowledge to be both an asset and disadvantage. Stating that although insider status may enable a more finally nuanced appreciation of the research context and offer both ease of access the facilitation of a deeper research rapport. Due to familiarity and commonalities, particular disadvantages offset these advantages. Firstly it is suggested that insider status, (familiarity) leaves the researcher vulnerable to complacency, whereby 'implicit taken for granted knowledge' is assumed and left unstated. Equally Kanuha (2000) suggests insider researchers may find it difficult, albeit necessary to separate their personal experiences from those of research participants, yet it is these particular junctures which hold greatest capacity for assumption rather than expressed opinion (Kanuha 2000, pp 442). Thus Kahuna states 'one must not assume that being an insider to a cultural group necessarily means that the insider researcher has intimate knowledge of the particular and situated experiences of all members of the group or that generalizations can or should be made about the knowledge the researcher holds about her own culture' (pp 443).

Rogers (2003) and Cooper and Rogers (2015), add to this debate and find these effects heightened when insider status is conferred on the basis of familial role. In particular it is cautioned that the sharing of confidences could be misconstrued as friendship. Duncombe and Jessop (2002) refer to this as 'faking friendship', and state that 'equating the process of 'doing rapport' with trust, and failing to question the insincerity of 'faking friendship, exhibits a disturbing ethical naivety' (pp 110). When

engaging with parents, these cautions were foremost in my mind and to the best of my ability I attempted to impress upon my respondents that my empathy extended from shared experience, but this did not of itself equate to friendship.

A further area of concern detailed by Cooper and Rogers (2013) is that the insider role may inhibit inclination to expand on response details, through the assumption of shared knowledge. The sharing of common experience or role summonses responsibilities that exceed the typical boundaries demarcated between the researcher and the researched; not least because the sharing of personal experiences (as insiders are liable to do) fosters impression of an intimacy that may develop into a dependency. This has implications for withdrawing from the research field at the end of data collection. Intimacy therefore conjures ethical issues in respect of emotional damage to respondents. This dilemma has been stated most directly by Stacy (1988) in relation to the egalitarian claims of feminist ethnography. It is nevertheless equally pertinent to other forms of insider research as it emphasises the potential for emotional damage:

‘the irony I now perceive is that the [feminist] ethnographic method exposes subjects to far greater danger and exploitation than do more positivist, abstract and “masculine” research methods. The greater the intimacy, the apparent mutuality of the of the researcher/researched relationship, the greater is the danger’ (pp 21).

Stacy’s caution challenges the possibility of an equal relationship between researchers and researched, even where there is a commonality as foundational as gender and aligned social oppressions. Stacy alludes to the risks extending from intimacy and this caution speaks directly to the relationship boundaries that Cooper and Rogers (2015) have also found. The potential for inegalitarian exchange that Stacy (1988) identifies escalate when the research gaze is on the researchers own family, engendering a duality of role responsibilities which summonses tensions in relation to the rights of disclosure (when experience involves a vulnerable child/adult) and the impact of the research on self and family members in the longer term. Indeed to this I would add a further dilemma, that being how to record or write openly, if the content of writing has potential to cause emotional distress, or to project an unflattering image of or the family members concerned. It is at this juncture that a conflict of interest can most clearly be evidenced between the role of researcher and that of familial member, dividing loyalties that need to be reconciled before the research commences.

In address of these issues I was led in the first instance by my family's willingness to be present in my research; but such permissions were swiftly swayed by doubts. These are discussed in depth in subsection 4.3 and resulted in the presentation of key events without accurate attribution to the families who narrated to them to me. I describe this as blended narrative, because essentially I assimilated all the data and presented it in a manner that deterred any ability to piece together any one family's chronology. In essence I decided to privilege the 'what' of experience by compromising on the 'who'. In this way I was able to overcome many concerns around anonymity or future participant regret and was able to bring out of the margins the parenting realities of parents of children with behavioural differences.

A further avenue of concern is expressed by Bahn (2012), likewise Darra (2008) and Emerald and Carpenter (2015) and concerns the potential for emotional damage to the researcher, particularly where the research foci requires the researcher to revisiting personally difficult experiences, which may be compounded by the disclosures of respondents. Notably it is found that ethics committees rarely seek confirmation of the inherent risks to the researcher as the lens they adopt is focused on both the researched and the research aims.

These dilemmas add credence to the contention that an outsider status is less complicated and makes one more aware and able to look with a fresh eye, able to record what one sees. As Kerstetter (2012) highlights; objective reflexivity may be difficult where there is a blurring of the boundaries between the personal and the professional. Nevertheless Dwyer and Buckle's (2009) suggest that there are advantages to being able to claim commonality on the basis of experience, particularly in regards to notions of empathy.

Kanuha (2000) draws a helpful distinction between being and going native which is considered particularly useful for visualising the finer nuances of the insider role and indeed breaching the insider/outsider divide. Not least because although insider/native research involves 'conducting research with communities or identity groups of which one is a member' (pp 440), there is uncertainty about the impact being a researcher has on group membership status, as Kanuha states 'the insider is no longer just another native when endowed with the credentials to study natives' (pp 444). Equally, the idea of being a native, an insider, may itself be overly simplistic, as it relies upon the ideal of non-hierarchical group equality, which has been in relation to the disabled population been challenged (Davis 2013). Kerstetter (2012) similarly

challenges the discreteness of the binary and claims there to be a grey area between the status of insider and outsider. Indeed Kerstetter suggests that there are very few occasions when one might be viewed as a complete insider or outsider given the fluidity and often ill refined nature of group membership. This is a pertinent point, particularly when one considers Davies (2009) and Holt (2013) visualisation of overlapping group memberships, whereupon the notion of discrete group norms and cultures are problematized.

Pollack and Eldridge (2016) question the representativeness of a standpoint position, even when the reporter claims insider status. Standpoint according to Pollack and Eldridge implies that the person observing and reporting 'has a more accurate, legitimate, or "objective" view' (pp133). Such claim hints at a direct power disparity, raising questions in respect of the extent to which an insider can, (or should), claim the others voice or perspective. For example as a mother of disabled children, do I share an absolute commonality with all other mothers with disabled children, or perhaps only those who share similar difficulties? Certainly the parents who engaged with me shared similar experiences, but there was also a lot which divided us. I was the only one conducting research and actively using personal experience to guide my research. As a result does insider status reside upon a balance of differences versus sameness? Nevertheless the practicalities of a multi-voice approach may be equally problematic, as it relies on idealised notions of putting multiple 'perspectives in conversation with one another' (pp 133). This too conjures wider address of whose voices, if it is everyone, how are voices balanced and disputes reconciled and who makes those judgements? These considerations had no absolute resolution, but did necessitate vigilance, hence during the final write up of my research I revisited my motivations for highlighting some stories over others, concluding that the justifications were academic and relevant to the research foci, rather than based on any personal preference.

A further consideration is raised by Taylor (2011) and addresses the implications of friendships that precede the respondent role. They note that even where research is conducted with close friendships, the output (what is chosen to be revealed by the researcher) is inevitably partial and a matter of interpretation (Taylor 2011). Taylor introduces the notion of 'insider blindness' (pp 11), relating it to the inevitable taken for granted knowledge inherent to any close relationship or membership. Notably

tensions are identified between the responsibilities of friendship and those of the researcher role, which impact on what is and can be said.

It would appear therefore that the benefits of intimate knowing are offset by the ethical obligations to protect and respect a close friendship. Taylor's cautions are pertinent to my research and it was indeed a prime decision to decide what I could share and what I could not. Nonetheless, in regards to partiality and interpretation, it is suggested that an autoethnographic approach can circumvent some of the identified difficulties as the lens is both focused on the personal and narrated by the personal. In this instance my accounts are framed from the maternal perspective as I observed events, they cannot however be seen to reflect the experience or opinions of my children. Further practical issues identified by Taylor (2011) include knowing when a confidence shared is on or off the record as well as an inevitable strain on existing friendships (implicated in the research). This conjures a costs benefit equation; particularly as there is uncertainty as to the extent a genuine friendship can be sustained where there is a duality of role.

Taylor's further cautions that embeddedness within a group or culture may make the researcher less than objective about any emergent critiques, which is suggested to blinker analytical capacity, equally Taylor cautions, 'friend' respondents may write to please (pp 11). As a consequence Taylor emphasises the necessity of 'unlearning the familiar' (pp 16). Although unlearning the familiar appears the antithesis of insider research, its practice offers to maximise the data richness insider research provides, whilst minimising the inherent risks of researcher complacency. Taylor (2011) notably denies any prescriptive formulae for addressing these dilemmas, stating that 'such encounters in the field will always be personal and partial, dependent on a great number of factors that cannot be prescribed, measured, calculated, estimated or anticipated prior to the engagement (pp 18). Such contention calls for not only an empathetic engagement where the boundaries of the personal and professional merge, it also demands stringent reflexivity.

Looking back although there is no absolute definition of insider research to draw upon, there are common concerns and cautions applicable across the spectrum of social research, in addition to those which pertain to the particulars of the insider approach (Rogers 2003, Bahn 2012, Emerald and Carpenter 2015, Cooper and Rogers 2015). The following subsection addresses these issues as they pertain to autoethnography as a method of research. It is therefore appropriate at this juncture

to end this section with Merriam and Tisdell's (2015) caution that human perception is highly subjective and as such is an inherently unreliable basis from which to make claims to truth whether as an insider or an outsider.

Such caution brings into question just how confident the knowledge claims of the social sciences can be; a concern which echoes the philosophical debates previously identified in subsection 4.1. In particular human capacity to make meaning holds irrevocable ramifications for objectivity and ability to represent phenomenon unfettered by subjectivity. Thus the expansion of insider research within the social sciences is a welcome step toward a redress of the dilemma of representativeness. It does nevertheless necessitate caution, both in terms of how inside one can ever claim to be and how objectively one might claim to view a research foci.

Essentially the integrity of research claims, stand or fall on the researchers own ontological position and whether research output makes claims to truth, or aspires to further understanding of experience and perspective. Practically nonetheless, the combination of being an insider and a researcher is a powerful research approach. It enables intimate (insider) knowledge to be used to extend (professionally) an identified research foci. Thus even though the merging of the personal and the professional may hold many cautions, equally it is reasonable to suggest it also holds latent checks and balances. Firstly through loyalty to the group to which membership is claimed and secondly, through the ethical protocols that are implicit to the research role, of which reflexivity is a central means. This section now proceeds to an address of autoethnography, its origins and forms, followed by a defence of the adoption of an analytical approach to found my research.

4.2.5 Autoethnography – a broad ranging method

Although autoethnography is classified as a discrete methodological approach, there are broad parameters of application which impact on focus, scope and ambition. It is necessary therefore to consider the range of approaches contained within the broad remit of autoethnography. Within my research I adopted an analytical autoethnographic approach: analytical because it draws upon the personal and interrogates and tests that experience and knowledge in the wider domain, focused upon 'improving theoretical understandings of broader social phenomenon' (Anderson 2006, pp 373). As analytical autoethnography broadens the research scope of the method through its ambition to extend from data derived from the self

toward an analytical analysis of the wider context, one might reasonably question whether such approach is actually autoethnographic. In answer there is no absolute definition to act as guide, most specifically because as a research approach, autoethnography is an emergent method (Sikes 2013). Although the adoption of the autoethnographic method has resulted in a broad interpretation of approach, there is a common emphasis on particular methodological aspects, in particular detailed description, analytical capacity, evocation of emotion and self-narrative (Anderson 2006, Ellis 2011, Pace 2012, Polczyk 2012). To offer contrast between these differing applications of the method, they may be crudely differentiated into two main approaches, evocative and analytical autoethnography and are described more fully in sections 4.2.7 and 4.2. 8.

Notably Denshire (2014) whilst acknowledging such binary, argues that there are other equally valid means of employing the method, particularly through accounts of professional practice. Employed in this manner autoethnography is stated to hold scope to be emancipatory, able to disturb and expose power relations (Denshire (2014). This potential counters some of the fundamental concerns levelled toward insider research, not least, claim that insider research tends toward partial observation and is complicit towards processes of othering (Taylor 2011). To the contrary Denshire maintains 'embodied autoethnographic accounts of professional practice in health and disability studies ... can reconfigure power relationships, opening out disembodied renderings of experience and remaking practice interactions' (pp 840). Looking at my research foci, an autoethnographic approach employed from a practitioner stance, holds scope to elucidate, not only pedagogical decisions and assumptions made, but also the 'natural attitude' (Schutz 1973), which I suspect is where the roots of exclusionary discourses reside.

Given the concerns surrounding how inside, insider researchers are, as well as the potential for distorted representation, it may be suggested that autoethnography is as close to insider status as it is practically possible to be. Autoethnography is also considered a method which can elucidate complex relational dynamics. Sikes (2013) states, 'autoethnography can provide a means of challenging traditional, hegemonic, and imposed power imbalances by creating a space for people (as individuals, as possessors of particular social characteristics, as members of certain socio-cultural groups) to describe their perceptions and experiences and to express their views,

beliefs and values, rather than being re-presented and interpreted by others, as has tended to be the case' (Sikes 2013, pp, xxv).

Ellis (2011) likewise contends that autoethnography exceeds simple description, stating rather it 'seeks to describe and systematically analyse personal experience' expanding beyond the scope of simple narrative or description (pp1). Allen (2011) extends this position stating that the autoethnographic approach differs from a layperson's introspective as 'what makes your story more valid is that you are a researcher, you have a set of theoretical and methodological tools and a research literature to use' (Allen cited in Ellis, 2011, pp 3). Certainly this sentiment resonated with my own employment of autoethnography; I felt it to be insufficient to simply tell my story, I wanted to develop a theoretical understanding of the experiences faced.

Autoethnography is a derivative of insider research', which through introspective focus on the personal, extends access to areas not always amenable to other forms of inquiry. Notably because autoethnography has evolved within the evocative tradition (Ellis 2004), it is situated in uncharted territory; straddling the arts, literature and social science. It thus commands a marginalised status within the field of research methods (Delamont 2007) and as (in research terms) fairly new approach, autoethnography may be seen to be grappling with identity issues which has fostered debates about direction and purpose. Anderson (2006) calls for a move from introspection to projection, proposing an analytical approach as an alternative to evocative autoethnography. Drawing upon the traditional Symbolic Interactionism tradition, Anderson cites three core criteria to define the analytic approach, these being that the researcher is (a) a full member of the research group or setting, (b) visible as such a member in the researcher's published texts and (c) committed to an analytical research agenda focused on improving theoretical understandings of broader social phenomenon (pp 373).

4.2.6 Origins

The ethnographic tradition is well established in sociological research and has its origins in the field of anthropology. As Anderson (2006) states 'there has always been an ethnographic element in qualitative sociological research' (pp 375), most infamously but not exclusively as pursued by Park and the professional collective known as the 'Chicago School' (McKenzie 1924, Park 1925, Burgess 1967).

Whilst the Chicago school were also instrumental in moving social science attention from a deterministic stance to focus on the micro dynamics of social life. The tendency to the autoethnographic method emerged through the foci of what is termed the 'second Chicago school' (Fine 1995). This approach signalled a refined appreciation of the dynamics of human agency and structure, most specifically in the areas of meaning making and the legitimation of such meaning, as informed by the work of Mead (1934) and the early period of symbolic interactionism.

4.2.7 The contribution of evocative autoethnography

Evocative autoethnography developed from the observational traditions of anthropology and the methodological principles of reflexivity and stands proudly as a distinct genre within the social science field. Reed-Danahay states 'autoethnography stands at the intersection of three genres of writing...native anthropology, ethnic autobiography and autobiographical ethnography' (in Sikes 2013a, pp 5), although autobiographical ethnography most closely resembles the evocate approach. Looking toward the contribution of the evocative approach, it may be said that the privileging of emotions within social science (as integral data) has led to an increasing recognition of the complexity of social life and the need to adjust research methods to reflect this awareness (Game 2001).

Law (2004) extends this foci and refers to the world as multi-textured; stating that emotions are embedded in social life, presenting 'unpredictability's rarely caught by social science methods' (pp 2). An increasing awareness of social and emotional complexity demands address of how much social scientists can know or record outside of individualised experience and sociohistoric frame. Thus although evocative autoethnography privileges each experience as unique, through their record, particular types of lives are rendered visible. Problematically, Medford (2006) states that people experience multiple co-present realities and tend toward a selectivity of account; these are termed 'mindful slippage' and deny the potential for accurate record, even a first person account.

Addressing this issue, Bochner (cited in Medford 2006) suggests partiality alters the objectives of the autoethnographic account; leading it to seek 'extraction of meaning from experience, rather than to depict experience exactly as it was lived' (pp 853).

Evocative autoethnography can also offer detailed and insightful account of lives lived, lives that are not always available for external research Walford (2004)

challenges the dominance of generalisability as a meter of research integrity and suggests ethnographers should not aspire to generalisability, but should focus on the integrity of insight. Such contention suggests that the employment of ethnography must be legitimated on the 'goodness of fit' of method to research foci (Duncan 2004), which ultimately remains the preserve of the researcher and research commissioners.

4.2.8 Analytical Autoethnography – strengths and weaknesses

Anderson's (2006) expresses ambition for the development of autoethnography to exceed the very personal nature of the evocative approach, which is stated by Anderson to be stifling of its latent potential. Anderson's vision for analytical autoethnography repositions autoethnography from an introspective individualised account, to that which extends in its interrogation practices from the personal to the public domain. In practice, the autoethnographic account is subject to reflexive analysis and managed as data like any other, which is then employed to guide further investigation into a given research arena. As a result, analytical practices are comparable in constitution to other methods which rely solely on external data sources (Anderson 2006).

The analytical autoethnographic method can be seen to be congruent with Bourdieu's ambition for reflexivity in the social sciences, stated to 'enable those who do science, to better understand the social mechanisms which orientate scientific practice' (Bourdieu 2004, pp viii). Looking at my research, the need for reflexivity was both obvious and obscured; necessitating not only an analysis of my own challenging experiences, but also it required me to view the key events I identified from the perspective of the other, most typically the aligned parties involved that I considered to be discriminative. The duality of this practice did nevertheless hold potential to reveal latent tensions which may have had a directive effect on other parties responses, thus enabling in principle a profile of cause and effect to be compiled.

Equally the address of a research foci from a first person perspective can elucidate social position, social identity and the assumptions upon which knowledge is produced. Looking toward my research; the assumptions I identified were firstly that I considered my children were entitled to an education, secondly that the medical labels given to explain their differences exonerated them from personal blame, where the actions attracting of blame could be reasonable viewed as symptomatic of their

disabilities. Taking the perspective of the other parties involved however, emphasised to me that these assumptions were not always shared and thus summonsed questioning as to why.

Vryan (2006) whilst endorsing calls for the advance of autoethnography as a credible research method, cautions that Anderson's efforts to bound criteria and stages of operation, may in fact be unduly restrictive, blurring autoethnographies identity as a discrete method. Vryan also takes issue with the undue emphasis on the previously acknowledged duality of approach, stating it to be 'unnecessary and counter-productive' (pp 407). Vryan concludes that the defining feature of the autoethnographic method is its ability 'to enable access to vital aspects of human experience that cannot be accessed using other available methods' (pp 407). This Vryan states is what should establish its identity and approach, not formulaic stages.

The unique access Vryan emphasises is practically illustrated by Bridgen (2007), who attests to the utility of the methods application to elucidate previously untold aspects of polio and Holocaust survival. I suggest therefore that insights accrued as a parent of children with challenges has, through a professional background, enabled questions to develop that have been only partially addressed in the course of more traditional third party research. Polczyk (2012) extends this sentiment and states that autoethnography widens the research field, as it extends 'a viable method for researchers who must overcome physical and/or cultural obstacles associated with disability' (pp 175). I considered this a particularly pertinent point, as despite the influence of feminism, there remains a scant representation of particular groups of women, particularly mothers of behaviourally challenged children', or dedicated research into the circumstances of their parenting realities. The concept of 'Visceral Verstehen' is particularly relevant at this juncture as it supports the methods ability to be guided by the personal, but not bounded by it. As Glass (2005), asserts, there is a need for appreciation of both 'sociohistoric circumstance' alongside the need to "re-live" the experience(s) of that other' (pp1) and it is notable that such guidance, resembles in practice the steps previously identified as necessary to implement an analytical approach.

Delamont (2007) has led an extensive critique toward autoethnography as a credible research method, stating that it is not as rigorous a method as other traditional social research methods. This critique, framed around six main points of contestation are addressed specifically in relation in the following subsection, yet can be defended

more broadly through emphasising that in implementation, autoethnography requires a high degree of introspection and dedication, not least to defend the method. It is reasonable therefore to infer that researchers engaging with this method have a commitment to the integrity of their account. It is however also fair to acknowledge that Sikes (2013a) alludes to the existence of poorly constructed accounts within the autoethnographic field. Nevertheless according to Sikes these are insufficient to devalue the method per se, as the same variability of standards are likely to be found in any research tradition and as Sikes emphasises, there are a greater number of examples of high quality autoethnographic research projects which serve to affirm the method.

4.2.9 A defence of analytical autoethnography

Delamont (2007) contends that 'autoethnography is essentially lazy – literally lazy and intellectually lazy' (pp 1), stating further that 'autoethnography is antithetical to the progress of social science, because it violates the two basic tasks of the social sciences, which are: to study the social world... and to move their discipline forward (ibid, pp 2). Toward a practical defence it is useful to outline the six broad objections Delamont raises and consider their caution against the methods specific usage within this thesis.

(a) Autoethnography cannot fight familiarity: In my research using personal experience to identify and explore a research field strengthened my determination to objectify the research arena and to problematize the familiar. In so doing it prompted me to de-construct events that were familiar for research purposes. Autoethnography in such instances holds potential to make a familiar context unfamiliar and in doing so may reveal research connections obscured from the personal.

(b) Autoethnography is almost impossible to write and publish ethically: many of the situations endured by myself and by my respondents have been life changing, producing changes (in emotive terms) that are of little research consequence outside of speculative interest. Nevertheless, in addition to their emotive impact, these experiences have also offered significant insight into procedural and structural processes that operate to disempower and indeed discriminate against young people and their families, particularly where disability impacts on behaviour in the school context.

Being immersed in the academic field, I considered it significant academically to write of significant events shared, using those events to make academic connections and a tentative explanation for the life events shared. I wanted to draw reference to the wider field of parents and teachers without compromising unduly the persons who were central or implicated in the data generated. Most specifically as I discuss in relation to ethical concerns in the following subchapter and also in relation to narrative in subchapter 4.4, there were issues of potential exposure which threatened to make my research impractical. In resolution as I discuss I decided to blend familial accounts (including my own) of key events, to guard against any identity breeches through chronological history, in the immediate and longer term for my respondents and indeed my own family.

(c) Research is supposed to be analytical not merely experiential: as stated previously, my approach has been to critically interrogate the experiential and reference it against the wider field, to test for similar experiences and ultimately explanation. In this way I developed a research initiative which could be described as being led by insider personal knowledge and developed using professional research skills, including an awareness of the broader academic terrain. In this manner the autoethnographic method employed was both experiential and analytical.

(d) Autoethnography focuses on the powerful and not the powerless to which we should be directing our sociological gaze: although it is acknowledged that as a doctoral researcher my voice has a clear [albeit competitive] channel of communication, it is questionable as to whether that assumes the status of powerful. Certainly throughout the duration of the parenting experiences referenced within this research, there was little power accessed. Indeed any parent of a volatile disabled child exists as a hostage to fortune and by necessity is responsive to the decisions and propensities of others. My research endeavoured to utilise these experiences, to generate meaning from what at times has resembled chaos. In doing so it has been possible to use such experience and to interrogate it in the wider domain, referenced against my wider educational and sociological knowledge.

(e) It abrogates our duty to go out and collect data: to the contrary, autoethnographic data was the beginning and not an end in itself. I likened it to a virtual map, whereupon personal experience provided the co-ordinates, which when referenced to wider literature and research, enabled these co-ordinates to be joined in a manner that was theoretically and methodologically principled. My personal account is

contrasted against received data generated from a previous research study (as detailed at 1.4), as well as multiple respondent groups, and observational data drawn from two lengthy placements. I was therefore able to triangulate my data, to strengthen the conclusions drawn.

(f) We are not interesting enough to write about in journals, to teach about, to expect the attention of others: such sentiment could be applied to many sociological research projects and is a judgement best conferred by the reader. In relation to this thesis, my personal observations have been tested against the contemporary field and appear to offer insights whether entertaining or not. Igniting an avenue of enquiry as valid as any which may have been sourced solely from a systematic literature review. The personal in this thesis has introduced an additional research step into the process, one which is most likely to be present in any research endeavour but lacks open stating. In conclusion any subsequent interest within the academic context will undoubtedly accrue from wider disciplinary involvement, this does not require sensationalism, simply honesty and appropriate referencing.

4.2.10 Considerations and practicalities

Doing autoethnography involves retrospective narrative, encompassing ‘epiphanies that stem from, or are made possible by being part of a culture and/or by possessing a particular cultural identity’ (Ellis 2011 pp3). To move this forward however it is necessary to compare personal record against the wider public domain. Ellis (2011) states this involves using ‘methodological tools and research literature to analyse experience’, in order to make a ‘culture familiar for insiders and outsiders’ (pp3). Equally, the adoption of an analytical approach did not concede the emotional dimension, rather my intent was to embrace the emotional realities of the circumstances faced and embed them within the wider structural domain, as it is inevitably in everyday life. Indeed the impact of emotion is considered an essential component for social science to embrace, not least as a core factor underpinning social motivations.

The centrality of emotion and the uniqueness of account, is recognised outside of the field of autoethnography, for example Game (2001) states that ‘the human body is not simply human, through interconnectedness, through our participation in the life of the world, humans are always forever mixed’ (pp 1). Game also cautions that experiences are ‘lived, not in conventional Euclidean space and linear time – but in

relational or in-between time and space' (ibid). Such sentiment has been directive of what is known as the affective turn and I concluded that autoethnography as a methodological approach was compatible with this sentiment, particularly when implemented in conjunction a free narrative approach to collect wider familial data.

In the absence of a prescriptive method, the doing of autoethnography is problematized. Ellis (2011) draws a distinction between doing and writing autoethnography, defining it as both process and product (pp1). An analytic approach however is considered to embody this process across the personal and public domains. This conjures some specific considerations, not least that despite appearing to be an easy means of gathering at least preliminary data, in practice it was not. Living amidst quite extreme experiences, whilst simultaneously trying to step back and objectify them was a challenge in its own right. There was also a temptation to over analyse, led by emotion in the moment, not reason. My thoughts therefore were recorded as notes in the moment and then parked, subject to revisiting at a later date. This approach enabled a more calculated appraisal of data outside of the immediate crisis point.

A further dilemma surrounded having an autoethnographic approach accepted within my field of education. Personal input is common practice within some fields of social science, particularly disability studies (Sinclair 1993, Cousner 1997, Shakespeare 2006, 2008, Curran 2013, Shakespeare 2014) and gender and queer research (Jones 1993, Yu 2011). Indeed Miller (cited in Yu 2011) states 'feminism has made it possible to see the personal is also the theoretical' (pp 874). This is a sentiment which I felt was equally applicable to disability in education, but it is equally a sentiment less accepted in my field and this raised credibility issues within my host institution. There were also specific ethical implications associated with an autoethnographic input which implicated my children and is discussed in the ethics section of this chapter. Overall however, as a parent navigating the complexity of childhood disability within and outside of education, I needed to consider how much I was willing to (or could) share or draw upon. Equally I needed to consider the research implications of anything I chose to omit. These dilemmas were foundational to whether I adopted this approach. In resolution I determined it possible to share key events as depicted previously, though the blending of personal events with those of other parents. This enabled me to depict key events and their consequences in an open and candid manner, without undue compromise to any of the children or

families. Toward a more directed appraisal of the fit of my context with the analytical autoethnographic approach, I referenced my personal context against Anderson's five criteria which are stated to typify the analytical approach. These are discussed below and were found to affirm my use of an analytical approach to pursue my research.

4.2.11 Anderson's criteria for analytical autoethnography

(1) The researcher should hold complete member status: as a parent of school age children I hold complete member status of the school community, further as a parent of 'challenging' disabled children I also held a bonifide member status amongst the wider parental respondent grouping.

(2) Analytical reflexivity: at all stages care was taken to review the impact of the personal on how the research was conducted. Reflexive consideration of the impact of my situatedness, in respect of the research structure, engagement during participant observation and collection of returned data collection was made incrementally and recorded.

(3) Narrative visibility of the researchers self; the researcher's personal context was embedded within the projects structure and openly disclosed in communication with respondent groups. My own personal context is also embedded at appropriate junctures within the thesis.

(4) Dialogue with informants beyond the self: although at appropriate junctures personal details were alluded to, these did not detract or direct the data collection process, every care was taken to guard against researcher bias and respondents understandings, opinions and experiences were recorded without alteration to maximise their presence within the research.

(5) Commitment to theoretical analysis; as a PhD candidate, my motivation extended beyond self-discovery and was committed to the interrogation of the wider research field. An overall aim was to develop an understanding of the conceptual and legal rationalisations for the disadvantages encountered and practices observed. This reflexivity necessitated wider address of relations of power, meaning making and the interplay of structure and agency.

I considered the criteria set out by Anderson to be a good fit to guide a study focused on disability accountability in the school context, where the impetus for such foci was grounded in the personal from a maternal perspective. I believed an analytical approach would have the potential to breach the divide between the personal and the

professional. In so doing by definition, this demanded a critically reflexive stance that addressed many of the previously discussed reservations regarding the qualitative approach. Sparkes (2000) defines autoethnography as 'highly personalized accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding' (pp 21). I therefore believed that a marker of research success in my research would be the extent to which such experience could indeed extend the understanding of not only the guise of disability accountability, but its underpinning impetus.

Despite this approach being a sound fit philosophically and suitably accommodating of my research foci, it presented many ethical challenges, which although intimated previously are considered more fully in the following section in conjunction with wider ethical issues which pertain to the varied respondent groupings and the ambition for the research project as a whole.

4.3 Ethics

4.3.1 Introduction

This section comprises two parts; part one considers the remit of ethics in relation to the nature and purpose of social research and details the ethical frame adopted for this research. I then apply this frame and discuss the questions raised in relation to the research participants in this study (both those who engaged personally and those I observed). I draw upon a framework developed by Gorman (Gorman in Campbell and Groundwater – Smith 2007). This frame is grounded by the ethical principles of Principlism as refined by Beauchamp and Childress (2001) and underpinned by the standard ethical markers of autonomy, beneficence, non-maleficence and justice. These principles are measured through a risks/benefit equation, which practically translates to the demand for voluntary respondent engagement, in pursuit of purposes considered of (wider social) benefit, utilising a research design that is mindful to reduce risk and guard against harm. Part two considers the ethical issues inherent to insider researcher, it also addresses the particular ethical challenges which accrue from adopting an autoethnographic approach to write about mothering experience. Looking at resolutions part two introduces the reader to both the need for and the employment of blended narrative, as a means of circumventing some of the issues identified.

4.3.2 Part one – ethical issues in the wider field

Gorman's guidelines are considered by Campbell and Groundwater-Smith (2007) to have a universal applicability, stating that 'regardless of the context, whether in a classroom or a clinic the questions remain the same ... it is our response that might differ' (pp 18). The framework comprises nine generic questions, although Evens (2000) cautions that the principles underpinning these questions are a product of their socio-historic context and lack absolute ethereal properties. The ideal of ethical principles deriving from a communal morality is also questioned by Evans, who states that 'decision making systems...do not become influential because they are the best or correct, but rather because the social conditions are right for those promoting the system to defeat the champions of competing ideas' (Evans 2000, pp 31).

Such caution resonates with Foucault's (1981) contention that discourse is the primary means through which power is accrued, effected and perpetuated. Particularly if one steps back and considers the influence ethical committees wield in relation to how and what is researched. Such influence has been an impetus for Hammersley (2006) to challenge the legal right of ethic committees to veto research, stating that such power is an impediment to the creative agency of the researcher. Hammersley has also questioned the ability of the Economic and Social Research Council (ESRC) to make determinations effectively, given the rapidly evolving nature of qualitative research.

Although the address of ethical implications is a mandatory process common to all forms of research, it is notable that there is no standard schedule to guide or standardise the process outside of broad philosophical standards. It is therefore unsurprising that the issue of ethics may be shown to be a contested field within the social sciences, linked to the role and function of social research generally. It is therefore appropriate to allude to these ongoing controversies as their implications exceed the protection of those involved in the research process, striking to the very shape and boundaries of knowledge progression. Henceforth although I have chosen Gorman's frame as an ethical template; I am both aware of, and sympathetic to, calls for the tailoring of ethical guidelines to reflect the very different subject matter of the social sciences and the purposes for which research is conducted. In particular the issue of both the purpose of research and the utility of its output, resonates with my motivation and ambition for this research initiative.

Concerns surrounding the transferability of ethical principles from the natural sciences to the social sciences have led to calls for a new model of ethics, one which reflects the altered vision of the role of social research in the wider political and knowledge field. These arguments crudely coalesce between those that see research as a vehicle for social and political change (Lincon 1995, Denzin and Giardina 2007, Mertens, Holmes and Harris 2009) and those that view research solely as a vehicle for the furtherance and creation of new knowledge (Hammersley and Traianou 2014). Looking at this distinction I would situate myself in the former camp as my ambition remains the address of disability discrimination. Such ambition is found to be ethically compatible; for example Denzin and Giardina speak persuasively of the responsibility of the research role, aligning 'the ethics of research with a politics of the oppressed' (pp 35). Equally Hastrup and Elsass (1990) claim that 'the rationale for advocacy is never ethnographic' (methodologically based), 'it remains essentially moral in the broadest sense of this term' (pp 301).

This conjures question as to the extent to which research styles and genres should dictate ethical frames adopted, or whether the standard for ethics should be linked to deeper issues of morality and indeed what morality is. This unfortunately conjures deeper philosophical concerns which are beyond the remit of this address. Importantly the decision as to whether the goal of research is socially driven or directed to 'the creation of new knowledge' has implications in respect of priorities privileged within the compilation of an ethical frame and to what extent the ends justify the means?

In address, Denzin and Giardina (2007) call for an ethics of care, punctuated by a primary accountability to those who are the foci of research and which is responsive to wider emotive referents such as hope and love in respect of impact and risks. Such call is dismissed by Hammersley and Traianou (2014), not only through adherence to the stance that research should be value neutral, but from a practical consideration of its implications in implementation. Reviewing the feasibility of an ethics of care in relation to the key principles of justice and care, Hammersley and Traianou (2014) challenge its ability in working practice to meet the objectives it purports. Not least because the concepts of justice and care themselves lack an overall agreed definition and that their association over time has expanded to incorporate issues relating to the distribution (and redistribution) of power.

Practically Hammersley and Traianou state that 'researchers do not usually have the power to promote justice on any wide scale', nor are they 'in a privileged position to determine what would and would not count as justice' (pp, 6). Looking at my ambition for this doctoral research I would tend to concur, any impact I may hope to have is likely to be the result of an arduous process of raising the profile of my research and engaging with other academics more senior in the field to take the ideas forward.

Miller, Strier and Pessach (2009) inadvertently contribute to this discussion through suggestion that the research relationship is unlikely to be convivial to an unfettered influence. Not least because it is a dynamic and mobile engagement, where the balance of influence shifts between researcher and respondent during the course of research. In this manner the research process is neither neutral nor emotionally led by the vision of the researcher, rather it is collaboratively negotiated. Such interplay, speaks of a fluidity which may notably be seen as inherent to many qualitative approaches. Looking at my research context, such fluidity was evident from the beginning, I was reliant upon approval, respondent engagement and honesty.

Blackman (2007) notes that the ethnographic method is not a detached observation, but is influenced by emotions which often remain undisclosed, but which can have serious effects on both researcher and the researched. Such issues were highly prominent throughout the course of my research and emerge of issue in both sections of this subchapter. Notably as is detailed in part two of this section, emotional effects relating to the duality of role, conjure very precise concerns in respect of autoethnography and insider research.

Looking at the intent of research and whether research should be led by issues of social justice and the pursuance of human rights, raises major implications in respect of ethical regulation. Not least as the pursuit of social justice may itself open, rather than close, spaces for respondent abuse. In particular where research is goal oriented, there is a moral equation generated, comprised of the welfare of individual respondents against the social goals identified. Equally where the subject of the research involves the identification of need and also the goal of solutions, the research output is vulnerable to being presented as confirmatory of such need and also its solution. Likewise the choosing of social goals is practically subjective and value laden, as such may be alternatively viewed as judgemental and perpetuating of dominant social values, not justice. Thus the ideal of research neutrality may be seen to extend safeguards to those who participate, yet the political neutrality of ethics

committees has already been brought into question (Hammersley 2006) and as such places the ethical onus onto the individual researcher or research team.

This brief interlude opens up spaces to consider in greater depth the extent to which ethical guidelines and permissions reflect best interest of all research participants. Particular where there is a crossover of roles or priorities. It is thus necessary to take a deeper reflexive stance in relation to not only the details of the research and the ethical assurances made, but to the underlying priorities and stance committees the researcher is making clearance applications to. I thus suggest that to decentre the respondent from the ethics process on the basis of a social agenda, is to invite the respondent's marginalisation. Hence this is seen to be inviting potential abuse if individual rights concede to the wider agendas of researchers and indeed the academic and funding bodies directing research.

For the purposes of this research therefore, it was determined that the standard markers of ethical determination (autonomy, beneficence, non-maleficence and justice) remained the best guidance for ethical integrity. Particularly as in working practice they retain the best interest of the respondent at the centre of the ethics frame of reference. This section now turns attention to the ethical implications of this study. Toward this I employ the nine direct questions which comprise Gorman's ethical template toward the wellbeing of my respondents (both participant and observed during volunteer placements). I equally consider these questions in relation to my own participation and that of my family.

4.3.3 Asking and answering Gorman's questions

Gorman's list of questions are framed in the current, however although they were considered prior to the research was undertaken, hence where appropriate I have expanded my answers to reflect the situation of the research now it is completed. In that way it was possible to consider if the actions taken were adequate and effective. In some cases issues arose that had not been anticipated and again these are indicated.

[1] Who might benefit? This question links to previous considerations regarding the role and nature of social science research; undeniably the tone of the question intimates that a costs versus benefits equation is a standard concern. However, this is a stance that is incongruent with the ideal of knowledge pursuit for its own ends, and raises wider issues in relation to whether all knowledge can ever be viewed as

equal. If not, then inherently any ethical address will need to evaluate the potential benefits of the knowledge sought.

To address this question I considered firstly the impetus for this study. This may be summarised as led from personal experience of disadvantages my children encountered in the school context. These experiences were considered of particular significance, because they set in motion chains of events that have resulted in long term life damage. It was therefore determined that research which is directed to address, and redress of such disadvantage, would undoubtedly be of benefit to other young people and families similarly placed, if the impetus for such experience could be laid bare. Likewise as my research aimed to interrogate latent attitudes toward a range of medical labels amongst teachers, it was considered possible that the data generated may be useful pedagogically, to highlight to teachers any unchecked negative opinions toward medical labels that may inadvertently be fostering unrecognised acts of discrimination.

Overall the data from this research led to the development of a conceptual model of disability to account for practices observed, and experiences/opinions conveyed. The ambition for this model was to raise awareness in the public domain of unfair practices which inhibit the possibility of disability equity in both the school context and the wider social domain. It was hence determined that the study satisfied the principles of both justice and beneficence. Not least because reflexive practitioner awareness was considered fundamental to guarding against responses which disadvantage, particularly attributions of accountability.

[2] Who might be harmed? Although harm was an ever present consideration across the respondent groups, two of the groups were considered more vulnerable than others. Teachers were considered vulnerable, due to their employed state and professional obligations, families equally so due to the risk of emotional effects as a result of discussing past and present difficulties. Additionally because of the public profile both individual interviewees enjoy, there were also identified as vulnerable, in regards to any public misrepresentation which may occur if their interview data were to be misquoted or interpreted in subsequent publications. Initially the interviewees identities were undisclosed in text, although I subsequently asked if such anonymity was required and both participants granted permissions for disclosure.

I was also highly aware of the risks of my data being misappropriated, as during a previous research project, data I had generated from teachers was used by the hosting institutions for purposes outside of the research context. I was as a result, very cautious about who might have access to data which needed to be stored in-institution for collection. To circumvent this vulnerability I toyed with the idea of providing stamped addressed envelopes, but the costs involved in implement this safeguard were prohibitive. In resolution I provided coded envelopes which matched the questionnaire schedules and requested respondents seal their completed ranking exercise schedules for collection. Equally all audio data was anonymised by pseudo names and stored on a private computer and backed to a portable memory stick which was duly locked in a secure case. This protocol was maintained during for all subsequent data transcriptions.

[3] How might they be harmed? A prime concern was whether teachers as employees would feel compromised if prompted to indicate attitudes that were incompatible with their institution: which in resolution may result in conditioned responses to reconcile tensions generated. I instituted strategies to circumvent these identified vulnerabilities, by inviting all respondents to rank in order of personally held validity a list of commonly diagnosed medical labels. In this way all respondents were invited to proffer opinions, alongside a further invitation to annotate the reasons for ranking choices made. Additionally assurances were offered in relation to the confidentiality of data, its purposes for an academic award and the opportunity to refuse to provide any demographic details. In regards to the family participants, I was aware that the process of relating personal narrative for families may conjure difficult emotions, which could persist after the conclusion of the interview. I attempted to reduce any possible discomfort by creating an empathetic atmosphere and identifying myself as a parent similarly placed.

Notably the impact on myself was a factor that was ill considered and mitigates against Delamont's (2007) assertion that autoethnography is an easy option. I felt at the research outset that I was in control and could draw seamlessly upon my parenting experience. However, as was previously discussed, research involvement is set within an ongoing life. One which I had not anticipated would unfold as it did, I was therefore unprepared for the series of catastrophic crises I managed in parallel with this research. Nor did I have a stock of coping strategies to fall back on, but the need to step back as a researcher, also forced me to be more clinical in my

responses to my children's difficulties and therefore a much more effective advocator. Nevertheless by the end of the research process and in particular its subsequent write ups, I had cause to consider the toll the process was taking on me personally. Not only in terms of time, but in terms of emotional pressure, not least because by the end of the research, some of the crises had resolved (or at least abated) and I wanted to move forward from them. However the process of writing and rewriting this research, necessitated the retention of a closeness to these circumstances than was perhaps wise.

[4] Does the potential harm outweigh the potential benefit? No I did not believe this to be the case, because as well as personal experiences of disadvantage, official statistics also indicate particular populations of pupils to have an enhanced vulnerability to educative exclusions for certain groups of pupils (DfE 2015b, 2016a). The charity ambitious about autism for example indicate that four out of ten autistic pupils have been subject to an illegal exclusion, which if 'applied to all of England's 70,785 children with autism could equate to more than 28,000 illegal exclusions' (AA 2014). These disadvantages are significant in their own right, but take on an added significance when one takes into consideration that marginalisation through exclusionary practices, predisposes to wider vulnerabilities which are themselves linked to negative life chances (McAura 2010, Krezmien 2014, Bacon 2015). Notably neither are these practices viewed as discriminatory; which of itself suggests they are being conceptualised outside of the boundaries of disability discrimination, irrespective of diagnosis, which was further held to suggest a different conceptualisation of behavioural disabilities. It was concluded that research which aimed to bring to public attention association of exclusionary practices as discriminatory could be life changing for families affected by disabilities of impact on challenging behaviours.

In terms of my own emotional toll and the potential for any future recognition of my family, again I concluded the potential benefits, exceeded the risks. Having navigated many difficult circumstances, I am fortunate to have the skills to be able to identify the discriminatory practices and incongruences of disability accountability. Indeed it has been such awareness that has strengthened my resolve to pursue this research.

[5] How can the possibility of harm be reduced? I aimed to reduce the potential for harm by implementing the safeguards previously stated in terms of storing data generated securely and inviting anonymity. I also provided each respondent with an

overview of my research, outlining the study aims, the possibilities of possible publication and the likely readership. I also offered an explanation of what this would involve for them as respondents, alongside additional assurances stating that withdrawal from participation was possible at any point without explanation. During the interviews with families I remained vigilant to the potential of emotional distress and was willing to halt an interview if it appeared to be causing undue anxiety.

In retrospect in regards to the effects on myself, I cannot see any means of preventing the emotional toil this type of research approach engenders. One possible avenue to explore is the potential for such involvement to be cathartic, aiding the healing process through the resolution of traumas faced. I would however dispute that for myself this value was realised. It was rather by the end, like picking a scab, counterproductive and contrary to any healing process. It was however an impact that I did not extend to my family as outside of their awareness that my research was based upon their own experiences, they had no interest in reading any of it, nor do I feel would I be minded to encourage them to do so. Is this dishonest? I do not believe it is, they are aware of their own histories, although they are not aware of the many flash crises which have been navigated successfully for them. Not only by myself, but through professional support networks along the way. It is therefore necessary in this instance to usurp the role of researcher in favour of the role as a mother.

[6] Are there any conflicts of interest for the researcher? In terms of neutrality it might be argued that I was more attuned to the familial perspective given my own circumstances. Nevertheless, the stating of these circumstances also led me to be over zealous in the scrutiny of my conduct as a researcher. In particular I endeavoured not to allow my own experiences to impose on the data generated, and incrementally I reconsidered whether my decisions were objective and balanced. Another further potential conflict of interest pertains to the personal nature of autoethnography as a method, for it not only discloses the narrator's personal context, it also implicates those surrounding them. I was therefore faced with many decisions regarding my children and wider family's privacy. Not least because my children have vulnerabilities which complicates the gold standard of informed consent, but also because of the availability of information in an age of digital access.

One of the participatory school's was also my children's school and this was considered a potential conflict of interest. Specifically because although such

familiarity was of initial benefit in terms of access, the effects of familiarity on the honesty of responses, or indeed even the questions that could be asked, could not be disregarded. I felt the potential for impact was most acute in regards to the SENCO interview I conducted in school, but in terms of the ranking exercises, I concluded that there was probably a minimum impact as I do not know all staff and I have had less contact with specific staff members than I have with senior management and the school SENCO.

A further conflict emerged during my observational volunteer placements where I found myself in contact with students known to my family. This was moderated to an extent as the pupils considered me another pair of hands, not a researcher. I did however find the overlap disconcerting, in that I was simultaneously occupying several roles. I was a PhD candidate, a classroom volunteer and known as the parent of several children with medical labels. As the two year period as a volunteer coincided with some acute crises at home I was keen to avoid having my research role impact on my ability to advocate effectively for my own children. As a consequence I made the decision early on that I would (if necessary) actively resist any placement of my children in the contexts I had volunteered in. Ironically throughout the duration of this research, contacts made through professional networks have been invaluable in my personal context. As was the respect accorded to me as a researcher by professionals I had engagement with as a parent.

[7] Have participants consented fully? As previously discussed, all participants were offered an outline of the study, verification of the researcher's doctoral status and the purpose of the study. Thus the issue of informed consent was straightforward for respondents who were engaging with my research from outside of the personal domain. Problematically, this was not the case for the permissions needed to look inwards to draw upon familial experience and is thus discussed in the second part of this section at 4.3.4

[8] What does the research involve for participants? As this was a layered research project with multiple respondent groups, the nature of participation varied across groupings. It consisted of personal introspection (in regards to my own role) throughout the duration of the research; observation one day a week through my engagement as a classroom volunteer; face to face semi-structured interviews of between half an hour and an hour duration (SENCOs); free narrative interviews ranging between one to two hours (families and key individual interviewees) and self-

complete questionnaires/ranking exercises which were devised to take no longer than 30 minutes to complete (teachers). Overall the research involvement was designed to be as unobtrusive as possible and time efficient. Particularly in regards to the impact on teachers who I had been advised upon initial contact with schools to be inundated with research requests. I thus sought to minimise any undue effect on each groupings daily routine.

[9] Awareness of risk: All respondents were fully aware of the purposes of the study and their contribution within it. There were no physical risks identified with this research and the greatest concern was any residual discomfort families may have experienced as a result of recalling previously difficult circumstances. The consideration of risks therefore were projected and ill-defined as I was unaware of the circumstances of the families difficulties prior to the interviews. During the interviews however I maintained an awareness and did not detect any discomfort from engagement in this research. To the contrary, there was an eagerness to engage with this research and a palpable level of irritation that their voice was more often silenced.

I did not foresee any additional risks for the respondents in my study that exceed the nine questions that comprise this template. Notably the area where there were unforeseen effects relate to those that impacted on me as both researcher and respondent. These effects are discussed in relation to myself at section 4.3.6 and looking back at my now completed research I would suggest they are significant and often understated in research methods texts. Would I have done things differently if advised? No but I would have been better prepared.

4.3.4 The ethics of insider research – inside does not necessarily mean equal

A preliminary question is 'how inside was I'? During the phase of data collection with other parents and indeed within schools, I considered myself an insider to the field of childhood disability in education, particularly disability which was associated with challenging behaviours. Thus I embarked on the research design, feeling an insider both as a parent amongst other parents and as a parent within the school system. I was familiar with both terrains. Nevertheless in the course of engaging with the literature around the topic of insider research, I was struck by Reay's (1996) cautions regarding claims to insider status and the disparities of power relations as an insider. Reay speaks passionately about the divisions that accrue from social class and how

class differences can distort the communality of other indices of membership, not least gender. Reay also speaks of the power researchers effect, not only in the immediate research engagement, but in the interpretations brought to bear during analysis. These cautions were unsettling to my notion of being 'inside' and caused me to reflect, at times uncomfortably as to how 'inside' or typical as a mother I was. These questions then led to further consideration of my own advocate role in relation to my children and to the extent my influence had effected distortion onto more typical sequences of events for children posing challenges as mine did.

There were two conclusions drawn from these thoughts, led initially by the work of Breen (2007), who noted that the act of insider research served to situate the researcher in a liminal space in-between being an insider or outsider. This was a position I had not really given thought to, but as Breen states 'taking on the role of the researcher often acts as a barrier that separates the insider from those in the setting they are researching' (pp164). Secondly I was minded of Reay's (1966) caution that 'challenging, working and writing to counter inequalities will only amount to so many empty words if it is not underpinned by a recognition of my current situation where I am now in a position of power' (pp63). Reay is referring to the privilege of being in the position of interpreting others meanings and realities, the privilege of being able to construct 'truth' from them. However Reay is also acutely aware of her own memberships which predispose to a particular lens, which in Reay's case is class.

Thus to conclude I acknowledged that on one level I was an insider; I was actively navigating my children's challenging childhoods alongside conducting this research. However it is fair to say this navigation was moderated, not so much at first, but certainly by the middle of this research by own professional standing and I needed to acknowledge that these were benefits not all of my parent respondents enjoyed (although some were more versed than me). It thus begged the question of how homogenous a group we could claim to be. I felt Breen's depiction of occupying a space in-between insider and outsider to be more accurate a description of positioning and it was hence necessary to consider more fully during analysis what this implied in terms of my research, observations and conclusions. The necessity of reflexivity to guard against bias was considered an essential practice and indeed I was able to see that at times I resisted parental blame as a legitimate response to challenging behaviours, because such blame struck a chord. However through the

process of reflection I was able to separate any second hand imputed critique and accept that my circumstances were not the same as many of my respondents, thus any evidence of blame, needed to be considered on its own merits.

Reay (1996) speaks also of 'othering', though the processes of identifying with some members of the insider group more than others, because of wider differences (in Reay's case class difference). This vulnerability demanded a reflexive eye, to assess who, if anyone I had separated as different and the reasons for this. Looking back I could identify with some parents more than others, particularly their need to be proactive and fight what were considered injustices using professional skills held. Did this serve to 'other' the parents whose responses were different to mine? I would argue not, if anything the parents who struggled to mobilise against unfair practices, highlighted more than the active parents the guise of discriminatory practices.

Early on in the process of this research, preliminary results indicated strongly that blame was pervasive and directed chiefly from schools to families in the guise of a nature versus nurture debate. The conclusions I drew at this preliminary stage was that there was an indication of discrimination toward pupils exhibiting challenging behaviours and a disconnect from the logic of disability as a state of being that is not chosen, but acquired through injury accident or genetic disposition. At this juncture it was indeed suggested to me that I was to quote 'teacher bashing'. At the time I was shocked and affronted at the insinuations behind such claim. However now, looking backwards I can appreciate from a methodological perspective the practical sentiment such remarks intimate. Indeed Drake (2010) cautions that 'the motivation for the research affects what the researcher learns' (pp 85). Drake also cautions that 'the same material generates accounts that emphasise different things' (ibid). To guard against these tendencies, in analysis I endeavoured to look at what may loosely be defined as the facts of events to generate themes, which were then referenced against my own parenting experiences. Similarly in conversation with parents I did not disclose actual events to families, but offered an empathetic ear to their narratives as they unfolded. Equally although I sought teachers opinions towards medical labels, I avoided asking any direct questions about teachers opinions towards what may be crudely termed 'different types' of parents. Nevertheless the implementation of diamond ranking exercises and invitation to annotate ranking choices revealed unsolicited opinion. I was therefore confident that I

was not leading responses as a result of my own positioning, or reading into the analysis only confirmatory factors.

An overall ethical question is whether my findings were engineered to fit my own experiences and insights? Looking back I do not believe they were; certainly my own context offered referents and leads, which by adopting an analytical autoethnographic approach I endeavoured to interrogate in the wider field, but this context was not directive, nor was it disclosed in any detail to respondents.

The finding of blame as pervasive across all the data sets, exceeded my experience and the manner in which data was collected did not reference blame in any manner. Indeed parents spoke of feeling blamed, even where behaviour was not a prime issue. Looking back at the data generated from families, I determined that it was fair to consider the narratives produced as both spontaneous and reflective of key events in each family's lives. Equally in relation to teachers and SENCOs, my status as a parent was not disclosed, essentially to prevent putting any pressure on respondents to answer in a particular manner. It was thus notable that both SENCOs and teachers referenced blame. In particular this was most heightened through teachers ranking choices and accompanying (unsolicited) annotations. This data indicated an uncertainty around issues of medical label validation, linked with wider questioning toward the root cause of a pupils difficulties; repeatedly divided between attributed causes of an organic/psychological nature, and those causes attributed to the child/young person's environment.

I was less certain of neutrality in relation to the volunteer placements my observations were drawn from and I felt compelled to re-read my overall assessments to test for possible bias or distortion. In conclusion although I detected both empathy and consideration of whether the schools I volunteered in would have been a better fit than the ones my children attended, I concluded that these did not influence the impressions and events that led the final analytic outcomes. It is also important to highlight that in both placement contexts, although senior management knew my parenting background, the staff teachers I volunteered with did not. I hence felt confident that the data I was generating was not led by my being a mother with personal experience of behavioural disabilities.

4.3.5 Ethical issues specific to my context and circumstance

Although many of the ethical issues which related to the practice of conducting insider research have been addressed in the previous sections, there were two issues which had a very precise impact on this research. These were firstly how to write about my experience of my children's disability disadvantages without compromising theirs, or my wider family's privacy and secondly, the personal effect of writing about traumatic events in the past tense. This section addresses these issues and offers an expansion on their eventual resolution. It finds overall that although there was no 'one size fits all' ethical solution to the issues which emerged, the act of blending narrative, reduced the privacy risks posed to wider family members, permitting a candid sharing of both personal and respondent experiences.

Insider research conjures specific ethical dilemmas as Cooper and Rogers (2015) observe. In particular questions are raised in relation to how 'honest, ethical and caring we can really be in placing the self into the research process' (pp1)?

Throughout the course of this research there was an ever present balance to be made between my loyalties to the social research profession and those as a mother I held to my family. In retrospect I can conclude that that there was no perfect solution. Not least because whilst I was willing to share my parenting experiences and insights in a broad sense, there were things that I considered off limits, not only out of respect to my families need of privacy, but equally in regards to the emotional toll of sharing.

I needed to find a means of balancing my professional integrity as a researcher and my responsibilities as a mother. Initially I explored issues linked to informed consent (Miller and Boulton 2007) and capacity to consent (O'Neill 2003, Parsons et al 2015) in conjunction with stated ethical complexities of being both insider and outsider to the research field (Rogers 2003, Cooper and Rogers 2015). The issues highlighted, although informative, were not exhaustive and some questions remained of issue. Not least I was concerned with how to protect my children's rights to anonymity, particularly as some were already adults with careers of their own. I resorted to the gold standard of informed consent, seeking permission from each of my children.

These permissions were granted, as my family felt it unlikely anyone they knew would ever read my thesis. Nevertheless other quandaries surfaced, not least that, my sons as vulnerable young men were reliant upon me to offer advice on consent. Likewise as my children hold labels which indicate neurodevelopmental differences,

their participation was very much by proxy; as although the accounts offered were about their experiences, the record of this experience was from my perspective. It is thus not only questionable as to what extent my children were able to absorb the wider ramifications of offering consent. It is equally questionable as to whether my perspectives would parallel their own with the passing of time.

There were also longer term implications, so it was ok now, but what in five, even ten years time? A challenging child has capacity to change and exposing my children's childhood felt akin to publishing the family photo album in the local shops. What if my any of my children wanted to pursue an academic career, would they cite my research or deny it? Would it cause embarrassment? The list expanded, particularly when I factored in the search capacity of internet browsing. What if someone managed to identify my family members, even worse what if they then shared on wider social media? The list of scenarios was endless and the implications racked up hypothetically.

From a broader perspective I was also aware that by using an autoethnographic approach I stood to expose wider family members, who although not directly referred to, are implicated through familial association. It was thus pertinent to consider how far the chain of informed consent needed to extend and for how long I should consider my family's identities vulnerable to exposure. These dilemmas were not necessarily reconcilable due to the dual roles inherent to the autoethnographic method. My choices were to either find means of minimising risks identified or abandon the project, rendering me also complicit in the silence identified as surround behavioural disabilities (Carpenter and Austin 2007, Carpenter and Emerald 2009, Emerald and Carpenter 2015).

One solution was drawn from the work of Medford (2006), who warning of the existence of multiple co-present realities suggests that the goal of autoethnographic accounts is to extract meaning, rather than to reproduce events in precise detail. Adopting this approach, it would be possible to make candid disclosures to illustrate the emergence of meaning, whilst simultaneously facilitating the rights of the disclosure to censor what is shared. I thus felt that this position offered means of reconciling omission of sensitive or considered private events without conceptual compromise to the integrity of accounts disclosed.

Medford's solution was however only partial as it could not address the issue of anonymity, or the potential for someone to piece together my family's identities through the chronology of events shared. I was thus faced with the prospect of accepting at face value the familial consents offered and of having to outline fully worse case scenarios to my family to satisfy the notion of informed consent. Nevertheless as a mother I was still not entirely convinced that 'informed' actually equated to understanding. During this period whilst considering the tensions inherent to this dual role, it occurred to me that there may be an alternative way of reconciling the issues outlined. Viewing myself not in a dual role, but rather a blended role, my solution was to also blend the childhoods presented, offering means to share both effects and issues raised. Essentially profiling a 'challenging childhood, drawn from real life data but without attribution to any one individual.

In resolution I advised my family that I aimed to disclose the essence of their experiences and notable events, without providing specific detail that might identify them at some later date. This was made possible by assimilating (blending) the narrative (experiences and events) of the participating families with my own disclosures, not only in terms of ownership, but also in terms of the chronology of events. In so doing I was able to share scenarios without chronological attribution to any one family. Whilst this situation was far from ideal, the nature of the data generated in terms of severity of behaviours demanded that discretion was of the utmost importance. Consequently, although the family respondents were given pseudo names, the chronology of life events were blended. In practice this entailed the detailing of key events without linear format, or consistent attribution to the originating family. Essentially I took the sum of events and mixed up which families they related to. In this way there was no linear trail which may afford identification.

Bahn (2012), likewise Emerald and Carpenter (2015), introduce a different ethical dilemma, namely the impact of the research field on the researcher. A focus I found highly significant as I remained straddled between two not entirely compatible roles. The emotional implications the authors discuss were highly pertinent toward the emotions conjured whilst writing my son's story and indeed those of my research respondents. Not wishing to denigrate any child's childhood, these young people were far from setting a happy ever after scenario. The formalising of such scenarios conjured strong emotion and emphasised to me how much easier it is to sublimate

such negatives amidst daily life, yet essential that they be exposed in order to reflect not only on a childhood lived, but on the material circumstances of its constitution.

As intimated previously, I was least prepared for the impact of my chosen approach on myself as the insider. Not only in regards to my own experiences and the discomfort of their revisit, but also of the effect of respondents accounts. These were twofold; there was the distressing life experiences narrated by families which resonated and there were the sometimes negative opinions of teachers which struck a chord. Nevertheless of everything encountered throughout the research journey, the starkest revelation was being faced with literature that framed my position from a feminist standpoint. This was something I had not considered, particularly the gendered nature of accountability and parental responsibility. Literary engagement thus offered an alternative lens from which to view my own experience and gave voice to feelings that had been ill formed. Jacquie Jackson's (2004) writing in particular resonated with my own relationship and mothering experience. In particular the following statement:

'Married at a young age, the children and their difficulties were totally absorbing and I considered them to be my 'job' in much the same way as my husband had his. To me, maybe unfairly, I was always a single parent in my mind, and divorce was inevitable and eventually became a reality' (Jackson, 2004).

For many years I too had struggled to understand not only the isolation of parenting children who were atypical, but the isolation I also felt within my partnership. I had no choice but to abandon a paid career, such were the care demands I faced. Yet the demands faced were rarely shared practically or emotionally insider or outside of my partners work hours. Thus in essence, Jackson's statement gave voice to the life I had led and was indeed still leading. These realisations however extended academic awareness and held potential to linger long after the research was concluded and in that sense they were effects for which I was unprepared.

I was hence unprepared for the emotions they conjured. They evoked in me a sense of loss, not only for the typicality my children would never have, but also for the partnership I felt I also lacked. In essence I felt extremely angry that the popular notion of autism does not belie its reality and for countless families the material and emotional circumstances of their lives remains shrouded. It is thus of great concern that as this section is written a news article is released that suggests 'super parenting' improves autism (Gallagher 2016).

The ongoing drive to place the onus of progress onto families remains a concern, as for some families it is unrealistic and impractical and extends yet another avenue of self and societal blame. Thus when looking at the overall pros and cons of insider and autoethnographic research from an ethical perspective, it was concluded that the potential benefits in terms of knowledge expansion and address of disability inequity outweighed any disadvantages to self, or identified risks to wider respondents.

4.3.6 Generic ethical issues pertaining to insider research

Insider research conjures ongoing ethical concerns which host ethical implications and impact of the integrity of the research. This subsection identifies both benefits and shortfalls, particularly in regards to the comprehensiveness of insider knowledge, empathetic ability, how to establish professional distance and disengage from the research context (Reay 1996, Labaree 2002, Breen 2007, Drake 2010). Rogers (2003) discussion of the dilemmas pertinent to being a 'mother researcher' is of specific significance for this research, as it raises awareness of the potential for a blurring of roles, where research interest can be misconstrued by respondents as friendship. This debate is extended by Cooper and Rogers (2015), who whilst acknowledging the benefits of insider knowledge, caution that insider status may inhibit details respondents share, or are asked to expand upon, through the assumption of shared knowledge which is assumed self-evident.

Cooper and Rogers also express concerns in regards to how the self is managed within the research relationship, both in terms of the effects on and the dimensions of self that are revealed and shared through the research relationship. As has been indicated previously, looking back the process of conducting this research has prompted me to think about my own circumstances differently and not always comfortably. I have also alluded to the boundaries of sharing and the rationalisation for the retention of some details, this leaves open the question of how open and honest my own presence was and indeed how open I could consider my respondents to be.

Cooper and Rogers (2015) suggest the 'insider' role is a powerful reflexive position used to gain deeper engagement and insight into participants understanding of lived experience'. Undoubtedly this was the case personally, but to what extent I would agree that my own position gave me privileged insight is less clear. Certainly familial participants emitted a conspiratorial air; punctuated through terms such as 'well you

know how it is' and 'I'm certain you have had the same difficulties'? These intimations were cohesive and positioned me on the inside, part of the exclusive 'special needs mothering club'. But it is necessary to question whether I really did or could know precisely what they meant. For just as my exposure of self or circumstance was partial, so undoubtedly was theirs. There were points during interviews, where in retrospect if I had revealed more of myself I feel I could have elicited more personal data, however this was not the purpose of the interviews. I specifically wanted to explore the extent of disadvantaging practices in education and for this purpose, concrete events such as exclusions or restrictions were key.

It is interesting that as parents we were all looking back at things that had happened, whilst during transcribing and analysing the interviews, I had through the passing of time, the privilege of knowing future events that had yet to occur at the time of interview. I was thus able to see how this lack of future knowledge had impacted on my engagement with respondents and how it if asked the same question it might differ in the current moment. For example, during one of my interviews I was asked if there was anything my son could do that would lead me to disown him. I answered with a convicted no, feeling glad that my own circumstances were seemingly brighter than my respondent. Nevertheless in the interim period between interviews and final analysis/write up, I faced many serious (and unanticipated) crises, which led me to appreciate (in principle) the sentiment behind the comment made. Hence although my answer to that question would still be no; the interview serves as a constant reminder of the impact of subjectivities, which by nature are fluid and of particular impact on the sense made of data which emanates from a context where the researcher claims insider status.

Labaree (2002) offers a helpful template which highlights five key points in the research process that introduce ethical concerns of specific relevance to insider researchers which I now employ in respect of my own research.

[1] Entering the field: looking at my conduct within this research I can attest that I was selective in the personal information I shared with each respondent group (as discussed in the previous section), but not in a misleading way. Rather I shared information as it was considered appropriate and omitted certain information that would have served to breach my family's rights to privacy. Additionally agreements to conduct research was obtained on the basis of my doctoral candidacy and validated

by my institution, I was therefore, at no point misleading in my engagement with respondents.

[2] Positioning (the membership identity brought to the research field): As previously discussed, I openly acknowledged to family respondents my own status as a mother similar placed. I also explained to them the outline of my research and my motivation for its pursuit. In relation to the other respondent groupings I tended to maintain the persona of a postgraduate research student, as it was considered possible that to do otherwise might condition responses offered. I did not feel that this was in any way misleading as the topic guide for SENCO interviews was generic and focused on organisational practices, not forging any communal identity to elicit information. Likewise the questionnaire and ranking exercises undertaken with teachers. Indeed it was only in engagement with families and with the individual interviews with Baroness Warnock and Leslie Henderson that my own context was relevant and shared openly were requested.

[3] Disclosures (how much is shared by the researcher): As stated I considered it pertinent to disclose my parental context to families in order to both engage on a mutual level with the families who had indicated willingness to participate and to foster an environment where candid disclosure was possible. Similarly during the individual interviews it seemed reasonable to address the disadvantages I had experienced personally as a further means of piecing together an understanding of the contingencies which had supported the disadvantages experienced. At all times during these interviews I was mindful that the purposes of engagement was not directly to discuss my circumstances, but to engage with others to widen the knowledge field toward an overall picture of disability response in this arena.

[4] Shared Relationships (marking boundaries): In relation to teachers and SENCOs and individual interviewees my relationship was demarcated as transient and task orientated. Similarly so the time parameters (one academic year) placed on my volunteering placements. The same may be said of the engagement I engineered with families, although I got the impression that some families were seeking inspiration through successful advocacy stories to further their own struggles. Inevitably in the course of interviews, personal information was shared. Some of this information at face value exceeded the scope of this research and was concerned with partnerships breakdowns and the behaviour of non-disabled siblings. At these junctures I felt the research relationship was in danger of being mistaken for a

support orientated friendship and this did cause concern. This was mitigated by the artificial nature of set interview sessions and the mutual knowledge that our connection was unlikely to exceed beyond these. Thus in the moment, during interviews, disclosures that appeared to exceed the scope of the interview, were handled tactfully and if I had advice or contact information which was relevant, I shared it, as I would with any acquaintance.

[5] Disengagement (leaving the field): I was fortunate disengagement was not an issue, for whilst I shared commonalities with the respondent families, we were not familiar with each other in any other guise. Thus I was able to arrange meeting dates, approximate time parameters of engagement and follow on invitations as applicable, without additional expectation. Similarly my volunteering placements were demarcated in advance and although at the end of each placement I was invited to stay, I declined genuinely due to study commitments.

Labree (2002) states that at the centre of these junctures is the general issue of 'whether the outcomes and interpretive conclusions would differ significantly if the study were to be conducted by an insider participant observer rather than an outsider' (pp 99). Looking back with the benefit of hindsight I feel that the study foci may have been able to be conducted by an outsider equally as efficiently, but it would have been different. Basically it would have lacked the protracted period of parenting experience that I as an autoethnographer am able to bring to the study. Most particularly it would have lacked the mapping referents which acted as the scaffolding to which all other data collection initiatives stemmed. Hence whilst an outside researcher would have held the research skills to conduct this research, an outsider would have been unlikely to have had either an equal insight, or the vantage of hands on engagement in education as a mother of children with disabilities across several significant educational junctures.

Looking at the broad terrain of ethical guidelines and issues referred to, I felt the old adage of no maleficence to be a universally applicable ethical ambition. Of equal value to the individual researcher as it is to wider participants. It was my guiding standard in all contexts and equally reflected in my research ambition, namely that I aimed to address disadvantage and raise awareness of practices which unfairly accorded accountability for the effects of a known or suspected disability.

4.4 Methodological approaches

This section looks at the practical implementation of the research; it commences with an exposition of the research process, methodological choices made and addresses both the rationale for a layered approach as well as its chronology. This is followed by an overview of the methods of data collection used and introduces the reader to both the background demographics of the family respondents and the geographical situation of the participant schools. This section then discusses the stages of analysis, focusing on how the process of coding led to the generation of initial themes which were then consolidated into two broad Meta themes. The section concludes with a consideration of how the validity of the study and its conclusions can be assessed.

4.4.1 Impetus for study, the layered approach and processes of data collection and generation.

This thesis endeavoured to seek evidence of, and explanation for disability discrimination in the wider school domain, led by in the first instance by personal experience. The research potential of personal experience is affirmed by other researchers who have embraced elements of the personal for both research purposes (Rogers 2003, Kingston 2007, Runswick–Cole 2016) and for consciousness raising (Jackson 2004 and Gallagher 2010b). Following their lead I determined that my experience alluded to systemic practices across a longitudinal time frame, which acted to disadvantage. Not only in the immediate, but in the longer term. My maternal experience also stood as testament to the negotiated and fluid nature of the maternal role[s], which were generative of often conflicting identities (both those sought and contested). Having raised a large family I was uniquely situated. Unknowingly at the time, part of an educational revolution which witnessed social and political shift from the policy of Integration, to that of Inclusion, and now one might argue, 'Post Inclusion'.

Yet during this period, my perception was not one of change. To the contrary, there appeared a persistent intolerance levelled toward children and young persons with behavioural difficulties. Despite sympathy and at times pity, there was always a point at which school could not, or would not continue to cope. When reflecting on my own experiences to inform the shape of this study, I was minded of the many parents I had encountered during these years, parents who like me had endured similar disadvantages. In particular the severing of a mainstream placement (sometimes

abruptly, other times gradual and quietly encroaching), leaving both child and family unsure of how to proceed. These realisations suggested that my experiences, although unique to me, might represent a wider a pattern of disavowal. In particular looking back, what was particularly perplexing, was that these acts of intolerance operated in conjunction with an emergent culture of medicalisation, which was fundamental to the now routine diagnostic explanation for the spectrum of childhood differences.

The adoption of an analytical autoethnographic method extended a growing awareness that my personal experiences were an important source of data. Whilst an analytical approach to the method itself (as discussed in section 4.2.8) enabled me to explore key aspects of my experience (systematically) in the wider domain. I wanted to forge an explanation for the disadvantages my children had faced; to make sense of why during a period of educational history, where childhood conduct was rationalised within a medical frame, children were simultaneously diagnosed as disabled, yet held accountable for exhibiting the symptoms of their disability. I was also concerned to understand why the logic of these practices was not questioned, but rather presented as a legitimate response, both in school and indeed the legal domain. Shifting through the many events that punctuated my children's school careers, two areas of research interest stood out. Firstly whether accountability stemmed from an unstated scepticism toward particular medical labels; and secondly why exclusionary responses were considered a reasonable response.

It was imperative that supporting methods of data collection were compatible, not only with the merging of the personal and professional, but with my held ontology (as discussed in section 4.2.1). In addition the methods of data collection I adopted needed to be able to elicit opinions which in a climate of Inclusion and anti-discrimination legislation could be viewed as socially (and as importantly) professionally controversial.

Drawing upon Stanley's (1992) contention that the self is always contextually situated and connected in terms of its constitution to other selves and collectives, I felt a layered approach was appropriate to reflect the inherent connectedness of the school context. Data was sought from a range of respondent groups using methods tailored to the nuances of each respondent group and the nature of information sought. I subsequently designed a layered study, whereupon each layer of data collection

contributed something specific to the whole), toward a snapshot of parental experience and professional attribution toward childhood disability (see appendix).

Data was collected from three main respondent groups, teachers, parents and SENCOs. In addition two individual persons were interviewed, chosen on the basis of their impact within the areas of Inclusive education and childhood disability support. These were Baroness Mary Warnock (Committee of Enquiry into the Education of Handicapped Children and Young People) and Leslie Henderson (founder of the Northern charity The Henderson Trust). The research was also informed by two periods of longitudinal participant observation, undertaken during the academic years 2011/12 and 2012/13 in an independent special school and a pupil referral unit.

Overall the thesis was conducted using an analytical autoethnographic approach (Anderson 2006), which involves the deployment of personal knowledge to guide the research foci in the wider field. Notably in implementation, not only did personal experience guide the data collection stages, each stage had potential to inform the next. Each data set presented its own challenges, despite being tailored to the particular nuances of each respondent grouping. Section 4.4.2 presents the research questions and the overall topic guide used to direct the research foci and analysis. Section 4.4.3 subsequently discusses each stage of research activity, introducing the various respondent groups and the approaches taken with them. Section 4.4.4 then describes and justifies the methods of data collection and generation employed through the research.

4.4.2 Research questions

RQ1. “Why do behavioural disabilities appear less tolerated and accountable in British mainstream schools when other presenting disabilities are not?”

RQ2. “What forms does accountability take”?

RQ3. “What are the implications of accountability for aspirations of disability equity and Inclusion in the school context and wider social domain”?

4.4.3 Overall topic guide

TG1. What are the range of presenting childhood disabilities in schools and what are their practical implications in regards to mainstream Inclusion?

TG2. To what extent are all medical labels (disabilities) considered equally valid by teachers and what factors account for their determinations?

TG3. What forms of knowing coalesce around children exhibiting challenging behaviour in the school and family context?

TG4. What factors can be found to impact on understandings across the respondent groups?

TG5. How do understandings of disability inform pedagogical practice in the special sector of education?

TG5. To what extent is disability accountability considered by teachers and parents to constitute an act of discrimination?

TG6. What barriers can be identified to inhibit disability equity in the school context?

4.4.4 Engaging with the respondent groups to elicit data

SENCOs: are by role are a main source of disability education, offering support to both teachers and parents. SENCOs also act as gatekeeper to specialist support and diagnostic services, assuming the lead role for continuing professional development [CPD], thus considered a central participant group. To engage SENCOs, a list of maintained secondary schools was compiled from a local authority guide for parents. Secondary schools were selected as this sector is found to be most heavily associated with the exclusion of pupils with SEN and/or disability (DfE 2011b, DfE 2012a, 2012b, DfE 2013b, DfE, 2014a, 2015b, 2016a). Invitations were extended to all schools in the area by email to their named SENCO, followed by telephone contact one week later. In total 51 invitations were extended and following telephone discussion 12 face to face interviews arranged, equating to a 25% response rate. To guide relevant areas of interest as defined in the topic guide and standardise interviews, a semi- structured schedule was considered most appropriate.

Interviews took place within institution and were digitally recorded to ensure accuracy of record. Each interview averaged between 45 minutes to one hour and fifteen minutes. On reflection the interviews were unproblematic. Nevertheless in some instances responses appeared conditioned by role and institutional policy and this was a concern as I felt that data gathered may reflect professional opinion, not personal beliefs. I subsequently determined that this risk may have been lessened if

interviews had been conducted on neutral territory. I also upon reflection wondered to what extent the topics discussed would have differed if I had approached SENCOs using a narrative approach, rather than a semi-structured interview. At the very least I determined that I would have had a greater impression of issues and concern prioritised by SENCOs. Time was another factor that SENCOs mentioned recurrently, emphasising to me that there was a limited capacity of school professionals to engage with researchers due to the pressures of the profession generally. These cautions served to be a bit unsettling and caused me to re-consider how I would engage with teachers to garner research access. In all cases I was informed that it was the school headships who had to sanction my access to the general teaching staff. Hence following each SENCO interview, I sent out an email request to the head teacher, requesting their agreement for me to distribute ranking exercise questionnaires.

Teachers NUT conference [external to institution]: I was forewarned by SENCOs that school heads may not be too accommodating to my request to engage teaching staff in my research. The reasons given were bureaucratic restrictions, time parameters and their already feeling of research saturation. In response I explored alternative ways to engage with teachers outside of their institutions and determined the national teaching union conferences might provide such means. This very fluid context however necessitated data collection methods amenable to a very restricted time frame and public setting. My methods needed to be essentially simple, user friendly and self-explanatory, although I still hoped to elicit complex opinions surrounding teachers attitudes towards medical labels. To resolve both time demands, data sought and communal setting, I determined that a diamond ranking exercise was the most appropriate means at my disposal. Particularly as I felt that such an exercise would facilitate the expression of any contestations toward medical labels and reduce any discomfort likely from a more direct request.

The NUT and the NASUWT are the largest teaching unions, both traditionally holding conferences on the same Easter weekend. Contact was made with both organisers offering a brief outline of the research and data collection request. The NUT organiser made prompt contact offering a one day stall within the display arena, this afforded the opportunity to display data (in the form of annotations) which had been formative to the research arena. Fortuitously my stall faced the canteen area so it was highly visible and facilitated the distribution of the exercise to delegates whilst

seated communally. It also provided the opportunity for respondents to collaborate, which is common practice during diamond ranking exercises. Fortuitously, I was also able to record field notes of conversations witnessed, this was an unanticipated source of additional data, which offered insight into frustrations felt. In particular, delegates were enthusiastic about engagement, stating that they found it refreshing to be able to consider these issues unconstrained by professional role. Overall, the issue of disability per se and discrete medical labels raised significant emotion and strong opinion, which was at times unanticipated.

In a bid to engage teachers outside of their employing institutions, there were also abandoned leads. Firstly the NASUWT declined my request to engage with delegates at their annual conference. It was indicated to me that they had recently conducted significant research amongst their members, hence felt that delegates participation may be muted. The national organiser did however suggest I contact one of the regional organisers and request permissions to distribute my diamond ranking questionnaire electronically on the unions Facebook page. Although I embraced this permission enthusiastically, response was insignificant and the approach was subsequently abandoned. At the same time I attempted contact with teachers more generally through Survey Monkey, which was similarly unsuccessful. I concluded that either my project was uninspiring or potential participants were sick of research initiatives, hence resistant. I thus concluded that where possible, face to face approaches were the most productive means of data collection.

Teachers [within institution]: Following SENCO interviews a research request was extended to each participant's school head seeking permission to engage teachers. As indicated my understanding was that teachers were time poor, this effected my decision to again distribute a self-complete questionnaire using a diamond ranking format. More commonly, the use of the repertory grid method is employed to elicit data of a hierarchical nature, a method which is also found to be highly compatible with a constructionist ontology. The repertory grid technique, method was however found to be impracticable as it requires intensive and sustained engagement, involving at least three interview rounds which was pragmatically dismissed as a viable approach. Diamond Ranking in contrast only involves a single data collection phase and was reemployed amongst teachers within institution.

The within school ranking questionnaire expanded on the conference format, involving five ranking exercises, framed around not only categorisation validity, but

also influences on disability understandings, and opinion toward the difference/similarities between SEN and disabilities. Despite mass invitation only three schools were willing to participate, generating a total of 25 returned questionnaires, which again supported the contention that schools were research weary.

One school kindly allowed me to occupy the staff room to distribute my questionnaires. This offered an important opportunity to gauge how well (or not), teachers were able to engage and it became evident that staff struggled to complete the exercises, even with on hand advice. This was a marked contrast to the experience at conference, where there was collaborative exchange and enthusiasm to rank. Interestingly there was little difference in completion rates amongst the remaining two schools which I did not attend. Notably one respondent referred to the research exercise as “the hardest questionnaire I have ever completed”. Which in conjunction with a low response rate, indicated need to simplify how information was sought. As a consequence I decided to try to elicit teachers opinions towards behavioural disabilities in a different manner. I was advised by a colleague that one means of combating the over thinking of research questions was to approach data collection using a method which is colloquially described as ‘quick and dirty’. In brief it trades depth of data (including biographical information), for the ability to ask about controversial subject matter in a benign way, through simple agree/disagree questions alongside others that request Likert scaling or sentence completion. This is described below and was implemented as a final attempt to engage teachers with my research.

Teachers - ‘Quick and Dirty’: I was advised that by reducing the depth of data sought, I could through methodological simplicity stimulate immediate responsive answers, which by their nature might reduce tendency for reflexive conditioned responses. Having struggled to engage a reasonable volume of teachers I devised a final questionnaire to distribute to willing schools. The schedule involved a series of controversial statements, and request that respondents score from a Likert scale. Thus placing the onus of denial onto the respondent, a technique considered to reduce respondent bias (Brooke, in Jordan 1996). To encourage annotation I interspersed the schedule with a small number of self-complete questions, as the phrase completion method has been viewed as an alternative to Likert scaling and is considered able to target attention to highly contentious areas (Hodge 2003, 2007).

I approached schools outside of the boundaries of Newcastle, for this round of data collection as I had prevailed on all secondary schools within the city boundary. Four schools agreed to participate generating 39 responses, which expanded the overall responses of teachers (within and without institution) to 104. Comparing both approaches I concluded that if this research was repeated I would combine the two approaches, beginning with the 'quick' questions to encourage confidence and ending with a ranking exercise.

Families: Initially it had been my intention to engage solely with teachers and SENCOs, in a bid to explicate the disadvantages that I had witnessed my own children subjected to. I wanted to understand why despite a medical label, my younger children were held as accountable as my older children had been over a decade earlier during a period which did not err toward medical explanations for difference. However during the design of my study I determined that there was a difference between stating an opinion and its manifestation in daily practice when embedded with other responsibilities. I thus determined that it was necessary not only to seek teachers and SENCOs opinions, I also needed to explore parents experiences, in particular their experiences of disability response and inclusion in the mainstream.

I initially attempted to reach out to parents through the regional Database of Children with Autism Spectrum Disorder Living in the North East (Daslne). Yet despite submitting a formal application and full ethics statement and attending a panel hearing attended by related psychologists my bid was rejected. It was felt that my research was not of value as it was not interventional and hence considered of little utility to the autistic community. At the time I was disappointed and demoralised; particularly as one of my sons had been one of the first children recorded on the database. In addition two professionals who were heavily involved with its founding were both central to my child's. Nevertheless the experience served to teach me that being both inside and outside is not always beneficial.

I then turned to another contact for advice, a local parent partnership officer, who advised I make contact with the parenting support group 'Contact a Family', as a means of engaging parents in the region with experience of local schools. Following an initial exchange by email and then by phone, I was granted permission to place a request for participants in their next newsletter (see appendix). I was unprepared for the immediacy of the response; within hours of the newsletter being dispatched

online I received several responses, plus two invitations to engage with local parents self-help groups (one for ADHD and one for Tourette's Disorder). I eventually agreed interviews with twelve families; and although I could have extended this number, I was simultaneously juggling my volunteer work and pursuing the collection of my other data, hence I did not want to make commitments I could not keep.

Unlike my engagement with teachers and SENCOs where I had a confident knowledge of what I wanted to know, my question for families was much broader. I essentially wanted to ask 'how school had been for them and more importantly their children', without guiding them to set areas for evaluation. I subsequently decided that I would approach these interviews with only my own broad topic guide as a flexible reference, should conversation be awkward (see appendix), hence after a preliminary introduction and recap about what my research entailed (alongside formal consent to be interviewed), I invited respondents to tell their story as they felt it should be told. A narrative approach was considered the most suitable approach to facilitate an open ended interview (and is discussed as a method more fully at point 4.4.2), equally so to make sense of my own reflections, which far from being linear, extended back and forth in response to what I perceived to be significant life events. I determined that only an open means of capturing data from families could act as a stimulus to the sharing of key events and emotions, which were considered to be important referents for coding during analysis.

The first interviews were arranged across the time span of two months and parents were based across the entire Tyne and Wear region. Practically I aimed to fit in one interview per week, as travel alone could impinge on the best part of a day. The interviews ranged from just over half an hour, to an average of one hour, although the longest was nearer to two hours. All the interviews were conducted in the respondents homes and most took place in the evening. It was easy to strike up a rapport, as it had been stated in my initial invitation that my interest as a researcher extended from my own parenting experiences. This commonality appeared highly significant towards the families willingness to engage, and apart from the routine of asking for permissions to record the interviews, the interviews were informal and resembled many other conversations I have had with casual acquaintances.

This was both an asset and a hindrance. There were issues which I would have liked to discuss more fully, but felt that I could not because such information was considered self-evident amongst persons with a common background. For example

when discussing school processes, it was tempting when faced with a parent saying 'oh well you know how it is', to state 'no, tell me', but such a probe I felt would serve to impinge on my insider status and introduce an awkwardness to the 'conversation'. This was an ongoing problem and as my experience grew, I became more adept at inviting expansion without seeming to request the obvious. One strategy was to respond by saying 'well I have mixed feelings, don't you'? In this way there was an invitation to expansion without steering the conversation on any particular direction. I did nevertheless have to guard against the tendency to blindly agree as I indeed at times I felt I did know what was being referred to. Equally it was important to be clear that my involvement was temporary; I did not want to offer impression of any wider engagement beyond that which I had invited. This was much easier in the initial interviews, as my ending was an invitation to recap experiences in a year's time. The final follow on interviews endings however were more problematic and in all honesty I managed each ending intuitively without any prescribed tactic.

This review now offers the reader an introduction to the family respondents and illustrates their diversity as a group. It is important to point out to the reader that the background details offered are those which each participant agreed to share, but the narrative of key events as related by each participating family in the following thematic chapters is deliberately mixed to protect their identities.

Introducing the families

Families were invited to engage with this research via an advert placed in the parental support group Contact a Family. I attracted families from a diverse range of locations across the North East. They can best be summed as a diverse population, mixed in terms of education, geography, relationship status and age. What they did share in common was the experiences of accountability in varying guises, depending on the presenting difficulties of their children. Equally the families differed in the resources they had to draw upon to and how they forged or resisted relationships with their children's schools. Collectively they shared the aspiration to shore up their children's educational experiences and spoke of the impact of their experiences on their child's identity and sense of self. Equally the parents spoke of feeling highly visible and accountable in the first instance. Parents narrative included strategies adopted to counter these tendencies and it was at this juncture that the effect of the resources available was most evident. The majority of parents had abandoned the mainstream context, some through choice and the pursuit of a special school

placement, others due to school exclusion and the limited choices available for replacing into a school context. For those parents whose children were most challenging, there was significant input from external services, including childrens services and the youth offending teams. In conjunction these services served to construct a profile of the children that the parents did not recognise. Collectively the parents spoke of feeling highly visible and vulnerable to public stigma. Equally the families likened their school relationships to that of a battle, a permanent fight for their childrens entitlements. Thus despite their differences, the families had more in common than that which divided them.

Andy: Andy is a well-educated local woman in her early forties, living in an affluent suburb in the North East. At the time of interview Andy was pursuing a Master's degree alongside full time employment. Andy's son aged 14 has a longstanding diagnosis of autism and associated learning difficulties and Andy is very keen to ensure he keeps an academic pace with his peers. Andy also impresses upon me that she involves herself in school support roles to ensure her voice is heard and that she is able to effect an influence. Andy also has an older daughter Lia, aged 17, who Andy relies on to support her brother at home, Andy is very keen to manage her son's difficulties herself without external support.

Angie: Angie and her husband Tom are the oldest of my respondents; aged in their mid-fifties Angie was keen to narrate her experiences to me retrospectively as she now runs an ADHD support group and finds that similar to myself, despite the advent of Inclusion and medical recognition for behavioural differences, discrimination persists. Angie and her husband have both held higher management professional posts. Tom in the civil service and Angie as a child protection case worker management for a regional branch of child services. Angie and Tom live in a quiet seaside suburb and have two (now adult) children who still live at home. Jacob 26 and Carole 28. Both children also have been given medical labels, which Angie states was an ongoing fight for recognition. Notably both children, despite adulthood are reliant on their parents and have significant living challenges. Angie is highly critical, not only of the school system, but also the wider aligned bodies whose remit it is to protect children. Angie also states that her own professional background was of limited use in her quest to secure needed support for her children.

Catlin: Catlin is in her late thirties and although not university educated has achieved vocationally through work centred administration credentials. Her and her

husband are both employed and have two daughters, who Catlin describes as total opposites. Alice, Catlin's elder daughter Emma is aged 12 and has significant learning and sensory disabilities. She has recently been given a diagnosis of ASD and a much sought after place at a special school. The family live in an average Tyneside terraced house in an area which is populated by a range of socio-economic households. Catlin confides that her life is dominated by her elder daughter's needs, which she states, mirror traits of her husband, who Catlin states does not see the difficulties his daughter has, or the strains this puts on Catlin or her younger daughter Jessica aged 10.

Donna: Donna is in her late thirties and has three children girls aged 20, 15 and 14. None of the children share the same father and currently Donna lives with her new partner who is step dad to all three girls. Donna until the escalation of her middle daughters difficulties following transfer to secondary school, worked as a disabilities care team manager for a local branch of social services. Donna's middle daughter, Sky has struggled in education, but this was contained in primary school. Since the onset of adolescence Sky's behaviours have escalated and now punctuate the family's lifestyle. Neither of Sky's siblings have any reported difficulties, although they do have to make significant adjustments to their home life as a result of Sky's difficulties. At the time of interview, Donna confesses to being unable to cope, she is frightened for her middle daughters wellbeing and also the wellbeing of her other children. Donna confides that she is reliant on the police to attend when her daughter is exhibiting violent behaviours and is highly disillusioned with the care wider agencies have provided.

Farah: Farah and her partner Steven are in their early fifties and have parental responsibility for two young boys aged 9 and 8. I am told they are the biological offspring of Farah's brother who has relinquished responsibility because of a history of offending and drug abuse; there is no explanation for their mother's absence. Both parents work, Steven in an ancillary position at a local hospital, whilst Farah holds an administration post at the same hospital. They live in a purpose built 1970s estate, which is known to have significant social problems, including deprivation and a high rate of youth offending. At the time of our first meeting both parents admit to being at the end of their tether and were facing difficulties with their elder son's behaviour both in school and in the community.

Freya: Freya (32) works at a local hospital as a nurse and is married to Ryan a local council worker. The couple have one son, Ryan aged 10. Ryan has both neurodevelopment difficulties and a physical bowel problem. Freya shares the impact Ryan's problems have within her family, particularly the possibility of Ryan being given a diagnosis of ADHD, which the wider family, particularly Freya's sister feel is an excusatory label. Freya is highly protective of her son, which causes marital tensions, as there is intimation that Freya is over protective. The family live in a 1970s purpose built estate and indicate modest aspirations.

Jules: Jules and her partner Paul have two sons aged 14 and 11. The eldest has exhibited serious behavioural difficulties consistently from an early age, whilst their younger son is exceeding expected attainment. Both parents hold undergraduate degrees and state they have a comfortable standard of living. Paul runs his own business, whilst Jules is pursuing a vocational qualification in nursing. They are therefore at a loss as to why their eldest son has so many difficulties. Recently their son has been given a diagnosis of Oppositional Defiance Disorder, which is a recognised psychological disability. The family live in a semi-rural Northern market town in an area that may also be described as economically comfortable, nevertheless there are pockets of deprivation and these areas are described by Jules as a magnet for her son.

Julie: Julie and her partner John (both in their late forty's) are parents to two boys, Zac aged 18 and Jon aged 15. Both boys are adopted and neither on adoption were believed to have any psychological difficulties. Nevertheless Zac soon dispelled this security and began displaying behaviours that were atypical for his age. Following significant assessment Zac was diagnosed as having Attachment Disorder, Fragile X Syndrome and Foetal Alcohol Syndrome. Julie and her partner live in a rural area and both hold degree level qualifications. Julie appears very confident and realistic and emphasises that she has an extensive professional network who mediate the negative responses she has encountered, both in-school and the criminal justice system. Nevertheless Julie also indicates that there have been significant effects on her identity in the community and at school, although at the time of our final interview these effects were moderated by their elder son joining a residential school. Julie indicates her lost career, stating that until recently there was no possibility of working, due to the unpredictability of her son's needs. Julie also indicates that the family

chose to send their younger son to a private school where his identity was not linked to his brothers.

Leanne: Leanne is a young mother in her late twenties who presents as having hearing difficulties. Leanne also confesses to having a limited education, the result of school disengagement and familial difficulties. Leanne and her partner Rob have five children (aged 13, 12, 9, 7 and 3), at the time of interview Leanne was expecting their sixth child. Neither parents hold further educational qualifications, nor indeed GCSEs or employment, although Rob is an active volunteer at their local church. Both parents indicate awareness of their own limitations and confess to being keen for their children to achieve educationally. Three of Leanne's children attend local mainstream, whilst their daughter aged nine attends a school for children with hearing difficulties. Kane their eldest child has unspecified behavioural and learning difficulties and was heavily supported in primary school. During my interview Leanne confides the difficulties she is facing with her son have exacerbated since he began secondary school and are local to school. At home Leanne describes her son as a 'typical teenager'.

Micha: Micha is a young Saudi woman in her late twenties, she and her husband (name not disclosed) at the time of interview were both studying at a local university. They have two young sons in primary school Hussain aged eight and Raj aged six. Hussain has learning and attention difficulties and at the time of interview was undergoing assessment. The family could be described as aspirational as many of Micha's close relatives hold higher degrees. Micha also suggests that latent intelligence is a family trait and refers proudly to her younger son Raj's abilities. This contrasts markedly with the confusion and familial/school recriminations that Hussain's problems have initiated. To address the issue, Micha's husband has employed a private tutor, to complement the intensive home tutoring the family conduct after school.

Sacha and Chris: Sacha and Chris are both in their mid-forties, have benefited from a university education and hold professional positions. Chris at a local university, Sacha for the adult disability team, based within social services in the adjoining borough. Sacha and Chris have two children David who at the time of meeting was ten, rising 11 and Erin aged 16. David has exhibited problems from a young age, yet has until recently not been given a diagnosis. He is now resident again in the family home after a lengthy period in a support home which specialised in the care of

children with serious psychological difficulties. By the end of my research David was attending a private special school where he appeared to be making progress and Erin had moved out of the family home.

Saz: Saz and her partner (name not disclosed) are parents to an adopted child Louis who was 17 at the time of interview. Louis has significant behavioural issues and has a diagnosis of Tourette's disorder, ADHD and suspected Attachment Disorder. Saz through ill health and Louis's demands has had to give up her job, leaving her partner as sole breadwinner. Saz has however dedicated her time to acting as her son's advocate/carer and to the support of other families similarly placed. Saz has founded a local support group for families with behaviourally challenged children as well as qualifying to provide training to schools on the management of Tourette's Disorder. Saz is passionate about her role and candid about the psychological effects the strains of managing have had. At our final interview Louis had left the family home and was now living in supported accommodation; a fact that Saz feels is directly a result of her social services department's unwillingness to provide familial support.

Voluntary placements: I was interested to view how challenging disabilities were responded to, within the specialist sector, particularly as I had always held mixed opinions in regards to my own children's attendance in the mainstream and was left wondering if outcomes may have differed if they had been placed into the specialist sector. I felt being able to observe every day practices in their 'natural environment' as opposed to a formal research context was an important means to deepen my understanding of how challenging behaviours were understood and responded to. I also felt such observation, might reveal unstated opinions that are perhaps taken for granted and hence unstated. I subsequently chose to seek placements in two disparate contexts; firstly an independent special school which caters to the needs of children with disabilities and secondly a pupil referral unit, offering education to children and young people who have difficulty accessing mainstream education, typically because of formal permanent exclusion.

I undertook voluntary work one day a week for over two academic years (one year in an independent special school (ISS), then one and a half years at a pupil referral unit (PRU). I found having a defined role, facilitated my assimilation into both institutions, as despite my initial introduction as a PhD research candidate, I was soon just considered another pair of hands (both to pupils and staff). Participant observation is an established social research method which holds both strengths and weaknesses.

It has been considered an amenable method to enable the 'researcher to see the way both students and teachers' classroom behaviour is influenced by the school, community and entire society in which they are located' (Brown 1984 pp 129). Hence I determined that data gathered in this manner was particularly useful, offering a further dimension to the layered profile of understanding I was aiming to compile. The longitudinal nature of this research did however have practical implications. In particular I found that as time progressed that the data I was accruing was causing a shift in my previously held position that the specialist sector, particularly the ISS, was a haven for children and young people who did not fit through disability into the mainstream. Consequently this necessitated constant vigilance to avoid me influencing my respondent families as many had high hopes for the special sector.

Placements were chosen to afford insight into the mechanics of the specialist sector. The first placement at the ISS, catered for pupils with physical and cognitive disabilities through both the primary and secondary sectors. Despite charitable status the school was managed on a highly regulated business model. The second placement, a maintained PRU, also catered for pupils spanning both primary and secondary level, offering provision for pupils excluded from neighbouring mainstream schools. Placement in the PRU was essentially temporary; the accepted norm a twelve week period to afford assessment of need, acting as precursor to future placement across the specialist and mainstream sector. In practice nevertheless some pupils were unable to secure (or sustain) a new provision and were placed in the PRU indefinitely.

Access to the ISS was facilitated by me being already known to the school (I had conducted previous research towards a master's degree) I was also known as a parent, as indeed one of my children had been placed in the school to inform needs prior to secondary school transfer. As a result I held multiple identities. Both placements were in key stage 2 classrooms (in the UK for children aged 7 – 11), although when short staffed this was extended to key stage 3 (for children aged 11 – 14). Extensive field notes were taken throughout my placements which were later analysed using a thematic content analysis method.

Individual interviews – Baroness Warnock: is most commonly associated with her role as the lead chair of the Committee of Enquiry into the Education of Handicapped Children and Young People and particularly its output known colloquially as the Warnock Report (Warnock 1978). The ensuing report resulted in a radical shakeup

of educational provisions for pupils with disabilities and challenged the parameters of surveillance, shifting focus from within child deficit to that of learning difficulty or special educational need. Overall the report radically altered both the demography and culture of mainstream schools, summoning new understandings and expectations of disabled pupils. Notably in 2005 Baroness Warnock initiated a fierce debate: delivering an open critique of Inclusion amidst concern toward the educative provision for certain pupils with disabilities and SEN (Warnock 2005). This introspection and open contestation of a policy that had been personally definitional, suggested significant shortcomings towards how some disabilities were being responded too. I made an initial contact to Baroness Warnock by email, outlining my own circumstances and my research foci, I was unsure as to whether she would respond, however she did and extended the invitation to discuss her views at her offices. I duly met with Baroness Warnock and conducted a recorded interview that again was in the style of free narrative, albeit stimulated by my research focus and experience. Indeed during this engagement I got the distinct impression that Baroness Warnock was fascinated by my personal circumstances being an impetus to research proactivity and it was a daunting task attempting to steer the interview to her perspectives not my own familial situation.

Individual interviews – Leslie Henderson/The Toby Henderson Trust [THT]: the THT was formally registered as a charity in 1999 and was founded by Leslie Henderson. The impetus to its establishment is stated by Leslie Henderson to have been a direct response to an experienced lack of support, following the diagnosis of her son Toby at the age of nine as autistic. The central aim of the charity remains ‘firmly rooted in empowering parents, families and carers’. Despite humble origins the Trust centre now boasts an impressive portfolio of services, ranging from family advice, liaison and support service, family training workshops, holiday play schemes, respite holiday accommodation, specialist counselling service, email support for ASD young adults and an outreach programme. The THT has expanded led by the negative experiences Leslie endured and now hosts an international network of support which emphasises both need for and lack of services outside of the charitable domain.

As Leslie Henderson remains a central driving force and holds considerable experience toward how Autism is received in multifarious arenas, both from the perspective of a professional and that of a parent, I considered her knowledge and

expertise to be highly relevant to my own research. Email contact was made outlining my research focus, parenting status and my desire to discuss further Leslie's own parenting insights. This resulted in an invitation to meet where I again conducted a free narrative interview.

Of all the interviews I conducted this was the most challenging. Firstly because request to record the interview was declined, necessitating manual records which although detailed, were less satisfactory in terms of review, than an audio recording would have been. Secondly because I felt distracted by the task of having to write down the conversation as it unfolded, it made the flow of conversation disjointed, which was made worse by the presence of other staff who were going about their business at the same time.

Looking back I was struck by how awkward I felt formally writing whilst Leslie spoke, even though I had taken records at all the other interviews. I could not even equate it as similar to my observation placements as I had recorded events and ideas at suitable times on my mobile phone, never in the presence of anyone else who was aware of what I was doing. This discomfort did however make me question how truthful the interviews were, in the sense of extracting information, as through the use of audio equipment I was able to create the illusion of a conversation. Yet the engagement differed from such guise, in that I was taking a permanent record of the engagement, whilst the other party was not. This simple fact above any other highlighted to me the power disparity between interviewed and interviewer.

Personal input using an analytical auto ethnographic approach: as previously stated I felt my parenting experiences a significant asset, not least through the longitudinal insight they offered. An analytical autoethnographic approach enabled this experience to guide my research, to enable its reference to the wider domain without overpowering it. Retrospective sense making of a life lived sounds easy, but in practice not. The process resembled a puzzle, locating and placing the pieces immediately to hand, whilst searching for others. This journey was supported by select artefacts still held in respect of my younger sons and through retrospective narrative of key events, the process of recollection conceded to processes of rationalisation and wider sense making. This concluded with what might be a series of researches which I felt merited testing and it was these that essentially acted as a guide to respondents chosen and research avenues pursued. On reflection, would I choose to engage in an autoethnographic study? I am not sure, yes in respect if

something positive can come from adversity, but not in the sense of the impact on myself and indirectly on my family.

To write auto ethnographically there needs to be a willingness to visit and revisit the past. This in the course of a life in progress is not always in your own or family's best interest as it inhibits the ability to heal from trauma and to move forward. I liken it to carrying around at all times personal baggage and it takes its toll. Yet despite these cautions being stated as was discussed in section 4.2, I would suggest that it is difficult to appreciate the actual effect until it has been tried. That said, do I, should I feel a sense of responsibility, because I am privy to experiences that are untypical and therefore may be described a research asset? I remain undecided, yet committed to the address of disadvantage.

4.4.5 Collecting and generating data

To execute an analytical approach I sought to find methods that were congruent with the philosophy and approach of autoethnography. This was a challenge as I wanted to collect data from three distinct groups in the school context (teachers, SENCOs and families). It quickly became apparent that one size would not fit all. I thus determined that an eclectic approach would be more suitable, enabling me to tailor my methods to the needs of each group, and indeed the types of information I aimed to elicit. From families, I wanted to not only find out the 'what' of experience, my aim was to have families state their experiences in their own words. Not least because I felt that through the process of telling, the most salient details (for each individual family) would be stated. This was in contrast to eliciting information in a standard schedule format across all of the respondent families, which may have given rise to conditioned answers. During analysis I did, however, impose a structure on the data received from families, through the devising of a short topic guide (as detailed in section four), although notably this guide was responsive to amendment where emergent data indicated this to be appropriate.

It was also felt that a narrative approach was helpful to guide analysis, in particular to guide the data produced by teachers in the form of annotations. In particular I wanted to identify key events that could guide the generation of codes and eventual themes and using a narrative approach facilitated this. Overall the principles and method of analytical autoethnography (previously discussed) guided the design and foci of my study, whilst a narrative approach guided how a significant proportion of my data was

collected and analysed. This section now considers the narrative approach, and its suitability to both data collection and analysis.

Narrative: Clandinin (2000) offers a very simple but comprehensive rationale for adopting a narrative approach; namely as a means 'to understand experience ... a collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus' (pp 20). Bruner (1991) states similarly; 'we organise our experience and our memory of human happenings mainly in the form of narrative, stories, excuses, myths, reasons for doing, and not doing and so on'(pp 5).

Bruner also emphasises the narrative research process is only a brief interlude in a respondent's life, thus the researcher needs to be minded that any account is not whole, it is part of an ongoing story.

Bruner's sentiment is a timely reminder that the data generated through narrative develops as a consequence of research engagement, which itself may be described as a temporary breach, a demarcated pause which enables the respondent to reflect on key events and their impact. It is not the whole story however, that is ongoing and during my research, events happened in the families lives (between initial and revisit meetings) which impacted on the sense they made of their stories. It is thus imperative to appreciate that a respondent's narrative is essentially incomplete and ever mobile. These features were foundational to my decision to employ a narrative approach and to invite families to follow up interviews one year after the first meeting to consider 'the story' later in its development.

At this point it would be reasonable to decide that each story is unique and hence incomparable. Floersch (2010) nevertheless maintains that whilst narrative 'adds temporality and plot', thematic analysis allows one to detect patterns in the data set' (pp 408). It may also be said to be a part of the researcher's task to make judgements about what is not included. Squire suggests that narrative approaches elucidate 'how narratives are silenced, contested or accepted' (ibid, pp2). In a similar vein, Rappert (2010) draws attention to the complication of not what is there, but what is not. The 'secrets and absences' inherent in social research (pp 571). Equally significant is that Tamboukou (cited in Andrews 2008) cautions against accepting narrative at face value, advocating for a genealogical approach which can reveal the 'discursive constructs of historical contingencies' (pp 104). This may be said to be calling for a wider interrogation of narrative, to discern the wider imperatives

impacting on individuals narratives. This task, at face value appears particularly onerous and deeply subjective, yet Webster and Mertova (2007), suggests narrative can be usefully referenced to critical events, 'events that are instrumental in changing or influencing understanding' (pp 73). It may therefore be plausible to consider these events against the wider domain, to form an impression of contingent factors in the wider domain.

Although narrative is traditionally associated with spoken accounts it has been suggested that all of life is 'known' through narrative (Czarniawska 2004) and indeed narrative may be said to be the way individual and collective experience is processed and understood, which renders it a prime source of data. Problematically however, although Bruner (1991) defines several core features of narrative, there is no stated method of operation. As a result, narrative research also presents as an approach, rather than a discrete method, although Bruner does define several core feature of narrative which are discussed in the following section.

Bruner's core features of narrative: Bruner (1991) offers a comprehensive list of key features that combine to define the constitution of a narrative. In this way despite the lack of a prescriptive method to guide a narrative approach, the defining of key features, enables us to visualise what it is as researchers we are attempting to elicit. Although the wording of these features is dense, their meaning when unpicked offers a common sense view of the particulars of a narrative. The first feature Bruner references is 'Narrative Diachronicity' (pp 6), which in translation means to occur over time (life span or part of, rather than single instance). My research met this criteria as I was requesting families take stock of past, present and future issues. The second feature listed is 'Particularity' (pp6) and refers to the taking as reference particular happenings. Looking at the foci of this research, not least disability disadvantage, I considered it to be implicit that it would be key events that emerged as relevant, rather than more mundane occurrences. Bruner goes on to list what is termed 'Intentional State Entailment' (pp7), by which it is stated that a key feature of narrative is that it refers to people acting in a setting, thus the 'the happenings' they reference must be relevant. As I invited families to discuss their experiences of their children's schooling, it was reasonable to expect the stories told would reflect that context.

The structure of account is also held to be a key feature by Bruner (1991), this is described as 'Hermeneutic Composability' (pp7) and demands that the component

parts of a narrative (the sequences of a story) serve as functions of the narrative structure as a whole. They therefore must have a part/whole textual interdependency. I anticipated the stories parents shared would have a logical congruence, and that as a whole the parts of the story would form an overall picture, although it was equally probable that not every word uttered would be relevant to the research foci.

Bruner states that during the act of recounting a narrative, not every aspect of the communication chain will constitute a narrative, indeed much of the communication process will consist of mundane (textual fillers) without any salient features. This feature points to an important role for the researcher conducting narrative research, namely the interpretation of what is or is not part of the overall narrative. Squire (cited in Andrews, 2008) states that 'narrative allows one to see different and sometimes contradictory layers of meaning and to bring them into useful dialogue with each other' (pp 1). Bruner further states that it is breaches of expectation which renders a respondent's account 'story worthy', a feature he termed 'Canonicity and Breach' (pp11). This may briefly be considered the contrast of the expected script and the breach of script through an event that is unanticipated, yet story worthy.

The notion of storytelling is suggestive of fiction, raising concerns over the validity of accounts. This is addressed by Bruner who suggests that the validation of a narrative relies upon its appearance of truth (verisimilitude). It is thus 'Referentiality', rather than its verifiability that is key. Overall a defining feature of a narrative, irrespective of foci, is that it should be commonly comprehensible and thus understandable. Bruner describes this (rather opaquely as the 'Genericness Genre'). Finally it is stated that due to issues of 'tellability', narrative is always 'Normative'. Essentially its overall guise, although historically and culturally fluid, is that it is both context dependent and culturally negotiable, governed by social and discipline traditions.

These descriptors further supported my decision to employ an unstructured 'interview. I also decided that to further situate myself as an 'insider', I would open the interviews with an outline of my own parenting experience. I considered this would be a positive way to reassure families that I was not going to judge them; and so make them more likely to share openly through narrative their experiences of the school system.

Equally it was determined that a narrative approach (using the broader meaning of the term narrative, in a manner similar to that implied by discourse), was equally of utility in relation to how I analysed data generated from my main respondent groups, but also the key individuals I interviewed and the longitudinal observations I undertook. This involved reviewing my data, looking for the body (themes) of the narrative and then tracing their relationship to other factors in the wider social and structural system. In this manner, a narrative approach was facilitative of the analytical stance discussed previously in relation to autoethnography in subsection 4.2; and essentially moved the data from a disjoint collection of individual recollections and opinions, to a coherent body of data which is able to reveal patterns and associations.

Semi – structured interviewing: A semi – structured approach was considered most suited to interviews conducted with SENCOs, primarily because I wanted to elicit specific information from them, which in constitution emanated from their role and its responsibilities. Horton (2004) recommends a semi-structured approach, stating it offers flexibility to enable respondents to focus on areas of greatest relevance and also enables researchers to probe and clarify pre-identified areas of interest. Certainly this sentiment was primary to my decision to adopt such approach with SENCOs, particularly as I was interested to probe not only whether any particular medical labels were contested, but how schools responded to behavioural difficulties in general and the extent to which they triggered association with disability. As Bryman (2008) states where the researcher has a clear notion of the research areas to be investigated, a semi – structured approach is appropriate. Bryman also emphasises that the semi-structured approach contains within itself considerable scope for flexibility, particularly in respect of how rigidly the interview (topic guide) is administered. The identification of such leverage partially addresses common concerns, not least the danger of leading response and limiting the opportunity for other priorities to be stated.

Silverman (2000) also alerts to further methodological issues, in particular whether 'interview responses are to be treated as giving direct access to 'experience' or as actively constructed narratives' (pp45). In respect of my own stance, I would argue that I tend toward the latter position, which is congruent with the overall research approach and philosophy. This does however summons the question as to why I did not use an open narrative approach with SENCOs as I have done with families and

indeed to a lesser degree with the individual interviewees. As I have stated previously, I considered SENCOs a preliminary source of information, to guide the ranking lists for teachers and to give me an overview of school positions and processes in regards to disability response and opinions toward medical labels generally. This required a degree of standardisation that only a loose structure could provide, although I was keen to avoid any approach which might restrain the expression of any emergent issues. Barriball (1994) states a semi-structured approach is appropriate when there is a need for response comparability as it can 'ensure that all questions are answered by each respondent' (pp 329). With such sentiment in mind I felt a semi-structured approach could be both justified for this aspect of my research and also compatible with the overall approach.

Diamond ranking exercises: Diamond Ranking is a popular method of visual data collection, typically employed by schools to engage childrens opinions (Europe 2006, Gateshill 2010, Woolner 2010, Niemi 2015).It also holds precedence with adults (Maceviciute 2009) and is a suitable method of data collection where evaluative opinions are sought. Rocket and Percival (2002) have referred to diamond ranking as a thinking skills tool, whilst O'Kane (2000) asserts 'diamond ranking activities are powerful tools for clarifying ideas and concepts as they involve discussion, sorting and prioritising of issues' (pp 149).

In essence this was what I required, I needed an easily (briskly) implemented stimulus to prompt teachers to evaluate their own opinions, essentially a means of extending permission for them to do so. I was conscious that such activity may have not been previously addressed and that for some teachers, thinking in this way may engender emotion akin to guilt. Particularly as the exercise required the respondent to think critically about medical labels, which through engagement may feel like a discriminative exercise, at odds with egalitarian principles of Inclusion.

Conventionally the ranking lists nine choices, demanding a hierarchical evaluation. Typically the method relies on the stimulation of group discussion which is considered as an important source of data as the ranking sequences themselves. Hence its employment as a solo exercise was considered ambitious and replaced joint discussion with the invitation to annotate.

As a social research method, diamond ranking it is stated to make explicit 'the overarching relationships by which we organise knowledge' (Clark 2012). This was a

key factor in my decision to employ it as a means of data collection from teachers, although it had not been my first choice. Typically adherents to Personal Construct Theory commonly employ a repertory grid method of data collection; method which enables the detailed profiling of conceptual constructs which accrue around a given topic. In this way it is possible to compile a detailed profile of the meanings attached to a given focus, along the axes of positive and negative. Its implementation was however impractical, taking into consideration the constraints on teachers time I had been cautioned about. Diamond Ranking exercises were thus considered the next best fit and are philosophically compatible with Personal Construct Theory as in implementation diamond ranking invites the hierarchical evaluation of a given point of focus, hence alludes to constructs held. Thus when conjoined with a request for annotation, ranking exercises offered an effective (and time efficient) means to stimulate the evaluation of medical labels.

Practically, to compile the list of medical labels for the ranking exercise I was led by the scope of information sought (as expanded upon in the next paragraph) and the most prevalent types of disability presenting in schools (as indicated by SENCOs). I subsequently referenced the listing compiled against similar listings of prevalence which are offered by online disability specialists Douglas Silas and the online teaching resource webpage, entitled 'Teachnology'.

The final listing whilst not exhaustive, was strategic. My intention was to include not only the most commonly presenting types of disabilities in schools, but also to include physical disabilities as a homogenous grouping, specifically to test for any crude differentiations held between physical and psychological disabilities. I was also keen to test if physical disabilities were universally accepted and to what extent actual physical indicators of disability generated validation, as opposed to impairments that might be deemed of organic origin. I subsequently included the category ME in the listing, alongside Autism and ADHD as two most commonly found conditions evident in schools, whilst also including the lesser known categorisations A/typical Autism and Pervasive Developmental Disorder, non -specified. These latter categorisations were at the time of the data collection, commonly used labels to explain otherwise undefined behavioural/psychological irregularities. They are now following the revision of DSM 5 consolidated within the spectrum of autistic disorders, thus it was interesting to test teachers familiarity with these labels; particularly as pupils

displaying similar symptoms will now be liable to be given the label ASD, which is a much more familiar term.

It was determined that only categorisation types consistent with 'normal' or 'average' intellectual ability would be included, as these would represent the range of students most commonly presenting in a mainstream school. I aspired to produce a balanced list, hence discrete medical categories were included alongside impairments that are more specific to the educational domain, namely Dyslexia and Dyspraxia and the generic category of Social, Emotional and Behavioural Disorders. This resulted in a final list of 11 categories which are listed in the appendix.

Drafting the ranking exercise question presented further challenges. I wanted to elicit as truthful a response as was possible, without stimulating wider debate around the utility of medical labels or indeed the implications of labelling. This determination did not reflect my own personal stance, or opinions on the subject of labelling; rather it extended from an awareness that medical labels are central to the sense made of difference in the school context and to resource entitlements, irrespective of wider debates around these issues. Medical labels were thus viewed as working tools and as such were considered a legitimate focus of study. To emphasise my position, I prefaced the exercise questionnaires with a statement acknowledging that although the medical labels listed implied engagement (and possibly endorsement) of a medical model, this was not necessarily my own stance, nor was I endorsing, or rejecting such stance.

In implementation I detected a level of reluctance and respondents at times struggled with the implications of what I was asking them to do. Notably some respondents refused to rank and simply scored out the list, stating all were equal. During analysis I grappled with the implication of this position, finding that just over 10% of respondents (13.3%) had indicated similarly. The outcome of these deliberations was to consider the other part of the equation, namely that over 80% of respondents were willing to rank and to offer reasons for doing so. Thereby indicating that medical labels attracted an inconsistent response in respect of validation.

Quick Questionnaire

The decision to implement a quick questionnaire was taken as previously discussed, firstly because of difficulties encountered engaging teachers and the realisation that some teachers were struggling with the exercises. Initially the approach appeared

contrary to my ambition to elicit a deeper appreciation of teachers opinions toward medical labels and issues of behaviour. I was however persuaded that a short easily completed questionnaire could complement the more finely nuanced data diamond ranking exercises had offered. Thus testing for broader opinions that may or may not be congruent with the ranking data generated. I was thus able to reconcile using this approach within a wider constructionist frame.

My intention had been to engage schools who had previously taken part in the ranking exercises, however there was a reluctance of schools to re-engage for a second time. On that basis I felt it could be justified to seek participation from schools outside of the immediate boundaries of the city. I intended to gauge familiarity toward the range of medical labels I had initially listed for my ranking exercise, although I did add in a question asking about familiarity towards genetic disorders. A preliminary consideration was the number of items to include in the scale. Mattel (1971) addressed this issue finding in relation to validity little difference between 5, 7 and 9 point scales. Nonetheless I was cautious that if I employed too many points, it might cause confusion and inhibit a respondent's ability to indicate finer distinctions. Jordan (1996) usefully suggests 'usability is not a quality that exists in any real or absolute sense, rather it is the scales 'appropriateness to a purpose' that is of greatest significance (pp 189).

Bryman (2008) notes both advantages and disadvantages to asking closed questions, in particular closed questions are stated to be easy to process and due to a standardisation of script, considered more comparable than questions that invite an expanded open ended answer. Bryman also suggests that closed questions can clarify the meaning of a question, by providing a list of possible answers. When determining the suitability of this approach, this point was particularly important and allowed me to ask direct and controversial questions that may not have been fully appreciated through open ended methods. There are however also disadvantages to a closed question approach, not least the curbing of creativity or expansion of answers, although this can be moderated by request for annotation. Bryman also suggests the use of an 'other' category enabling respondents to indicate alternative responses if none of the closed answers are applicable.

Following Jordan's protocol I decided it appropriate to attempt to stimulate 'extreme expressions of the attitudes being captured' (pp 191). In the case of my research, this involved exploring both familiarity of and confidence toward medical labels. I also

wanted to probe to what extent teachers considered behaviour to be symptomatic of disability. For example I asked outright whether teachers felt confident that all medical labels were equally valid. I also probed opinion as to whether teachers felt confident that the expansion of medical labels questions represented medical progress. These were questions which struck to the core of my research and I found the approach highly user friendly, both in time and in pressure. The questions I addressed were there; thus there was no subtle intimidation. Thus although controversial, a useful amount of data was generated which confirmed the existence of challenge which was intimated in the data elicited from the ranking exercises, both in and out of institution.

It is worthwhile at this juncture to illustrate to the reader the diversity of the participating schools, this is presented on the following page in table 3. As can be seen there was significant variation between schools although all were what is termed mainstream schools. Nevertheless within the participating schools there was a faith single sex school, a school with an additionally resourced centre (ARC) and a cross section of mixed maintained secondary schools from a wide geographical area. The schools may therefore be seen to be representative of the range of available state schools within the area.

4.4.6 The Schools

Aldridge: Aldridge school was a local authority maintained secondary school at the time of engagement and was on the point of being placed in special measures. It has now been taken over by a neighbouring school and operates as a skills specific academy. It catered for up to 1200 pupils and was situated on the outskirts of a main city in what may be described as an area with low aspirations, punctuated by high unemployment and social deprivation. At the time of interview over one third of pupils were eligible for free school meals and the school indicated a high number of pupils had SEN status. It was however plagued by management difficulties and parental discontent, which may itself reflect the area of social unrest it was located in.

Brown Meadow: Brown Meadow School is a small local authority maintained secondary school situated in a densely populated urban area, mostly comprised of social housing. It is host to many transient populations and there is a high percentage of children for whom English is a second (or for some third) language. Brown Meadow also has a high take up of free school meals and looked after children. Although the school is small, hosting only approximately 600 pupils, it is keen to expand its supportive network and at the time of engagement was looking to join with partner schools to form a Trust.

Highfields: Highfields School is a large local authority maintained secondary school set amidst a heavily populated area which exhibits extreme social contrasts. To the left of the school are some of the most expensive homes in the city and to the right is a large former (and in some cases current) council estate. The school has over 2000 pupils and is heavily oversubscribed, it attracts pupils from all over the city, although the majority of pupils reside within the catchment area. Highfields has had a mixed reputation, which has historically resulted in a change of headship. Currently Highfields maintains a reputation for delivering above average examination results alongside a highly inclusive and creative culture of leadership.

Low Ridge Secondary: Low Ridge Secondary School is a local authority maintained school situated on the outskirts of the city amidst what was in the 1970s termed locally as a new estate. The estate itself was a housing initiative to rehome many council house tenets following the council's slum clearance initiative of the period. The area remains predominantly comprised of rented social housing and high

unemployment. Nevertheless Low Ridge Secondary presents itself to be an innovative and inclusive, promoting the welfare of both pupils and their families. Low Ridge Secondary hosts approximately 1200 pupils and has approximately one third of its pupils entitled to free school meals.

Saint John's: Saint John's Secondary School is an independent faith school for girls which has just attained academy status. The school is located in a densely populated area just outside of the immediate city boundary. It is housed in a former grammar school which is badly in need of investment to update it. Saint John's Secondary school boasts of a Catholic inclusivity which underpins its pedagogical approach. The catchment area is predominantly within the local dioceses, however it also attracts pupils from outside of the area. Most recently it has started to outsource some of its pupils to a bordering Catholic boys school for subject specific classes at A-level. The school describes itself as one of a consortium of Catholic faith schools. The school hosts approximately 1000 pupils and has only an average percentage (14.5%) of its pupils entitled to free school meals

Saint Francis: Saint Francis is a co-educational local authority maintained Catholic secondary school set on the crossroads of three established suburban areas. It has provision for approximately 1600 pupils and was established in the late 1960s. Saint Francis attracts pupils from across the city on the basis of being co-educational. Saint Francis pupils are socially and ethnically diverse and reflect the overall social makeup of the surrounding areas. Saint Francis was at the time of engagement preparing to undergo a new build, this regeneration was reflected in their stated pedagogical vision. Saint Francis boasts of having a rapidly expanding and responsive learning support centre and prides itself on its ability to retain pupils.

Saint Luke's: Saint Luke's is a Catholic all boys school who is partnered with Saint John's all-girls school and accommodates approximately 1500 pupils. Saint Luke's has recently been awarded academy status and admits to being highly competitive. It is located just outside of the city boundaries and attracts pupils from across the region. Saint Luke's may be described as oriented to a traditional education with a clearly delineated hierarchy. Saint Luke's also emphasises the virtues of discipline and self-motivation. It notably does not allude to a policy on inclusivity, although does indicate its pupil base to be diverse. The surrounding area is densely populated

and exhibits many contrasts of modest affluence and social deprivation. Nevertheless school meals entitlement is indicated to be below average.

Wellington: Wellington School is situated on the outskirts of the city in an area that is best described as rural. It is a former mining community and many of the local residents retain former connections to the industry. Despite being situated in an area of relative social need, Wellington may be described as aspirational and inclusive. It has recently been accepted to host an additionally resourced unit (ARC) for pupils on the autistic spectrum and prides itself on its abilities to retain pupils exhibiting additional needs. Wellington indicates an above average level of free school meals take up and this is congruent with the social makeup of the area. It provides educational provision for approximately 1300 pupils although as the green belt area it borders is subject to development, the school anticipates its population to expand.

Participant observation

Dewalt and Dewalt (2011) describe participant observation as 'a method in which a researcher takes part in the daily activities, rituals, interactions and events of a group of people as one of the means of learning the explicit and tacit aspects of their life routines and their culture' (pp 12). This differentiation between explicit and tacit knowledge highlights the essential utility of this approach and my rationale for its use. Tacit knowledge is stated by Dewalt to be 'outside our awareness or consciousness' (pp 12) and it was this unstated but present knowledge that I was most interested in. As a parent of children with behavioural issues I had felt that the special sector may logically have a greater tolerance of challenging behaviours and by default less inclination to level accountability. Certainly previous data elicited from the ISS had indicated this to be the case. Equally I was aware of the PRU and knew it to be the place where children with behavioural difficulties were sent, following mainstream placement breakdown. Indeed in the mainstream school my own children attended, the PRU was spoken about to children and parents as a veiled threat. I was therefore eager to both interview the acting SENCO and to view for myself how these views played out in practice.

Spradley (2016) states that when studying other cultures (and I would argue that this is equally applicable to one's own culture) that there are three main elements of note. These elements are what people do, what they know and what they make and

use. I felt these guidelines were highly useful to guide broadly my observation and indeed it was interesting to reference what teachers actually did, against what I as a parent and what other teachers in the mainstream suggested they did. This underpinned my overall desire to find out, what if anything was special about the special sector. Finding out what teachers knew was equally pertinent in respect of medical labels and the state of disability and challenging. I like many of the families engaged with my research, felt the special sector would be more insightful into the implications of the medical labels our children had, or were being assessed for. It was therefore a great opportunity to be able to step back and observe teachers knowledge in implementation and informal speak. The area of what people make and use was particularly revolutionary to me, as this line of observation emphasised to me that schools in conjunction with families are constitutional to the making of a child/young person's identity and that at times there is an incongruence of identities sought between schools and families.

There are however many ethical and practical issues which surround the method and these needed to be reconciled before my placements commenced. Li (2008) states that ethnography is particularly suited to the study of sensitive issues; able to produce rich data that records what people do, rather than what they say they do. Li further asserts that participant observation is non – interventional (in the research sense), thus the method holds capacity to deliver more 'honest data' (pp 101) unimpeded by the research process. These factors as previously intimated were a main factor in my decision to employ an observational approach within my research. Nevertheless Li also alludes to ethical dilemmas which emerged whilst in the field. One of the most pressing issues encountered by Li was the tension of knowing when (or if) to intercede on your respondent's behalf and this indecision speaks very much to the dilemmas observed by Cooper and Rogers (2015) and by Rogers (2003).

The resolution of these boundaries may be said to have been addressed in my case as I was not aiming for a covert status, unlike Li. Nevertheless there were still questions of boundaries to be addressed and I resolved that issues of safeguarding were notifiable as a matter of course. Problematically whilst conducting my placements, this issue resurfaced, not in the clear cut realm of safeguarding, but in respect of practices that triggered concerns, but ill formed concerns that as a parent would have made me uneasy. I was therefore placed in a situation where I had to

determine which role I was operating under. As a parent of children with disabilities, there were times I observed practices that were to me questionable, but as a volunteer classroom assistant, I had neither the status, nor the legal rights to intercede. I found no easy resolution, apart from to write my concerns into my research, as indeed they were integral to my eventual determinations. On reflection I feel I was perhaps a little unprepared for the range of issues that I faced, hence if I were to pursue similar research, I feel that there would need to be greater pre-determination of similar issues, rather than deal with such issues reactively.

Li (2008) concludes that the 'revelation of hidden realities and the pitfall of ethical dilemmas are co-existed realities that are not easy to reconcile' (pp108). I would tend to agree, particularly as in my case I was familiar with some parents from the ISS and indeed my sons knew pupils from the PRU. The decision as to which role to follow is difficult and it is untenable to believe that all roles are compatible. I chose to honour my role as a researcher and as a volunteer classroom assistant and felt it best to leave 'niggling' concerns. Not particularly because I felt unsure of their voicing, but because I felt little good could come of such voice, with the status held, I may simply summons anxieties and resentment and in so doing jeopardise the bigger picture. Li (2008) speaks of the need for 'psychological preparedness' (pp109) and I would concur that this is indeed warranted.

The issues I faced conjured dilemmas that were not easily reconciled, yet these dilemmas may be seen to be led in part by the nature of the field being entered and the profile of the group within. An extreme example is provided by Pearson (2009), who poses some very difficult questions in relation to research being conducted on criminal groups. Although this was not a field I was entering, the sentiment is still valid. Pearson states that insider participant observation is sometimes the only means of gaining access to groups that are generally distrustful, as indeed Li (2008) found similarly. Nevertheless as Pearson emphasises, there are uncertainties about how to fulfil this role as guidelines 'give little guidance either to individual researchers or ethics committees on how such methods can be used in practice (pp 252). This lack of guidance was indeed an issue as the mainstay of ethical research is informed consent and in certain instances it was not easy to gather or reinforce incrementally such consent when my placement was over a longitudinal time frame. Particularly as after the first few weeks I ceased to be seen as a researcher, but rather a junior

member of the classroom staff. I would therefore concur with Pearson that there needs to be more guidance to enable researchers make informed decisions, both prior to entering and whilst in the field.

4.4.7 Determining a frame for analysis

May (1993) states, 'Social theory is not something that can be separated from the process of social research...theory informs our thinking, which in turn assists us in making research decisions and sense of the world around us' (pp 20). I was mindful of this sentiment both in my study foci, research design and means of analysis. This section considers the manner of analysis and the practical implications of an analytical approach, particularly in relation to the notion of criticality. This section also introduces to the reader to an analytical template which was employed as a guide to the final research conclusions. Both of which were considered congruent with the ontology outlined in section 4.1 and the methods employed as detailed at point 4.4.3.

Anderson's claim to analytical autoethnography as a discrete approach may be seen to extend from the sentiment of what has been termed critical ethnography.

Hardcastle (2006) states that 'critical ethnography aims to link social phenomena to wider sociohistoric events to expose prevailing systems of domination, hidden assumptions, ideologies and discourses (pp 151). Such linkage which was found to an essential consideration in respect of disability as a state of being and the medical labels used to explanation both cause and effect. Not least as section 2.1 and 2.5 illustrate, the past and present are irrevocably intertwined in terms of knowledge, practices and beliefs (Foucault 1981, Fuss 1989, Sagan 2011).

Critical research may be considered to represent a synthesis of Constructionism and Post Structuralist approaches, as developed methodologically by Cannella and Lincon (2009). It is viewed as an essential guide to research enquiry and analysis as it directs address to both the individual and collective domains. A critical approach is framed around two foundational questions asking who or what is helped, privileged and legitimated and who or what is harmed, oppressed or disqualified'? (pp 54).

Although the critical approach is attributed to a more recent research past, its previous influence can also be evidenced. For example Carspecken (1996) developed five stages of critical research, referencing what is told, to what

structurally and relationally exists and although this research does not replicate the stages advocated by Carspecken, the sentiment summed by Carspecken's statement (below) has informed the research intent, design and analysis:

'Those of us who openly call ourselves 'criticalists' definitely share a value orientation. We are all concerned about social inequalities, and we direct our work toward positive social change. We also share a concern with social theory and some of the basic issues it has struggled with since the nineteenth century. These include the nature of social structure, power, culture and human agency, we use our research to refine social theory rather than merely describe social life' (pp3).

It was however considered insufficient to make claims to criticality without a plan to effect the stance. I therefore framed my analytical approach around a series of questions posed by Willig (2008), these are discussed below in relation to my research and are fully listed in my appendix.

Firstly Willig directs us to consider how the 'discursive object' (be it medical label or pupil identity) is constructed through language and social practices. This approach demands a critical eye, one that is mindful of the both relationships of power and the generation of meaning through social engagement. It is therefore highly useful for a study focused upon disability disadvantage. Willig then indicates need to consider what type of object is being constructed. This invites one to look at the data in terms of the values being conferred, in this respect in terms of familial status, pupil status and indeed disability status. A central question for me was how is accountability warranted and in analysis it is found that disability status is inconsistent where behaviour is an issue and indeed disability status is found to be superseded by other objects/labels which pertain to conduct and psychological status. For example EBD pupil and youth offender.

Willig's template continues by inviting address of the foundations identified discourses are built upon; and in terms of my research these were found to extend from the fields of medicine, pedagogy and law. Notably as previously discussed, these discourses are not always congruent with each other, leading to the supersession of some priorities over others (O'Connell 2016). Practically such approach necessitates a 'tracing of the dots' in conjunction with as Willig indicates, consideration of the relationship between discourses. This can be seen as a call for the appreciation of connectedness, which in regards to disability and social position, necessitates both an historical understanding and a contemporary consideration of

the functions served through identified discourses. Willig's template progresses to ask what the constructions identified from discourses achieve, a consideration which became foundational to the development of the Culpability Model. Most specifically it was found that accountability (as evidenced through school exclusions and disadvantage), served to enable schools to maintain legal compliance with the demands of inclusivity and governmental demand to evidence ever increasing school attainment.

Willig's template subsequently directs attention to the subject positions extending from identified discourses. In terms of my research, the most obvious construction was blameworthiness, both in respect of the child and indeed the family. Willig's call to consider the possibilities of action deriving from identified subject positions is also helpful, as it highlights the exercise of power. Indeed the narratives parents shared, indicated that the ability to exercise leverage in terms of accountability was directly linked to the occupation of wider subject positions, themselves determined by both ownership and access to cultural and capital resources. These took the form of traditional class indices, namely education, occupation and wider network connections (ONS 2010). Notably Willig's last direction asks 'what can potentially be felt through and experienced from the available subject positions' (Willig 2008, pp 129). This last directive draws attention most strongly to the life effects of social engagement and the subject positions which accrue. These presented as both positive and negative and in the case of my research extended a life trajectory, which rebounded into wider arenas across the child's life span.

Overall Willig's template invites us to think about how people and objects are constructed, signalling an approach that implies a disavowal of absolute agency. I felt this approach to be particularly useful given the arbitrary nature of medical diagnosis, particularly the criteria underpinning medical labels. The nature of engagement within both the medical profession and the school system sustains the contention that there is an unequal relational element to both subject positions and the exercise of free will. This was found to be foundational to the capacity to adopt or reject a subject position, not least in regards to childhood diagnosis, where consent is given by a parent carer.

Looking further at these issues it was determined that the act of diagnosis, of defining subject positions and indeed of their acceptance or rejection was led by the

knowing of the person by the other. Children are therefore vulnerable to being tainted or protected by the identity of their parents/carers. It is therefore suggested that processes of identity are less than objective, hence amenable to Willig's frame.

4.4.8 Thematic content analysis

A narrative approach was adopted to guide a **Thematic Content Analysis** (TCA) and its employment led me to focus on key events that respondents had narrated to me. It also caused me to reflect on the key events I had picked out to act as referents for my study. TCA is an accepted 'method for identifying, analysing, and reporting patterns (Braun 2006). Nevertheless it is also cautioned that 'thematic analysis is a poorly demarcated yet widely used qualitative analytical method' (ibid pp 4).

Smith (in Reiss 2000) endorses textual analysis, suggesting 'content and narrative analysis can provide information that may not be accessible by other methods' (pp 313). It is further stated that 'language tells more about people than they want to disclose, or that they know about themselves' (ibid). Considering the scope of my research, particularly its focus on subjective understandings, the employment of a narrative led Thematic Content Analysis was considered the most suitable choice for analysing the majority of data gathered.

I still needed to address Braun's cautions in relation to the employment of TCA and in address Braun (2006) demarcates five stages to guide the analytic process. These were a helpful prescription to guide a novice researcher and discussed presently and are listed in my appendix. The first stage Braun indicates surrounds a general familiarisation with the data, essentially an overview to stimulate initial impressions. This it is anticipated will set in motion the delineation of general initial codes, which can be refined into initial themes. In respect of my research one of the most common impressions gained was the search for explanation of difference/disability and determinations were found to divide between organic versus cultural/environmental explanations. A second impression surrounded explanations for an inability to meet the challenges and needs of certain pupils, which was directed by both teachers and parents to a variety of sources. Across the data sets a list of themes was developed which upon review led me to determine that there a divide evident in respect of which disabilities were considered accountable and which were not. Blame was found to be evident (in different guises across the data sets), whereas accountability

emerged as linked to the type of disability manifesting and was primary to the development of the twin pathways of attribution. Overall Braun's breakdown of the method of TCA offered a practical guide to 'doing TCP'.

Looking at the wider implications of the data as was discussed in relation to the adoption of a critical approach and Willig's (2006) template, Smith (ibid) also offers practical guidance to the coding process. This involves the implementation of two levels of analysis: firstly observance of the manifest/ordinary meaning in data, and secondly latent/inferred or underlying meaning. These guidelines were also considered a practical means to meet the practical requirements of both a critical approach and the stages of analysis as demarcated by Braun (2006), yet in my final decision were felt to offer little more in terms of depth of analysis than is offered by Willig's template. Finally it is acknowledged that the analytic process is highly subjective in practice and demands decisions, rather than a clinical overview of data and that such subjectivity is most apparent during the coding process. As a consequence the analytical stages were iterative, involving retrospective reflexivity to guard against the superimposition of meaning on the data.

4.4.9 Descriptive statistics

Descriptive statistics were employed to manage the quantifiable data generated through ranking exercises which led to a hierarchical evaluation of medical labels commonly diagnosed in childhood and on the basis of which the status of disability is conferred. Although numerical composition might appear to be the antithesis of meaning and understanding, numerical collation held potential to expose patterns of evaluation and acted to enhance the visibility of a large data set. This enabled me to generate graphic representations which were an aid to understanding and analytical connections. I did not however employ parametric analysis even though Norman (2010) challenges the parametric assumptions of statistical usage, suggesting that 'it does not seem to matter either way if they are violated' (pp 626). Whilst such position was acknowledged, employment of the statistical software SPSS was restricted within the study to calculation of frequencies, reflecting the nonparametric nature of the data obtained.

4.4.10 The generation of themes

Across the data sets there were multiple initial codes and a wide selection of themes. These themes were often context specific and related to particular circumstances of the respondent groups. When reviewed systematically they revealed a deeper rationale, which was foundational to the contextual themes identified. For example training was found to be a recurrent issue for both teachers and for parents. However, this issue was led from the perception of a lack. Lack of competency, self-efficacy, empathy or disability specific knowledge are but a few examples. Similarly parenting was a recurring theme for teachers and emerged in varying guises, for example parental engagement with school, diet at home and coping resources are but a few examples. However the implicit subtext underpinning these themes is one of accountability. The disabilities or unattributed challenges are seen to derive from an environmental source and are thus accountable. Thus as is illustrated in the next section it was determined that the accordance of two Meta Themes could be justified as the sentiment they embody pervaded all of the subordinate themes across the data sets.

4.4.11 Meta themes

Overall two Meta themes were determined and which were considered to represent the driving sentiment behind all of the subordinate themes detected across the data sets. These were identified as **Accountability** and **Lack**. Accountability because it signified the validation of the practical enactment of blame in varying guises and lack because across the data sets discourses were punctuated by the concept of what was missing, of lacking. These 'lacks' included lack of support, lack of ability, lack of understanding and for the challenging child, lack of control, both personal and familial. Lack was therefore punctuated by absence in conjunction with conjectural rhetoric as to what was needed. This of itself was not unsurprising, however what was notable was that even when a disability was identified and a medical label accorded, discourses of personal and familial lack in respect of control persisted.

4.4.12 Reliability of data

There is increasing concern that the subject matter of social science is unamenable to scientific research due to an inherent 'messiness' of the social world Law (2004).

This not only suggests that energies expended on methodological purity may detract from social richness, it also suggests that the yardstick for the evaluation of research output must change and indeed no longer meets the criteria for the scientific markers of validity and reliability. Law invites us to 'imagine methods where they no longer seek the definitive, the repeatable, the more or less stable, where they no longer assume that this is what they are after' (pp 6).

This contention strikes at the heart of the qualitative or quantitative debate. It also has important ramifications for the issue of scientific integrity (Donmoyer 1996) as the delineation of validity is intrinsically linked to the conceptualisation of the subject matter studied. Equally so philosophical position on the nature and guise of knowledge. Claims to truth are hence a lesser issue for many qualitative researchers as 'truth' itself is a contested term. Nevertheless, the means to assess data validity remains of issue. Creswell and Miller (2000) find the traditional markers of validity and reliability to be problematic where a qualitative approach is employed, stating that there is a 'confusing array of terms for validity' and a lack of consensus in relation to choices (pp 124). They conclude that two perspectives govern choices; the 'overall lens' researchers bring to their study' and the 'researchers paradigmatic assumptions' (ibid).

Taking forward Creswell and Millers markers, I was guided by the latter criteria in respect of my own data's validity. Subsequently an evaluative approach which was sensitive to the complexity of social science subject material was adopted. Therefore as I aimed to compile a snapshot of diverse and at times contradictory understandings, each response was considered equally valid where shared openly and honestly. This stance had the effect of making validity and reliability one and the same. Hence the yardstick adopted to assess for validity and reliability were an evaluation of the means used to encourage such candour. This necessitated a reflexive appraisal of the data collection methods used prior to and post implementation, paying particular attention to the potential for leading response and/or tendency to conditioned response.

This chapter has introduced the reader to the overarching philosophy which underpinned this study, looking at the nature of the qualitative tradition and the claims to knowledge that accompany its philosophy. In particular this chapter has

justified the employment of a social constructivist frame and illustrates how this translates into a philosophy of action which acknowledges unequal social relations. This chapter has also addressed broadly in the first instance, the ethical ramifications of insider research and specifically autoethnography. This was followed by an address of ethical issues specific to this study. The chapter then proceeded to an exposition of the methods employed and an overview of the biographical details of respondent families and schools. The chapter concludes with an overview of the process of analysis and a consideration of issues of reliability and validity.

Chapter 5. ‘Challenging disabilities in childhood – the construction of a life trajectory’

5.1 Introduction

The first part of the chapters title ‘challenging disability in childhood’ is designed to convey dual meaning, signalling not only the type of disability shared, but also challenge toward generic, sentimental and tragic notions of childhood disability frequently found privileged and distorted through stereotyping (BFI 2010) and gender bias (Keith 2001). Bias which operates to disassociate behaviour from disability and silence the darker effects of these disabilities impact on behaviour (Paivi 2008, Berg – Dallara 2014, Vargas 2013, Anonymous 2014). This chapter thus identifies both lack of and need for, equal presence and response. It emphasises the need to re-conceptualise childhood disability as a spectrum of physical and psychological effects, responsive to the developmental ebb and flow of childhood. Furthermore that for some children and young people, these effects are at times unpalatable and generative of adverse behaviours, as such stimulating of responses which result in negative social identities. Accordingly the second half of the chapter’s title ‘construction of a life trajectory’, emphasises how societal responses in certain instances, generate enduring and negative profiles, constructing life pathways for the child and at times family, which are hard to circumvent even after the developmental phase ends.

The chapter begins with a brief background to the area under discussion, followed by consideration of the ethical implications raised when sharing sensitive personal experiences, involving not only a young person with vulnerabilities, but an entire family. The chapter then turns attention to how the challenging child is seen in the first instance and notes parental differentiation between what was considered to be a deep ‘emotive seeing’ (‘familial knowing’) and the more formal ‘seeing’ parents considered schools engaged in (‘formal knowing’). These processes were found to result in a differing understanding (‘knowing’) of the child. Parents indicated that they ‘saw’ their child as more than the sum of their disability challenges, whereas schools appeared disposed to form impressions based on the challenges the childrens disabilities posed, tendency which was termed ‘formal knowing’. ‘Formal knowing’

appeared common in impersonal contexts such as school, where 'seeing' and 'knowing' is led by task oriented motives (learning), alongside responsibility for population management (pupil control). Thus ability and risk posed to others emerge frequently to be the primary considerations in this context, which contrasts sharply with the nurturing role parents are motivated to perform and which appears to predispose to focus on positive attributes rather than negative ones.

The chapter proceeds to offer the reader a brief outline of narrative kindly shared by Sacha, in response to my invitation to share her experience as a parent. Sacha's story demonstrates how schools can actively resist parental claims of challenging behaviour until it is evident in the classroom. Sacha also offers a flavour of how mainstream schools struggle to respond to complex psychological need. Led not from intent, but unfamiliarity and limited resources, lack which leaves both child and family dangerously unsupported. This section is followed by the sharing of blended narrative², offering a flavour of how challenging childhoods have been experienced by families across two educational time frames. These periods refer to the primary school phase, catering for children between the ages of 4 – 11 and that of the secondary sector extending between the ages of 11 – 18. Division which emphasises to the reader how challenges which are manageable during younger childhood can, without appropriate interventions and support, escalate and develop more sinister undertones as the child approaches and navigates adolescence.

Vulnerability to disengagement during the secondary phase of education is evident statistically, sixty percent of all school exclusions relate to pupils between the ages of 12 – 16, incidence which peaks for pupils aged 14. It is also telling that although boys are three times more likely to be excluded, seven in ten of all permanent exclusions relate to pupils with special educational needs, both with and without a statement. Similarly that of these exclusions, the most frequent explanation cited pertains to behaviour (DfE 2015b).

By offering a flavour of a challenging childhood, this chapter aims to show how external accountability and limited support are not only unhelpful but unjust. The chapter concludes that there is need for pre-emptive support and intervention during younger childhood, demonstrating proactivity rather than reactivity. It is further noted

² Autoethnographic account and that of participant families is merged together to enable the sharing of such data without compromising anonymity.

that although government initiatives have founded schemes to intervene in families experiencing difficulties (Casey 2012a, 2012b), these initiatives target disproportionately families considered dysfunctional, rather than families managing a serious behavioural disability. The 'Troubled Families Programme' (Casey 2012 a b) is a contemporary example of how families have to be seen to fail to access help, rather than be identified as at risk of failing and given pre-emptive support to succeed (Bunting 2015).

As a family we struggled to find any disability specific support to manage our own challenges and despite the promises of respite and support made in childhood, up until our son was fifteen not one instance of support can be documented. Facing crisis as our son progressed through puberty we became acutely aware that we did not fit any criteria for help and indeed there appeared none to be had. Our situation echoed that which Leslie Henderson (Toby Henderson Trust) explained had acted as the impetus to the founding of the Trust. Leslie explained that not only was there a service lack for families managing a child with an ASD, but also that the knowledge wider agencies held was sporadic and often resided upon individual competencies and motivation, hence it the supports available were a lottery.

The Troubled Families Programme boasts a joined up approach, dedicated to offering holistic intervention to 'turn around' troubled families. However although the design and rationale of the programme is laudable, citing a lack of inter-agency communication as an impediment to effective support, the premises of inclusion reside upon parental and individual deficit across three core indices of disadvantage (work, education and crime), criteria which many families of disabled children do not meet. Additionally this programme emphasises how agencies assume familial crisis and behavioural challenges stem from deficit, rather as was our experience from a disability. Thus the typical advantages of education, career and home ownership become an impediment to support, irrespective of challenges faced. There is a notable absence therefore of any comparable government scheme to support parents of children with serious behavioural disabilities and as such reveals the official mind-sets which meter supports available, leaving charities and ad hoc parental groups to fill the void.

The scenarios depicted within this chapter indicate both lack of, and need for, understanding and timely intervention: understanding based on a consolidation of

'familial' and 'formal knowing, and intervention which is embedded within a disability frame and disavowing of blame for its symptomatic effects. Furthermore this narrative also demonstrates the need to be mindful of the potential for behavioural symptoms evident in younger childhood to exacerbate in adolescence. Finally as collective parental experience indicates lack of appropriate support, this chapter invites discussion as to whether such lack amounts to medical negligence, as would be considered the case if medical intervention was similarly denied to someone exhibiting a physical disability.

5.1.1 The link between 'challenging behaviour', behavioural disability and exclusion.

Challenging behaviour is heavily implicated in permanent and fixed period exclusions from school. Challenging behaviour is also a feature of some neurodevelopmental disabilities, conditions which have been linked with educational exclusion (O'Regan 2009, AA 2012, CAF 2013, CEREBRA 2013). In addition, both neurodevelopmental disabilities and school exclusion are found to foster vulnerability to youth offending (Belcher 2004, Allen 2008, Bishop 2008). As Hawkins et al (2015) observe, 'behavioural health problems in childhood and adolescence take a heavy toll over a life time, with significant impacts on rates of economic independence, morbidity and mortality (pp3). What is less clearly stated however is the extent of association of challenging behaviours with disability both within and without the school context? Such association is often unrecognised and poorly understood (CEREBRA 2013), lacking of first person account (Holt 2010b) and hence undermining of its invocation as mitigation. Problematically the prevalence of association may be unknowable in light of the rapid classificatory expansions which have been witnessed (Southall 2007) and are attributed to emergent clinical knowledge. Pathological Demand Avoidance Syndrome (PDA) offers useful example. Now assimilated within the autistic spectrum, the presentations of PDA were however until recently poorly understood, leading to its symptomatic indicators dismissal as simply 'poor behaviour' (Newsom 2003, Christie 2007, 2012, Graham-White 2015, NAS 2015, O'Nion 2015).

Recent statistics indicate that persistent disruptive behaviour now accounts for 32.7% of school exclusions in the UK (DfE 2015b), an increase of 2.1% on previous recorded statistics (DfE 2013b). These statistics also indicate that although gender, socio-economic status and ethnicity are linked with vulnerability to school exclusion,

by far greatest vulnerability extends to pupils identified as having special educational needs, both with and without a formal educational statement. The strength of association is staggering as the last published records indicate, recording that seven out of ten permanent exclusions involve a pupil with an SEN (ibid).

The significance of the statistics stated above exceed educational implication as disaffection from school is also considered to increase vulnerability to youth offending (Allardyce 2013, Henry 2012), as are certain neurodevelopmental and communication impairments, particularly ADHD (Loucks 2007, Bishop 2008, Hughes 2012, NACRO 2011, Wasik 2015). Consequently exclusion may be seen to compound an already known vulnerability, setting in motion a life trajectory for young people who are vulnerable to 'challenging' behaviours through disability. Although as Hawkins (ibid) cautions, 'behavioural health problems reflect and perpetuate social inequities' (pp 4). This sentiment suggests there to be a complex interplay of social variables contributing to disability inequity, or more precisely a person's ability to resist disability inequity.

This chapter draws upon familial narrative to illustrate how the vulnerabilities cited above, and the discourses surrounding them are generative of a negative persona which impedes the child's potential for change. Finding in addition that the personas created are often unrecognised by the child's family and do not belie the vulnerabilities neurodevelopmental and behavioural disabilities generate in relation to inappropriate conduct. The association of behaviour and exclusion with SEN (DfE 2015b) in conjunction with a vulnerability to criminal offending (McAura 2010, Krezmien 2014, Bacon 2015), suggest that persons with behavioural disabilities are at heightened risk of becoming locked into a cycle of accountability and deficit profile which they are least able to break. Such trajectory may also be said to mask the young person's vulnerability as similarly the injustice of disability accountability is masked.

These concerns teased from family narrative and personal experience are however not unique, nor under researched. Indeed the link between exclusion and offending was re-emphasised following the findings of the Edinburgh study of youth transitions and crime (McAura 2010). The Edinburgh study discovered key transitional moments in a young person's life which heightened vulnerabilities, one of which being

exclusion from school. 'Our findings have shown that school exclusion is a key moment impacting adversely on subsequent conviction trajectories' (pp 201). These findings in conjunction with the already cited vulnerabilities to offending consequent upon disability, extends even greater need to theorise and challenge not only the lack of disability association, but also the basis of societal inertia. Inertia which permits the continuance of known factors associated to generate disadvantage without proactive preventative intervention.

Seventy one percent of fixed period exclusions are found issued to pupils in the secondary sector, although exclusions within the primary sector are also indicated to be on the increase (DfE 2015b). The weighting of these figures concurs with familial experience which illustrated how the nature of challenging behaviours can exacerbate during adolescence. Experience which also indicated there to be limited interventions available to mitigate against such escalation.

Looking at the specific detail of disability symptoms, it is found that impulsivity and inappropriate social behaviour are also symptomatic of common childhood disabilities (Ballan 2012, Barkley 2002, 2011, 2012), factors also known to predispose a young person to infractions of the law. Such association necessitates therapeutic intervention rather than exclusion and criminalisation, for which the individual and his/her family are held equally accountable (Blum 2007, Carpenter 2007, 2009, Austin 2008, Holt 2008, 2012, Frigerio 2013, Macleod 2013, Wasik 2015).

Parental experience indicates how that the manifestations of challenging behaviours in childhood can result in the young person's family becoming a hostage to fate:, rather than as is often inferred, complicit in misconduct, leading to vilification through overt and covert blameworthiness (Blum 2007, Gill 2011, Macleod 2013).

Blameworthiness which is suggested to be responsive to stereotypical illusion of the good mother, successful pupil and childhood per se (Tardy 2000, Landsman 2009, Buckingham 2013). Toward address the reader is offered the opportunity to engage with real life experiences shared by families whose children exhibit extremities of behaviour that most parents will never experience. The events narrated by families challenge the assumption that families can without on the basis of parental authority halt the progression of these behaviours and thus failure to do so is held

accountable. Familial experience is juxtaposed in Chapters five and six against how challenging behaviour and behavioural disabilities are experienced and understood by teachers and SENCOs in both the mainstream and special school contexts. In combination Chapters four, five and six offer a contrast which supports contention that behavioural disabilities are set apart from other forms of disability, and that both child and family face direct and indirect accountability as a result.

Using blended parental narrative, this chapter illustrates how families struggle and are marginalised from the protections typically accorded to all other forms of disability. The inequalities which emerge from such disadvantage are found to prompt a defensive response, deflecting attention from the support families feel are needed to prevent an exacerbation of disability effects into adolescence and adulthood.

Parental narrative illustrates how unfavourable responses can generate a life trajectory for some young people from which it is hard to recover, and how accountability across the expanse of childhood is both unhelpful practically and productive of negative identities. Subsequently it is suggested that there is an urgent need to challenge discourses of accountability, and to reframe them where applied to behaviours led from a disability as discriminatory. This assertion is based on the belief that the accordance of accountability toward disability derived behaviour is logically incongruent with the definition of disability generally as it is understood within a medical model. Furthermore that the logic of the medical model indicates a rehabilitative response to be the most appropriate, if instituted in parity with other physical disability presentations.

In continuance it is also maintained that interventions should where practical be focused toward prevention, and in recognition of the familial experiences shared that these should be delivered prior to the onset of adolescence. Notably similar interventions have been found to be an effective means of reducing the negative effects of behavioural disabilities (Read 2005, Hawkins et al 2015), thus hold potential to cushion the effects of disability, particularly vulnerability to disengagement from school and escalation of risk inducing and offending behaviours.

5.1.2 The ethical implications of being an insider sharing personal experience that involve vulnerable family members.

Specific ethical implications emerge from being both the researcher and the researched and although discussed in depth in Chapter 3, it is helpful to revisit these issues in the specific context of how to narrate sensitive familial experience in a specific academic scenario. Particularly as it was found that despite exploring issues linked to informed consent (Miller and Boulton 2007), capacity to consent (O'Neill 2003, Parsons et al 2015) and the ethical complexities of being both insider and outsider to the research field (Rogers 2003, Cooper and Rogers 2015), further questions surfaced. These questions surrounded the implications of sharing sensitive personal experience for research purposes which could be traced to wider family members. It is one thing to draw upon insider knowledge, it is another to put it into the public domain under one's own name.

The most pressing issues surrounded how to protect my children's anonymity, not only now but in the future. I initially sought research permission across the entire family, permission which although granted was upon further reflection insufficient. I found that although I could outline hypothetical risks they could never be all encompassing, particularly as the nature of technological change left little means of covering every eventuality, which as a mother is a natural inclination. In addition as my own son consequent upon his disabilities is a vulnerable young adult, he is heavily reliant upon me to offer advice on consent issues, posing what could amount to a conflict of interests.

Rogers (2003) addresses ethical issues emergent from the mother/researcher role, particularly those that coalesce around the research relationship and the issues the dual roles of researcher and maternal peer raise, not least whether professional distance can ever be fully established. This debate is extended further by Cooper and Rogers (2015), finding both dilemmas and benefits to accrue from insider research. Benefits in respect of the depth of knowledge insider status accords, alongside a heightened empathetic ability, facilitating of attention to detail that may not be readily noted or appreciated by an outsider. Conversely however insider status is also found to inhibit expansive respondent responses, due to assumptions of shared knowledge, calling into question the balance of benefit versus shortcomings in relation to the use of this method.

Although these issues were pertinent to my research context and addressed the issues faced with my respondents, they held a lesser relevance to how I could share my son's childhood without compromise, now or in the future. Looking to a resolution I determined that tension extended not only from a blurring of roles, but from discomforts emanating from an inevitable enmeshing of roles. I felt neither an archetypical mother nor researcher, feeling which generated specific tensions in respect of maternal loyalty and considered research justification. This justification was heightened as I had experienced first-hand, the injustices, struggle and marginalisation other families similar to my own were facing.

Bahn (2012), likewise Emerald and Carpenter (2015) raise a further ethical dilemma concerning the impact of the research process on the researcher. This was an issue I had not considered fully at the research's inception. Nevertheless its relevance became clearer as my research progressed, due to the strain of looking back and recalling situations and a period of my life that was, and still, is highly emotive. Not wishing to denigrate any child's childhood, these young people were far from setting a happy ever after scenario and the formalising of these scenarios in text conjured emotions I was ill prepared for.

To avoid being complicit in the silences that are suggested to surround behavioural disabilities (Carpenter and Austin 2007, Carpenter and Emerald 2009, Emerald and Carpenter 2015), I needed to find a solution. By chance this solution presented itself to me as I pondered over the implications of my dual role. The resolution I determined was to blend the childhoods I presented, merging personal and parental experiences. This enabled me to share the nature of these childhoods and the issues they raise without attribution to any one individual. This chapter therefore extends real life narrative, in a blended form to protect respondent anonymity. It begins with a section devoted to how the 'challenging child' is seen and the implications of different ways of 'seeing'.

5.2 'Seeing' and 'knowing' the Challenging Child

How does one describe a child with a disability which impacts negatively on behaviour? Having had many years to ponder this question, the answer emerged as both simple and significant. A child with a behavioural disability, or indeed a disability which presents symptomatically as 'behaviour', is simply a child, like any other. Reliant on adults to respond in the longer term to needs presented, to protect the

childhood un-lived, similarly the adulthood not yet realised. However to be simply a child, is for many children with disabilities, ambition rather than reality as the 1990s ESRC funded study 'Life as a Disabled Child' indicated (Watson 1999). It is telling therefore that such a dilemma persists, yet Traustadóttir's (2015) assertion that 'disabled children should first and foremost be viewed as children' (pp 13) indicates its persistence. Traustadóttir's sentiment conjures not only agreement, but raises the question as to why children remain secondary to the manifestations of a disability, although such sentiment is practically problematized when the indices of challenging exceed socially determined safety levels.

5.2.1 Organisational priorities

Both personal experience and that shared by respondent families affirm that where challenging behaviours are an issue, it is the behaviour which presents at school which is 'seen' rarely the inner child, nor the child 'known' by his/her family. Parental experience also illustrates how these tendencies play out in the organisational routine of school and during placement application. In brief, parental experience suggests that organisational priorities prioritise the maintenance of order over inclusivity as Saz sums:

"The schools approach was not about how does this impact on X and how can we support him, no it was how does this impact on us, can we cope with this, can we deal with this in school. And particularly as he had Coprolalia, the swearing, it was can we accept this in school, it wasn't how do we work around it, how do we make sure he does not feel bad about it, it was all about them, it wasn't about him. It wasn't even about the other children; it was all about them [staff] and their ability to manage the class which is really very sad when it is supposed to be every child matters. Well every child doesn't matter" [Saz].

For Saz her child's difficulties were viewed as the barrier to mainstream admission, rather than signifying any organisational inability to cope. Response which could be alternatively viewed as disavowing of the original ethos of full inclusion. For Saz as for other parents, inclusion had a hollow ring which conjured feelings of lack of worth, as another mum Anna states. "Yes I mean you ask yourself well why she is not good enough. I mean you see the banners outside the school saying every child matters, and you think well that's a lie".

It is useful to question why some pupils appear less welcome than others. Typically my own parenting experience indicated there to be an incongruence between the ideal of inclusion and schools ability to deliver. Typically the language used was

inclusive and child centric, centred on pupil needs and ability to meet that need. However school actions spoke differently: hinting at mixed priorities that were at times irreconcilable based upon practical and organisational needs, typically to maintain order, foster positive academic results and promote (as is required by law) inclusivity.

The tendency parents observed of schools to prioritise order has been similarly observed by O'Regan (2009), finding persistent disruptive behaviour (PDB) a frequent trigger to school exclusion: and as previously indicated PDB remains the most frequent reason cited by schools for exclusion (DfE 2015b). Problematically PDB is also a broad descriptor, lacking precise quantifiable measures to enable a consistency across institutions. Hence PDB emerges as a subjective and non-contrastable indices, whose typical range of behaviours mirror many common behavioural traits associated with childhood disabilities. Consequently the frequency of exclusionary response suggest a disavowal of behaviour as a legitimate symptom of disability. Although as Sacha's story below suggests, it is equally plausible that schools genuinely struggle to know when 'challenging' behaviour extends from disability. Equally schools have limited resources in terms of time and expertise to respond effectively, generating a shortfall which impedes an accurate 'seeing' of the child as disabled and further compounds difficulties faced.

5.2.2 Sacha's story

Background: Sacha and Chris's story is shared below, Sacha and Chris at the onset of their child's problems were in their mid-thirties, both had successful careers, Chris in a local university, Sacha with a regional social services department specialising in disability provision for adults. Living in what can be described as an unremarkable middle class suburb and with an older child who was successful in the school system, their outward appearances did not allude to the eventual difficulties they faced. Both parents were articulate and confident, yet demonstrate that over time, this self-identity was submerged beneath the difficulties faced and their inability to find desperately needed support. Sacha and Chris illustrate that background and the skills advantages a university education brings is no deterrent to the development and progression of psychological disability.

Sacha and Chris's story also indicates how social status can be an impediment to the procurement of supports needed, rather than as is commonly stated an example of cultural capital (Lareau 1997). Sacha's experience also illustrates the difference between cultural capital and cultural resources that Goldthorpe (2007) identifies. Hence whilst Sacha and David held cultural capital in the form of status, they lacked the cultural resources necessary to obtain the supports needed.

Lack of effective support is paradoxically often a tipping point for families: found to compound suggestion of parental insufficiency, both ascribed and self-directed, deflecting assertion of structural failings (Rogers 2007a). Particularly problematic is that families struggle to provide the detail of support needed (Rogers 2011), despite awareness of generic need and indeed many of my respondents knew they needed support but couldn't articulate its form. Notably the difficulties David posed had implications for every facet of Sacha and Chris's familial life, impacting both emotionally, practically and financially, it was hence unsurprising that they struggled to provide precise support needs.

Neither is their experience an isolated event as a similar scenario was related to me by Angie, whose occupation was also presented as a barrier to support:

"And he just kept on rabbiting on about the greater needs of other children and you know few resources and I just said you know I am not interested in the other children, I am here about my daughter (aged 6) and so I am an uninformed parent standing outside this education establishment, I do not agree with you, where do I go from here. And he said to me 'come of it Mrs Thompson, you are not an uninformed parent; you work for social services, as if that had anything to do with it whatsoever".

Sacha's story (related below) and indeed Angie's experience, suggests strongly that there are systemic failings in mainstream: not least assumption that parental occupations can act as an indicator of ability to cope. Both schools in these instances dismissed parental concerns, similarly so the signals their children was emitting. Sacha's experience also demonstrates how an esteemed parental profile in school can act to inhibit exclusion. These are barriers which question the school system as an equal meritocracy which is responsive to need. Paradoxically in Sacha's case an esteemed social position within the school organisation was found to not be in her child's best interest. Not least because the mainstream school Sacha's son attended had few active resources to draw upon, nor the relevant expertise necessary to include and support a child exhibiting serious psychological distress. School resistance is where Sacha's story begins:

R: "Did school alert you to David's [son] problems"?

S: "No, I mean we went to school rather than them coming to us. So they... I think, they were concerned about him in some ways, well let's say they were concerned because he was quite challenging most of the time [laughs], you know, so they started talking to us, sending notes in the communication book, that sort of thing [nursery]. But when he went into reception they just said he was eccentric".

S: "There was a period from September to March in year 2 where regularly I was stood outside school at six o'clock at night, because I could not get David [son] in the car. Because he would cope in school, he would keep calm all day, then I would walk in the playground and he would just explode".

Despite Sacha indicating an escalation of challenges at home, Sacha notes that school failed to fully appreciate the seriousness of David's symptoms, until they impacted on school:

S: "But when he went into year 3, he found year 3 very difficult and his behaviour became much more challenging. I think then school finally started to understand what we were talking about in terms of the challenges at home".

This conversation illustrates how school systems can dismiss concerns raised by parents until observed first hand, it also illustrates how parental voice can be lost amidst an unequal power relationship. Sacha goes on to indicate how serious things were becoming at home and at school, yet despite a series of aggressive outbursts in the classroom and escalating school support, school still underplayed the situation being faced and the symptoms David was exhibiting. It was at this juncture that Sacha revealed a disadvantage to the active role she had previously enjoyed at David's school, paradoxically as a parent governor, specialising in SEN:

S: "At that point, I kind of felt like what they should have done was exclude him, so in the end I went to the head and said you know the kind of things that David's doing in school, if he wasn't my child and I wasn't on governors, what would have happened, and she said he would have been excluded. And I said right 'I want you to exclude him right now'. Because actually she couldn't manage, for that fortnight it was every day, it was taking us at least three hours to get him into school, so he rarely was in school before 12 o'clock, and then there were days when I left, within half an hour when they would phone me up and say 'you will have to come back and get him'".

As can be seen parental recognition of David's problems did not lead to effective support, indeed the support David's parents identified as necessary were resisted due to Sacha's involvement in the school and schools unwillingness to accept they could not manage. Indeed parents become a hostage to such willingness, as without school formally indicating an inability to meet needs, alternative funded provision is unobtainable. Sacha confided that supports were so ineffective that David eventually lashed out at his peers and on more than one occasion posed them serious a physical threat, resulting in their classroom being evacuated as a safety measure.

Eventually following Sacha's demand for equal treatment David was excluded aged only nine.

On reflection the school was caught in a compromised position and this was acknowledged by David's parents, who recognised David's difficulties were complex and there was insufficient staff expertise to respond effectively, As Chris, David's dad stated:

C: "I think the point is the school didn't know what to do, we didn't know what to do, when we got the supplementary funding we sort of got this kid who was straight out of college [support assistant], and he didn't have any clear idea of what to do, it wasn't his fault, he was just young".

The experiences Sacha and Chris shared although tragic to the family concerned hold a wider relevance. Not least they demonstrate that not only does the vision of full inclusion concede to the reality of its practice, but also that school in this instance held tendency to operate as a reactive organisation, rather than proactively as the new SEN code now demands (DfE 2015a). The 'seeing' of David was resisted, due to a combination of his mum's role in school and David's initial lack of negative impact in the classroom.

Nonetheless with hindsight a collaborative 'seeing' held potential to set in motion appropriate supports and referrals, which may have deterred David's difficulties from becoming as acute. David's case although unique to him is not that uncommon, as the latest national well-being survey indicates, showing that fourteen percent of children under 16 had reported some level of mental health problems (ONN 2016). The urgency of timely intervention and prompt response is emphasised by consideration of what happened following David's exclusion as Chris and Sacha explain:

S: "Well we got a morning [following David's exclusion], we had one morning of about 3 hours, and then the shit hit the fan. And he [David] just fell to bits and we had six weeks of absolute hell on earth and he was just an absolute state"...

C: [interjects] a naked boy just running around

S: Naked yes just an absolute state

Sacha confides that for a period David would not wear clothes as he was concerned they had germs on them, confiding that he would spend hours scrubbing himself in the bath and scrutinised everything he ate. Chris and Sacha go on to explain how David's breakdown led to his eventual placement in a residential unit for autistic

children, where he spent eighteen months. Following his reintegration home, despite reservations David was returned to his former mainstream school, a placement which entailed two support workers at all times. This placement lasted three weeks and finally following intense negotiation David was offered a placement in a special school. This placement at our last interview was working well, Sacha states it offers the support David and she needs, although David's longer term support needs post school remain uncertain.

Chris and Sacha's story points to a disconnection between what parents confide to schools about their children and what schools take on board. Although it is beyond the scope of this data to proffer any explanation as to why, David's case suggests that his school needed to see 'challenge' before its magnitude could be appreciated. Such demand for evidence eludes to the nature of the parent/school partnership active in this case, however similar instances have been conveyed by other parent respondents, signalling this to be a wider trend.

It is equally significant that David's mainstream school had few effective coping resources at their disposal to facilitate his placement, even after the scale of his difficulties were realised. Such lack suggests boundaries to inclusivity, which in the case of 'challenging' children appear implicit rather than stated. Equally troublingly in relation to David, is that not only were his family left to cope with his escalating break down, David's peers were also exposed to significant risk, for which David would have been held accountable. However neither David nor his parents had any real control over his school placement or the supports available and indeed to effect resolution of an untenable situation, Sacha had to request David's exclusion.

One of the complications of David's story was that David initially held no formal diagnosis. Although school considered him a little eccentric, they failed to explore these differences within a disability frame. Sacha's narrative does not allude to the reasons for this, but as one secondary SENCO stated schools do devote significant time to particular processes of 'knowing', the sorting of the "cannots from the will nots". Pupils who cannot behave as opposed to those who won't behave.

These ways of formal 'knowing' are explored in Chapter 5, nevertheless such throwaway comment brings to our attention the dialogues which coalesce around 'seeing' the 'challenging' child in school. However these dialogues are not always

helpful as Sacha's story emphasises. Schools rarely hold relevant medical or mental health expertise, yet are entrusted as a first point of identification and are primary to the production of 'evidence' necessary to facilitate clinical assessment. Schools however are only part of the equation as Sacha's story indicates, but where school organisations resist parental input, there is heightened vulnerability towards a distorted view of the child's needs. Although David's case may be seen as untypical of the routine challenges met in the classroom, the difficulties faced speak of both systemic and pedagogical failings. Raising issues around teaching staffs competency to both identify and respond to complex psychological difficulties which manifest in the first instance as behaviour.

Nevertheless behaviour management is now a core part of teacher training, yet as Garner (2013) indicates, teaching programmes show limited progression in how 'challenging' behaviours are responded to, and appear directed chiefly by political vision and dictate. Consequently teacher training has failed to keep pace and act in unison with the sentiment of behaviour as a symptomatic manifestation. Garner suggests that political discourses surrounding ill-discipline and an increasing emphasis on control rather than understanding has compounded schools tendency to merge all 'behaviour' under the generic term emotional and behavioural difficulties, an umbrella term which does not concede to any drivers behind a child's difficulties, but does speak of need for containment.

Garner (ibid) notes how pedagogical responses to behaviour have been inconsistent and led by changing political direction. To example he contrasts the approach adopted by New Labour with changes made following the coalition governments ascent to office in 2010. Both periods cited to impact on teacher training and how 'behavioural' challenges were both understood and responded to. Garner cites New Labour's policies of Every Child Matters and the SEAL programme as indication of a child centric approach that privileged holistically understandings for behaviour and sought address through the use of positive encouragements. 'Understanding of child and adolescent development was placed at the heart of a positive approach to pupil behaviour as opposed to a reactive behaviour management approach' (pp 332) that had prevailed during the years of Conservative rule.

Nevertheless New Labour's approach will be found historically to be situated between two extended periods of Conservative led government whose political stance is predicated upon the control rather than understanding of 'behaviour'. These political shifts are echoed in pedagogical training and practice. Noting the 'back to basics' rhetoric of the coalition government and disproportionate emphasis 'on the legal powers and duties of school staff' (pp333), Garner highlights how the formerly accessible training resources available to inform trainee teachers of the causes of behaviour were archived in favour of material dedicated to the control elements of the teaching role. Hence the generic grouping of behavioural manifestations under the term 'behaviour' is actively endorsed by government directed teacher training programmes. A message that is reinforced on trainee teachers school placements which currently represent two thirds of the training programme. As Garner cautions 'trainee teachers will absorb the messages sent out by some schools that managing behaviour, including that of pupils who have significant EBDs, is all about adopting a rule-governed, inflexible and hierarchical approach' (Garner pp 333). Move which does not direct attention to the causes of behaviour.

Indeed the term emotional and behavioural difficulties is entrenched in pedagogical vernacular and as such presents an illusion of a legitimate classification into which 'challenging' pupils fit, serving to deflect attention from its psychological drivers. Even though its usage is now contraindicated (DfE 2015), old habits persist and it is hence notable that Sacha's story underscores the need to seek a refined diagnosis of difficulty, whilst also alluding to the consequences of not.

Causing further complication however are the motivations schools may hold for embrace of an expanded classificatory system. Slee (2013) suggests that they act to serve school interests primarily. Stating that 'risk- averse schools need to protect against the deleterious effects of dysfunctional individual children on their overall results and standing in league tables' (pp 28). This protection is accorded from the establishing of deficit behavioural identities as legitimate explanation for school failings. Funding implications have also been imputed as a motive for schools to embrace a diagnostic route, a motivation Baroness Warnock remarked on during our interview.

Irrespective of motivation, there also appears to be a shortfall of understanding amongst teachers around the implications of behavioural conditions both on the child and his/her family. Such limitation was alluded to in the annotations teachers offered in addition to the diamond ranking exercises conducted in this study. Limitation that is discussed fully in Chapter five and was considered to support a view that parental 'seeing' is vital to a well-balanced appreciation of the effects of a disability on a child. Furthermore that it could serve to not only complement and supplement formal training, but also inform school management contingencies through parents intimate knowledge of their child. Nonetheless Sacha's story and the following familial narrative suggests this to be widely resisted by schools and indeed at times denied.

5.2.3 Breaking the silence

Why did I choose to expose my personal experience within this research? In part it was a response to the injustices metred in the name of inclusion and safeguarding. It also stemmed from appreciation that our situation was not unique and that similar difficulties were ongoing for other families. These difficulties for a minority were extreme and life changing, for others there were ongoing barriers to social and educative participation, yet common to us all was the silence that surrounded our situation, silence which not only perpetuated the injustices metred, but also did little to combat a common misconception that 'behaviour' is a tangible thing that can be classified and also that bad behaviour is someone's failing, be it child or parent. The families who participated in this research hailed from varied backgrounds, yet were striking in their ordinariness. They did not befit controversial documentary, or sensational exposure in print or social media, they were simply a collection of typical parents, united by circumstance. By sharing my own experiences, it is hoped that others will be similarly inspired to add their voice and though doing so expose behavioural disabilities to be just that, a genuine disability of as acute an impact as physical disability.

Disabilities which impact on behaviour or mental health are nevertheless controversial. Personal and wider familial experience suggests that schools tend to respond to the outer manifestations of the child's core difficulty and to construct the child's profile accordingly. Whilst the concerns parents raise hold implication in relation to understanding and response, Garner's (2013) suggestion of diagnostic

manipulation challenges the integrity of mainstream inclusion for all children. Certainly personally the sentiment of child first holds a hollow ring and my experience that 'challenging' children forfeit their childhoods and their educative rights on account of the problems they present. It is thus telling that school based concerns rarely privilege the childhood jeopardised, or seek connection with the child behind the behaviour, prioritising instead matters of containment and consequence.

Attempting to review my own children's childhoods and the impact of their own difficulties, I concluded that I rarely viewed my sons as disabled, or 'challenging', rather I saw them, simply as them. Sentiment which is poignantly expressed by Berube (1996) and to which I can add little:

'I have tried on occasion to step back, and see him as others might see him, as an instance of a category, one item on the long list of human subgroups...I have even tried to imagine him as he would have been in other eras, other places: This is a retarded child. And even this is a Mongoloid child, but I cannot imagine how they might think them in a way that prevents them from seeing Jamie as Jamie' (Berube, pp xii).

Although there is a vast literature base pertaining to behavioural disabilities and its management in and out of education, there is limited parental narrative available to convey the child or childhood behind the manifestations of difficulty. Silence which is understandable as parents are frequently viewed as part of the problem, (discourses of blame are more widely discussed in Chapter 6), thus required to be compliant to external expertise (Macleod 2013), or resist blame by deflective strategies (Tardy 2000, Holt 2008, 2010a).

Frigerio (2013) found the impact of blame pervasive to the adult and professional relationships which circulate around children with behavioural disabilities. Activity which Frigerio suggests operates to position the differing parties. Notably finding that parents adopt various roles to deflect blame. Indeed it is suggested that the pervasive nature of familial blame serves to disincline parents from openly sharing their parenting experiences, compounding marginalisation and deficit identity. As Holt (2008) found, parents rationalise their child's difficulties, seeking explanation for difficulties faced and part of that process is to draw upon evidence which is personally exonerative.

As a parent similarly placed, I can attest that these discourses often form part of an inner conversation, in the manner of Shriver's (2003) 'we need to talk about Kevin'. Signalling a dialogue that is pre-emptive of external condemnation, rather looks

toward personal reassurances, which in my mind is fundamental to the maintenance of a positive maternal identity. Nevertheless, breaking the silence holds promise to draw attention to one of the most stigmatised groups within the disabled population, children and young people with behavioural difficulties. And despite some representations of behavioural disability having seeped into urban myth and cartoon fiction, for example Bart Simpson and Horrid Henry as depictions of ADHD and Rain man and the Big Bang Theory to depict Autism (Kirkland 1999, Murray 2006, Google 2012), many of the darker effects remain hidden (Vargas 2013, Anonymous 2014, Berg-Dallara 2014). Indeed the physical and psychological effects of children and young people who have serious behavioural disabilities are rarely spoken about openly. They typically only surface following extreme circumstances, effecting a latter day social taboo conjuring of association with domestic abuse, not disability. In conversation Freya (mum of Ryan aged 10) suggests that willingness to expose disability realities is growing, referring to a recent documentary on autism she had watched she states:

“There is this one clip where the guy filming asks the mother if she want the camera off as she was restraining her son, but she replied 'no, because this is how it actually is, and I think people should see it as it is, rather than the impression given by the media. She rightly said this is real; this is what autism is really like, not like all this 'Rain Man' stuff'. [r6]

To give voice therefore is to challenge the silence that supports child and familial accountability. This silence can also act as a strong indication that the nature of behavioural disabilities is generative of tenuous disability status, resulting for some an uncertain position situated between deviance and disability.

Of equal significance is Holt's (2010b) assertion that 'the absence of young people diagnosed with EBD in critical disability both reflects and reinforces their marginalised position in a variety of forms' (pp 148). Yet despite such marginalisation 'they form an absent presence within debates about educational inclusion and this is reflected in the field of critical disability studies. This absence leaves unquestioned, dominant, individual tragedy conceptions, which employ the cause of EBD within the individual' (pp 148). This simultaneous presence and absence is according to Holt, deflative of the mechanisms of social disablement which serve to heighten the appearance of EBD. As Graham has noted in relation to the cited characteristics of ADHD, a significant percentage 'reinforce normative notions of mainstream, general or traditional schooling' (pp 28). Norms which serve to belie their constructiveness

and foster illusion that such indices represent a medical equilibrium, from which pathology can be identified, thus deflecting the role of context toward its appearance. The disassociation of behavioural disabilities from the mainstay of disability is thus counterproductive to both status as disability from within the medical model and to recognition of the processes of disablement that accrue from the social, equating to further marginalisation within the disability lobby.

It is also useful to contextualise the profile of childhood behavioural disabilities within the contemporary status of young people generally. Indeed it is suggested that Neoliberal individualism has given rise to the marginalization of young people generally, resulting in distinct and unequal relationships with wider social agencies, themselves shaped by the economic structure within which they are embedded. These contentions are heavily associated with the work of Henry Giroux (Robbins 2012) and considered foundational to practices and intimations which are diminishing of many childrens potential for 'becoming'. Terminology which refers to a child's latent potential and is directive of future societal worth and role. Bauman (2004) argues similarly, indicating a surplus population to be an inherent feature of a global capitalist economy, excess which gives rise to creative rationalisations for their existence. Problematically although Giroux links youth vulnerability with wider social variables, (particularly gender ethnicity and culture), he fails to attach any serious recognition to disability as a variable in its own right. Nevertheless these demographic factors are implicated heavily in regards of parental ability to resist negative ascriptions (Holt 2008, 2010a, Nind 2008, Holt 2012).

Toward means of defining the 'challenging child' outside of a medical frame, it is considered reasonable to view such child as emergent: the culmination of social and economic relations, responsive to individual actions, professional assessment and the ascription of others. Such a view calls for counter balance, a rebuff to stereotype and accountability and it is notable that Shakespeare (2015) notes the sustained absence of children and young persons voices, silence which he considers to inhibit the ambition of disability equity and redress of disadvantage.

Such absence is also noted by Huws (2011), finding even print media accounts of disability to be lacking first person narrative. Problematically neither author refers specifically to behaviourally challenging children, an omission which I consider telling

and typical. Indeed one of the most draining tasks parents of 'behaviourally challenging' children have indicated, is how to express the severity of their child's challenges in a way that invites support and not shock or condemnation. Take for example the case of Farah, her adopted son then aged eight had a fascination with fire and was accused of at the time of interview with two separate charges of arson. Fire setting is an extreme behaviour that holds association with ASDs, yet the conversations that Farah alludes to appeared to dismiss their concerns as Farah states:

"We feel that he may be on the autistic spectrum, because of his fascination with fire, and he keeps on repeating himself all the time, but I don't think they take our opinions seriously, not even the consultant, and she is challenging what we say. The one before [doc] was great, she understood, she had children with problems".

This statement underlines the dismissal families expressed in interview, a feeling of not being taken seriously and of school in particular's preoccupation with response rather than understanding as Ryan, Farah's partner expressed:

"They [school] just respond to his behaviour by punishing him, by keeping him in on a break time, and punishing him by not letting him into assembly's and things like that, they keep him in a room. I mean last time he was in the IT room he used the phone to contact reception [doesn't say why], and they banned him from the IT room for two weeks".

Ryan continues to express dissatisfaction and hints at prejudicial treatment, which was not the first occasion parents had expressed such feeling. "Well they don't accept him for how he is, not in the same way as they do with the kids who have physical disabilities".

A similar sentiment was expressed by Leanne, following what she states has been a fruitless search for an esteemed diagnosis, placing her and her son in a difficult position in school:

"I don't think the school know enough about the different types of disabilities, I don't think they look into it properly, I mean I know X has been identified as having a developmental delay, but I don't think school see that as important as something like Asperger's. I mean if they can't get funding for it, they don't seem to want to help, I mean developmental delay isn't a big diagnosis, I think the schools seem to look better on some conditions than other, I mean the support worker keeps asking if he has ADHD, but he's been tested for it every year since he was three, but because he is borderline he doesn't meet the funding criterion".

Leanne's concerns extend those of Ryan and introduce unfavourable treatment that is financially motivated. Nevertheless the practical reality for families is their need for support in the immediate, yet to do so necessitates exposing vulnerabilities that it is

a natural inclination to hide amidst a climate that as Garner (2013) indicated is politically inconsistent.

Needs must however, such is the blur between the private and the personal for families with behaviourally challenged children. Interestingly another parent (Leanne) during her interview suggested that disclosure of her child's difficulties to 'outsiders' was strategic, led by assumed understandings held and avoiding of those less familiar.

"I have to select what to put on. I usually put on ADHD, because I know people think they know what the behaviours are like, he throws things you see and I can say 'oh well he has ADHD', if it is a club that takes in disabled kids and has a bit of a clue what we are on about I will sometimes put on mildly Autistic, because again people think they know what that is, but just to cover myself sometimes I will put on AD or XYY, so I can say well I did tell you, but I can see that people don't know what it is or how it presents, so I am just covering myself really".

This sentiment not only supports the utility of insider research as a means of inviting parental sharing, it also exposes the dilemmas parents routinely face in social settings. Furthermore it is unclear as to what extent selecting processes seep into professional engagements, causing parents to underplay or conceal difficulties in an attempt to present a more favourable impression. This manipulation of social appearances resembles what Goffman (1990a; b) termed frontstage and backstage performances: and indeed the presentation of self or indeed selves is foundational to social Constructionism and linked to processes of positioning (Harre 1999, 2009).

Behavioural disability compromises the projection of a positive maternal self and by proxy that of one's children. Initiating a need to embrace wider more favourable positioning roles, such as those observed by Frigerio (2013). These roles however also serve to mask the extent of struggle some parents endure. Similarly they also hold potential to generate divisions between parents, those who cope and those that do not. They do not however further the association of behaviour with disability, nor do they challenge the often education based significance that behavioural disabilities conjure. For parents there is little potential of time out from their children, whereas exclusion figures attest to such strategies employment in schools and signal further a denial of the difficulties families face. Difficulties which during the course of my research such difficulties were found to compromise the child's safety - as Farah's narrative indicates:

“I mean I don't think people understand that we have this all the time, day and night, they think it is just a school problem and all the support is to enable the school to manage, not us...I just lost it, I tossed his videos as well and marked his face so school got the social workers out, mind I have heard nothing more since, I mean I told them you live with him 24/7”.

Farah's desperation spoke not only of lack of support and the risks associated with this, it also very powerfully illustrates how the effects of childhood disability in the private domain of home are often triaged in favour of the more public spheres of school and community. Effecting a marginalisation which runs counter to the paternalistic spirit of state involvement in the family, although its condemnation is evident through accountability discourses and the regulatory functions of schools (David 2015).

In terms of actual support however, this area remains one aspect of family involvement that evades timely attention. Throughout my study practices of marginalisation within the family were found to yield as much desperation as accountability led discriminatory practices. I now present 'challenging childhood' from two distinct timeframes referenced against the school systems of primary and secondary provision, blended from the narratives parents shared and as has been experienced personally.

5.2.4 The challenging child – the early and primary years

My son like many of my respondent's children was not born challenging: but at 18 months old following an unattributed virus was, post recovery, restless and changed. Over time lack of speech and subtle behavioural cues led me to seek help. My first port of call, the health visitor, who agreed that there was something, but what? Four years later following many clinician visits my son was diagnosed firstly with Atypical Autism and then ADHD, soon to be followed by Oppositional Defiance Disorder. In between clinical visits, my son's aspirations were similar to his peers, except for the manner by which he expressed himself. Always out of step, my son's presentation outside of the clinical setting was alternatively described as 'difficult' as opposed to the paediatrician's explanation that he had a neurological dysfunction. Concerns raised were frequently punctuated by hypothetical outcomes. One teachers comment still echoes, she said "if he doesn't learn to shut his mouth he is going to get into a lot of trouble when he is older". I was shocked, suspended between the clinical explanation that my son's actions were associated with a neurological developmental impairment and the schools projected future which was punctuated by unspecified

'trouble'. Many of the concerns school raised regarding my son were things I knew and accepted, yet schools resisted any counter 'knowing' of my child beyond his challenges.

This story although unique touches upon trends other parents indicated they too had faced, a common point of reference. Parents spoke of stark contrasts. The child they 'knew' and the child reflected back to them through school and professional agencies. The primary school years up to the age of 11 emerged as the most accepting of these 'challenging' children. This acceptance was conveyed with gratitude and also sadness. Although my son was also 'behaviourally challenging' at home, there was a discrete difference of response between the private and public domains. As family our acceptance was unconditional, but outside in the public view, unconditional acceptance was not the norm. So it is telling that although all of my respondent's children, my son included had started a mainstream school at primary level aged 4, educational inclusion was conditional, not least as only one of the older children had completed their statutory secondary education in mainstream at the age of 16.

As a group though we all shared a common bond, the love of our children and a deep sadness at the way they were viewed. We differed in age, life experience, ethnicity, class and economic status. These differences mattered in relation to the resources we held in the ongoing processes of negotiating how our children were viewed. Our different coping resources and the means by which these were employed echoed the findings of Nind (2008) and challenging any notion that as mothers we were an equal or homogeneous group.

Despite parents suggested inclusivity of the primary sector, as the parents narratives developed, this inclusivity was challenged. A disturbing picture emerged indicating patterns of rejection and punishment, accountability and fruitless searches for support. Experiences which although echoed in wider literature (Lamb 2009, CEREBRA 2013, OCC 2013, AA 2014) lacked less savoury details, serving to detract from the severity of situations many families face. Many of the parents acknowledged feelings of shame and stigma, feelings which were deflected by support group camaraderie and anecdotal tales of wider parenting successes

involving other siblings. These mirrored strategies were observed by Holt (2008, 2010a) toward deflection of the stigma felt at having a parenting order imposed.

'Challenging childhood' during the primary years seemed to produce a binary 'knowing', 'familial' and 'formal' knowing, reflective of the private and public domains the child frequented. Practically the childhoods portrayed were lonely, as social ostracism frequently followed challenging behaviour. Parents spoke of social impact and how their child's negative identity spilled out into their community, or stimulated school humiliation which impacted on other siblings as was Julie's experience:

"She [the head] came storming out at the football match in front of all the other parents saying 'get him out of the school', he was excluded you see, she just kept on saying 'get him out'. But I had my younger son who was then five present, just wanting to play his match and I told her that I really needed to stay with him and she said 'well if you do, you still need to get him [excluded son] out of here'. The other parents were just gobsmacked, she was so dogmatic... she actually had John my husband in tears [not in front of her]"

Although lack of understanding was a common theme, for Farah it could have resulted in her losing her home under the terms of the 2014 Anti-Social Behaviour Crime and Policing Act:

"They even got the anti-behaviour person out from the council, then we had to go and have a meeting with all the residents that had complained about Sean, and Unite, which is a conciliation service they got involved. And they all said 'Oh we didn't know about his conditions'. And I said that I didn't feel need to broadcast it, so they suggested that they might be more understanding in future".

Although early intervention offers promise of reducing any escalation of difficulties, the types of interventions available for under 18's who display behavioural difficulties, rely upon the concept of personal restraint, through the maintenance of behaviour contracts. This strategy clearly indicates belief that behavioural difficulties are the result of intent, rather than a symptomatic indicator of a disability. Few of the parents who engaged in my study indicated ability to disassociate themselves in personally from their child's disability. Effecting what Goffman (1968b) describes as 'courtesy stigma', action which is contemporarily termed discrimination by association (Parliament 2010). Julie illustrates the way such stigma attached itself to the wider family:

"I think that is the hardest thing when you have a child that everybody avoids, I mean the kids, there is a cut down the side of our house and the police actually told the kids to walk all the way round when the mothers complained that their kids couldn't walk down the cut because of Zac. The police just told them to walk all the way round just to avoid him".

Julie's comment suggests not only psychological stigma, but also physical isolation and humiliation, similar in nature to that observed by Doublet and Ostrosky (2015).

Troublingly the difficulties parents record, extend not only from their children's challenges, but are compounded further by official responses to the difficulties faced and impact across the entire family unit. It is thus unsurprising that economic and emotional strain are found linked with childhood disability (Emerson and Hatton 2007, Rogers 2007, 2007a, 2013) alongside poor maternal mental and physical health (Dobson 2001, Eisenhower 2005, McConkey 2008, Griffith 2010, Woodman 2015).

Parent/school partnerships imply a forum for the sharing of these private and public identities and indeed for some they were. It was here that parental skills were most frequently evidenced and employed. Some parents positioned themselves strategically in administration positions to effect influence in school, whilst others assimilated into disability specific lobby groups. Saz had even founded a training sessions for schools, establishing networks that were sufficiently malleable to benefit their own personal circumstances. The network Saz was actively involved with extended across a county and replicated many statutory childrens services including respite care. I resorted to an academic career and became well versed in education law. We were the fortunate parents, others fought using limited skills and were unsuccessful in addressing the injustices their children faced. As Leanne discloses in the following excerpt:

“The SENCO she is a waste of space... how many time have we phoned or emailed her, saying can we have a meeting, and she never gets back to us, when we did get a chance to meet with her, we thought we had a meeting for X, but she took us upstairs and indicated us to come in this room and it was full of parents, it was a parent support group. I mean it was full of parents telling their story, saying how bad their children were, how violent and naughty, and I said well I don't want to know about your children, my sons not like that, he doesn't get violent like that”.

Leanne had spent many years as her son progressed through the school system to get a diagnosis and to reframe his actions as the manifestation of an underlying driver. Yet during our interview it became apparent that although school also felt there was a problem, the problem as they perceived it was indeed Leanne and her partner. Both parents were unemployed and had obtained only minimal education and acknowledged that they were in their own words 'getting the run around', by not only the school, but also CYPS, (the diagnostic service for young people).

At our final meeting a year after the first interviews were conducted, little appeared to have changed, clinical assessments were still ongoing and although Leanne

indicated that the medical professionals were acknowledging of her son's problems, school was not. I asked Leanne what her son was being tested for and there was an uncertainty, what was evident however, was that the motivation appeared to extend from the profile her son held in school:

"It's just because school think he is just naughty, but everyone else knows he has underlying problems and the assessment is just to make school aware that he does have underlying problems, then school will have to understand that the difficulties are because of these problems".

The difficulties Leanne displays, in the immediate and over time may be considered to reflect her cultural resources, which like Sacha were limited. Both cases although contrastive in terms of social and educative status, demonstrate the importance of school in terms of identity and supports in education.

The strategies parents adopt to maintain support for their children and deflect accountability appeared divided between parents who relied on others to advocate for their children, generally medical professionals and social workers and parents who undertook the task themselves as Andy indicates:

"I think you just have to be a bit more proactive really, if the school, I mean if you don't hear anything, it doesn't mean that everything is all right; I think you have to remind yourself to ring up and just check. I think I am going to get a better relationship with this new SENCO gradually, I am also chair of the HSA, the home school association, and I am like a school governor. I do that so like they won't forget him" [sounds sad].

For parents who felt reassured that resources could be obtained using skills held or acquired, such success was however time referenced, as the ability to cope and negotiate became a barrier to much needed support once our children passed through adolescence.

Parents displayed mixed emotions and concerns appeared punctuated by the age the children were at the point of interview. By far our greatest commonality was a collective sadness at the impact our children's differences had on their emergent identities. This sadness was a major impetus to fight for educational opportunities that could nurture spirit as well as manage presenting challenges. This recognition first surfaced for me when my son became aware of being socially shunned. However more problematic was the complicity of school toward such segregation. This complicity became evident following an unrelated incident, whereupon school as background information admitted to preventing our son from eating lunch communally, demanding he eat alone separately with staff.

Such practice was not responsive in the immediate, rather as we were to later learn formed part of an ongoing policy, which had already extended across an academic year. In stark contrast to the social risk he was considered to pose, the reality of his disability was an inability to communicate these injustices.

Other parents indicated similar experiences during the primary years, signalling a distinct pattern of what can only be described as discrimination. Certain incidents stood out and were unexpected in their severity and reminiscent of a now outmoded era of education. The first instance is the case of an eight year old boy, given a designated carpet square to sit on during circle time by his class teacher and indeed any other times his conduct was viewed as unacceptable. Not only was the child forbidden to leave it, other children were told to keep a stated distance from him. Another example relates to a boy of six, left to wander his school corridors as staff claimed he refused to stay in his classroom and so were limited in what they could do. These incidents were related to as recent events and both parents were still struggling through the primary sector.

Equally troubling were instances where placement applications were actively resisted, others told how their school denied their child's problems until clinical proof was provided. Action which was undermining of their parental concern as Angie illustrates:

"The head she called our daughter in and said 'your mummy thinks you have a problem with reading, but we don't think you have, what do you think'? Well a child of 9 will say what the adult wants them to say, so I had thought that was really underhand and made me more determined to get an official diagnosis".

This dialogue illustrates how parental concerns can be undermined in an informal manner and more troublingly serve to plant seeds of doubts into the child's mind. Unsurprisingly in this instance, the action set in motion positions of defence which detrimental to the well-being of the child.

Conversations digressed depending on the age of respondents children: interestingly also the narrative parents shared was reflective, alternating and comparing recent and historic incidents. This chronological mobility demonstrates the flexibility of narrative as a data collection method as indeed the stories parents told pertained to critical events (Webster and Mertova 2007) that were definitional of their school experiences.

At primary level before the onset of adolescence parents indicated hope, alongside determination to obtain better educational provision and social support. This optimism was jaded amongst the parents whose children were at or nearing the end of their childhood journeys. Indeed it was experiences shared amongst this parent group that indicated most strongly the implications of a behaviourally challenging childhood. Not only in regards to risk inducing actions, but the deficit profiles that accrued as a result. These profiles however did not infer disability, only the outer manifestations of its symptoms and the risk factors they pose.

5.2.5 The secondary years

Adolescence and transfer to the secondary stage of education was for some a turning point, signalling a period when things became dangerously out of control. School placement was central and for some parents a successful placement offered routine and guidance to their child, which following its completion was sadly met with a void, unfilled by further provision as it is common practice for children whose intellectual functioning is severely impaired.

Saz spoke of the implications of this void:

“You know looking in terms of the life span, school is very very difficult, you are trying to put a square peg in a round hole but actually when you have a mild ASD or Tourette’s or ADHD, the lack of structure that comes around after school if you can’t get a job is much more threatening than school. I mean he says he is happier since he has left school, but he isn’t really and we have come across all sorts of problems in the community, from drugs and alcohol and other types of criminal activity, sexual exploitation all sorts of stuff that he was protected from at school, having a statement”.

Such sentiment held a touch of irony as other parents spoke of endless cycles of exclusion and limited reinstatement, the parameters of which are summed by

Leanne:

“I mean they offer him twilight, 55 minutes a day, and he does work, but only a very little in that time... They have a pathway, twilight, exclusion and total exclusion and often it just goes round and round like a roundabout and you can’t get off”.

These conversations echoed desperation and a resignation of the limited opportunities for their child to complete their education successfully.

Tellingly only one family had managed to navigate mainstream placement through the secondary years. For some like Leanne there were turbulent and fluctuating provisions offered, impeding ability for her or her partner to seek work. For a few

escalating levels of support and interventions by children's social services, not however offering disability support, rather supervision

Parents were candid about the challenges their children were posing even though many the behaviours were extreme. Parents also indicated that they had received limited support or effective interventions through the early years when engagement was less likely to be resisted. A few of the children discussed were involved in criminal activity, drug use and promiscuity. Two mothers who participated indicated that they regularly searched for their children late at night after they had failed to come home. Saz in desperation confessed to placing a tracker device into her son's phone to narrow the search. At first this seemed extreme, until she expanded on the reasons behind this decision:

"Louis tends to put himself at risk with older people, even people his own age will ask 'what are you doing with him, can you not tell he is a smack head'? Once he stayed overnight in a tent with this man, yet Louis thought it was ok because he had had his medication. Louis sat up all night and tended the fire, he thought that meant everything was fine. We had the helicopters out looking for him, and his friend actually got locked up in a flat with the same person for 36 hours who pumped him full of Temazepam, and schizophrenic drugs, so those are the dangerous situations he is putting himself in".

Donna spoke of the worries she had for her daughter after she commenced a pattern of drug abuse and absconding with random men:

"I mean what can I do, it's only a matter of time before something really bad happens, but if I try to stop her she runs off anyway, turns off her phone, stays off Facebook, she's not stupid in that respect, but she doesn't see the risks and then you get scum feeding her legal highs".

In a similar vein, Tracy related the fears held when her son regularly slept in a derelict building with other disaffected young people, despite leaving a worried family behind. An indication of the desperation felt was offered by another mum who explained that she had forfeited her son's DLA to avoid his misuse of it post 16, the point where young people are deemed able to manage their own finances by the benefits agency. This child had developed an unhealthy interest in fire arms and had posted a wanted advert on eBay. As neurodevelopmental disabilities are suggested to predispose to risky behaviours (Gudjonsson 2012, Van Wijngaarden-Cremers 2015), it was not unreasonable to anticipate proactive response, however few were mentioned.

As the young peoples challenges grew in severity, so too in inverse proportions did their recognisability. Adolescence is known to be problematic for many young

people, but for challenging children it holds greater risks. Just when other children are developing greater independence, these children appear to need less for their own protection. Problematically perceptions of the strange annoying child who was shunned take on more sinister undertones when that child presents as a man, effecting altered perceptions of the risks posed. For one family these risks were seen as sexual in nature and resulted for a period in a loss of liberty. Allegations were later found to be erroneous, but left a shadow on the profile he now held. Paradoxically the nature of this young person's disability inhibited ability to construct an effective defence.

These limited examples offer a flavour of the profiles behaviour challenges conjure outside of the family. Often the responses generated are formative of negative identities and are constructed by professional bodies with fleeting knowledges of the persons they are entrusted to help. It is thus telling that two of the families I engaged with spoke of relief when their children were placed in alternative accommodation. Donna spoke of the frustration she felt that there was no one willing to offer her child a secure placement. This mother spoke of her child's violence and her fears for the future. Sadly this was not an isolated case, of the two families whose children had left the family home, violence, drug use and stealing were a significant factor. Of those still navigating their child's challenges, contingency plans were essential, necessitating small adjustments such as hiding knives, locking rooms and medicine cabinet:

"Well James, Zac's little brother, he has got loads of trophies from sport and he knows we have to put them really up high because they are heavy, and they are liable to be thrown at someone or a window. It's really hard being on constant lookout for things that can be used as weapons".

Notably however theses are strategies that disavow the basic freedoms most parents assume as right after their children pass from early childhood and is illustrative of the developmental delays many 'challenging children' exhibit. Needs which are denying of their chronological age and evidence of the adjustments many families have to make, adjustment however which is rarely matched in the wider domain and indicates the different 'seeing' across the two domains.

Julie makes reference to what she terms her 'real' son, referring to the child she feels she knows and contrasts this against the external identity her son has

generated amongst his peers in the community. These few words underline the different 'seeing' practices that have been referred to:

"Yes well I mean Zac is half his chronological age in respect of emotion, so you have an 18 year old going on 10. Zac regresses to his cuddly toys, once he has come home and got back into normal Zac mode, the cuddly toys come out and he talks to them and takes them to bed and all the rest, and if his street friends could see that [laughs], but that to me is the real Zac. That's where he is happy, that is where he is comfortable, but he's not allowed to do that because he is 18".

The picture painted of these older children and young people differs dramatically from the mainly school based concerns expressed pre-adolescence, but they are connected. Many years before its onset I had raised concerns toward my own son's adolescence, as had some of the parents in this study. These concerns were met with a wait and see attitude and indeed it was at this juncture that parental competency became a hindrance to the gaining of effective external support. Parents also indicated that requests for support, both pre-emptive and those responsive to immediate pressures were denied on the assumption of familial competency as Angie and Sacha's experience showed.

In a culture punctuated by ever shrinking social resources, there is a definite logic to this stance, however parental competency and social skills do not axiomatically equate to the wherewithal to manage behavioural extremes. Such failings were common to the experiences shared yet offered few coping supports. Even pre-emptive measures such as keeping their child in were denied as Jules states:

"We were told that we would be prosecuted under section 47 of the Human Rights Act for keeping him in, because my husband used to bar the door to keep him in when we thought there was risk, because there was a guy in the village that was giving him stuff, so we told him that he was not going out. But we were told that we couldn't do that, it is so contradictory".

This final narrative from Jules offers first hand perspective on the rock and a hard place parents of behaviourally disabled children face. The issues as described are complex and multi-faceted and do not fit easily into any single theoretical frame. Nevertheless they indicate a consistent pattern, firstly a denial of symptomatic effect into adulthood and as a result a corresponding failure to employ early interventions to support families through the adolescent developmental phase. Secondly responses recorded were reactive, but only to the manifestations of the young person's difficulty, they rarely signalled any real engagement with the nature of the disability

faced, neither its effects. Equally unaddressed were the vulnerabilities or core qualities the young person held, until actions reached crisis point.

The life scenarios depicted from the outside appear extreme and untypical, certainly my own experiences at the time felt unique only to me. It was therefore unanticipated that the parents who participated in this study would have experienced similar struggles. Although the detail of the difficulties, places, persons involved change, the underlying circumstances and lack of appropriate supports were consistent. Indeed even within the literature such lack is demonstrated as the following unattributed quotation indicates:

'When are people going to understand that an autistic child isn't killed because he/she is autistic? It's not that the autistic child is being targeted, it's that the support for challenging, special needs children is so limited, that an otherwise perfectly "normal," competent parent snaps on that proverbial last straw. The child ends up abused or killed, not because the parent is a cruel, horrible person who thought they had a right to "take out an autistic child" as though it were a piece of trash. It happened because the support was lacking. Support asked for and not received' (Anonymous 2014).

Contained within this statement are several of the issues parents within this study indicated, most typically escalating pressure and crisis, lack of support despite fruitless searches which led to an eventual desperation. This is the reality for too many parents who care for a challenging child.

It is also notable that this statement leaves out many of the other pressures parents indicated, not least external condemnation for failing to stop the challenges, social isolation and unrealistic care demands due to fluctuating school placements. It is a heady mix and one that is unsustainable in the longer term, as four of the families involved in the study found, leading to alternative living arrangements for their child.

As the parent of a 'challenging' child, my social circle over the years has revealed similar vulnerabilities and outcomes for other families. These are not sporadic, the same indicators in early childhood are found, followed by a lack of appropriate and timely support. For some there is an extended network of friends and family to share the burden, but for others the demands can be overwhelming. Paradoxically in light of excessive visibility and regulation, what is often overlooked in these tragic scenarios is the child, the practical implications of the disabilities held and the lost childhood at the centre of the crisis. Lack of appropriate support in any other disabled context would be viewed as negligent, yet it remains silently endorsed for 'challenging' children, even where interventions are offered, they emerge in a

correctional capacity, to plug what are viewed as failings, either of the child or parents.

Notably during the parents interviews a sense of loss was detected, a yearning for the normal. These yearnings did not appear to be motivated by material factors, or responsive to stigma or demands felt. Rather loss was emotive, a desire for the smaller trophies of parenthood and a realisation that such desires would most likely remain unfulfilled, as Saz summarised:

“I mean at home you have to be flexible, to meet the needs of the child you have to adjust, and I think you are always dealing with your own disappointments, you know the no mothers day card, and you are thinking wouldn't it be nice to have a card, and I suppose it's not really important”.

5.2.6 Lessons learnt?

Looking at the data generated from parents it is useful to ask whether anything has changed through the benefit of time in terms of practice or attitudes, given the life trajectories that are known to extend from behavioural disabilities, educational disadvantage and exclusion (Belcher 2014, Allen 2008, Bishop 2008, Hawkins et al 2015). Certainly the parents who had younger children suggested not, the same battles were being fought amidst the same exclusionary discourses generative of placement insecurity as Farah expressed in relation to her son:

“He has two more years left in primary [mainstream], and they keep on turning around and saying he is fine, he's fine, but I can see the time coming when they turn around and.. you see we are getting a new head teacher and this teacher tries to keep everything in house and quiet and I think that she will turn around and say 'no he is out', I can see it coming”.

Notably the most recent changes to the SEN code of practice (DfE 2015a) demand consideration of behaviour as a symptomatic indicator, although they do not reference this conceptual shift in relation to placement security or educative rights. Such move is however accompanied by a corresponding change of classificatory terminology: rendering obsolete the category behavioural social and emotional disorder (BESD) and replacing it with that of social, emotional and mental health (SEMH). These changes are too historically recent to offer any predication as to impact or change of mind-set, nevertheless it is possible to state that there has been no dramatic drop in formal or permanent exclusion figures (DfE 2015b).

There has however been a dramatic drop in the numbers of pupils being identified with SEN, indicating a reduction from 17.9% in 2014, to 15.4% in 2015 (DfE

2016aa). This reduction may well reflect the latest changes to the way children are classified and the move from the old school action and school action plus system to the new amalgamated classification of SEN support. The new system indicates a tendency to move from reliance on medical diagnosis and is titled SEN support (but no specific assessment of need). Such move may indicate teachers are willing to support children pedagogically without out reliance on disability labels, or more cynically it may equally reflect budgetary cuts amidst governmental drive to cut support budgets in all sectors. The implications for children and families are acute, move from medical explanations of difference opens further spaces for accountability and the most recent legislation may have removed 'behaviour' as a standalone indicator of deficit, yet it has replaced it with 'social'. For children the 'social' is most typically the familial context, which as has been shown is historically linked with varying accordances of blame. These tendencies make the current changes more troubling, which can only problematize further the challenges families such as those who engaged in my research faced.

5.2.7 Returning to base

So returning to base, 'who is the behaviourally challenging child' and what is the nature of his or her childhood? The 'behaviourally challenging child' may thus be summed as a child of contrast. Their childhood one of regulation and dysregulation, visibility and private shame. Yet it is unfathomable that against a backdrop of greater awareness and identification of behavioural disabilities, that parents and most particularly mothers, have to endure risks of violence and desperation borne of fear for their children. These support voids which would be indefensible if levelled against someone with a physical condition.

Mowat (2010) suggests that 'the degree to which young people are held to be responsible for their behaviour (and to be able to exercise agency upon it) is likely to be influenced by the conceptions which are held of the 'problem child' (pp 191). It is notable therefore that educational programmes which have been dedicated to emotional development, such as the SEAL programme (DfES 2005) appear limited in their ability to respond to either the finer nuances of behavioural disabilities, or their excesses. Practically nonetheless, some of the experiences shared were so complex, they defied layperson understanding. Undeniably nevertheless it has been

suggested that schools are inept in differentiating between presentations of 'challenging' (Soles 2008), leaving teachers vulnerable to feelings of professional impotency, which act as an impetus to creative positioning strategies, to retain and reclaim professional status (Frigerio 2007). Of equal interest is the underpinning rationale for teaching initiatives such as SEAL, framed seemingly in pupils best interest, but which on closer inspection also appear linked to wider political discourses concerning behavioural and discipline standards (Gillborn and Youdell 2000).

It is equally telling that initiatives specifically designed to combat behaviour are embedded within a discourse of 'problem families'. The most contemporary example being the 'troubled families' programme, whose impetus is to 'turn families around' in a specified time frame (Casey 2012a, 2012b). What is less openly stated amidst such rhetoric is the not the reasons underpinning 'trouble' as indeed unemployment, alcohol and drug abuse to name but a few are cited as variables leading to the social circumstance of being a 'problem family'. Rather it is the systems and structures that direct people into such circumstances in the first instance, ingrained inequalities, cumulative failings and oversights. The lack of disability appropriate response toward challenging behaviours represents only one small aspect of a much bigger problem and as the next section shows, the rhetoric behind government vision, is often heavily doctored, shrouding of more latent intents.

'Behaviourally challenged' childhoods may be typified however as essentially interrupted, differing from non- disabled and other disabled childhoods alike. The visibility and regulation conjured, contradicting of popular representations of behaviour challenges as evidence of un-regulation and lack of control. In common with many disabled childhoods, external professional input is at times intrusive. Irrespective of necessity where it differs is that for the 'challenging child, such input is accompanied by accountability and judgement which is definitional of both child and family. Generative of a dysfunctional profile which holds potential to taint the adulthood as yet unreached. This demands questioning as to why such tendencies have not been challenged on the basis of discrimination. Certainly the parental stories shared during the process of this research speak of unfavourable treatment which is directly linked to the effects of a disability, warranting of protection and support. Toward an understanding of the impetus behind inclusion and it's

contemporary enactment, I requested and was granted an interview with Baroness Warnock, I was interested to understand why inclusion was hailed as the solution to educative (at least) inequalities and also why for myself and other parents it failed to deliver.

5.3 Historic cautions

The political nature of disability response within the sphere of challenging behaviours was demonstrated during an interview held with Baroness Warnock (BW), chair of the educationally infamous Warnock report. During this conversation, it was indicated to me that the tensions which continue to extend from the goal of full inclusion in mainstream, particularly those stemming from 'challenging' children were historically anticipated:

BW: "I and one other member who a psychiatrist specialising in adolescent children, thought full inclusion to be a nonsense, because among the children that we were talking about were children whose difficulties were psychological not physical difficulties".

At the centre of these concerns were the practical logistics of adjustment essential to cater for such difficulties, alongside the effects of 'forced inclusion' on the child. As Baroness Warnock states:

"The most difficult children to include were what used to be called 'maladjusted children', now I think that is a very good name and it includes all the children that would now be described as EBD and ADHD and all the other categories that have sprung up. But maladjusted was a very good description because that was what they were, they did not adjust to the school environment in various different ways. And many of these children before they went to school seemed to have no particular difficulties at all".

These cautions are interesting and challenge the revolutionary history of the Warnock Committee. Most particularly its role within the inclusion movement, which claims to privilege at its core the equal value of all children (Booth 2002). Nevertheless inclusion when contrasted against the experiences of the parents in this study and the reservations Baroness Warnock expressed is less certain as a vision of integrity. It was hence notable to discover that the political backdrop to inclusion was according to Baroness Warnock more strategic than history suggests. Stated to be led not by child centric values, but political and professional determination to further the move to comprehensive education:

BW: "The atmosphere of the committee was very very difficult. Because there was already a very strong element, emanating partly from the department of education I think, but largely from the trade unions and the teachers NUT, who thought that the logical development of the

movement for comprehensive schools was to have all the children, absolutely all children educated in mainstream schools and to abolish altogether special schools”.

It is interesting to ask looking now at the mature realisation of mainstream inclusion whether some pupils are dealt a disservice, not through intent or complacency, but through the system as it presents. Certainly teaching unions express serious concerns about the effects of behaviour, yet few allude to the problems caused equally to the pupil (NASUWT 2008, 2012a, NFER 2012). Behavioural disabilities impact jointly on the individual and those who encounter the child. Should such impact however deflect from recognition as disabled? The families who shared their experiences would argue not, as would I, disability inconvenience should not negate disability rights, nor should an inability to respond to difference in an informed manner, pre-emptively to minimise the symptomatic effects of disability. Failure to adjust responses to a therapeutic frame, situated within a disability discourse perpetuate disability accountability and diminish the credibility of behavioural disabilities within the broader umbrella of disability presentations.

5.4 But what does this mean for parents children and schools?

Review of current academic literature confirms a need for ethnographic writing which can depict the familial impact of the challenging child and the holistic impact of challenging behaviours on the child across the expanse of childhood. Although much is written about ‘behaviour’ and the ‘challenging child’ from several disciplinary perspectives (particularly sociology, law, education and medicine) (Barkley 2002, Hardwood 2006, Green 2008, Cross 2011, Garner 2013, Ribbens-McCarthy 2013, Slee 2013). Very little narrative is available to expose actual childhoods displaced by behavioural disability, or its effect upon the entire family (Austin 2008, Carpenter 2007, 2009). This lack serves to distance the embodied and lived reality of behavioural disabilities, leaving only piecemeal discipline specific research to inform on the issues ‘challenging’ behaviours raise. Of equal concern is the poverty of behavioural disabilities representation within disability studies literature, which serves to disassociate behaviour from disability and marginalises further this grouping within both the disabled and non – disabled community.

The lived impact of behavioural disabilities do not fit easily with the frequently used genres that represent childhood disability. Most typically representations are evocative and conjuring of positive, sympathetic or humorous emotion. This has

been typified socially in various manners, ranging from mysterious and distanced undertones evoked through imagery (Sarrett 2007), sentimentality evoked through classic fiction (Keith 2001) social commentary embedded within cartoon animation (Kirkland 1999, Google 2012) and literary drama alluding to the darker undertones of disability and the maternal role within it (Shriver 2003). In particular characters such as Bart Simpson and Horrid Henry, deliver safe and comical scenarios for public consumption, which although intimating of behavioural difficulties, are also sanitising of the reality of actual behavioural disabilities.

Hence the identities which form around disability types are distortive of actual embodied presence. One of the most frequent sentiments that were conveyed to me by families was that outsiders, particularly schools 'just don't get it' (Sacha). I too had felt similarly and many times felt that it would be useful for schools and other professionals to actually experience life as it can be with a child with a behavioural disability. It was simple factors for us, such as getting to school on time, having homework completed and even keeping school books. These were the simple things which held sway to snowball, both in terms of sanctions and in terms of family stress. As Freya had expressed to me in interview:

"School can make it worse, I mean you'll know yourself, we always find September to Xmas is horrendous, new teachers, new classroom everything, we get it every year, the stimming the rocking, the cannot cope, all of that... But I went in this year and I said 'right, you do not keep Kieran in at break times, or lunch times, he needs to be out there running around, because he is coming home and he is flipping his kite, you know literally".

This disconnect between school and home is important and reinforces the symbiotic effect each has on the other, it also emphasises the need for a holistic appreciation of the child/young person. Problematically there are also few texts which allude openly to the constitutive effects of behaviourally disturbed childhoods into adulthood, despite the expanse of literature which is focused upon the impact of childhood disability within the family (McLaughlin 2008a, 2008b, McLaughlin 2016, Rogers 2007, 2007a, 2011, 2016), similarly on the family's social, health and economic wellbeing (Dobson 2001, Eisenhower 2005, McConkey 2008, Griffith 2010) and issues of maternal oppression and gender discrimination (Tardy 2000, Home 2002, Blum 2007, Kingston 2007, Holt 2008, 2010a, Rogers 2007; 2007c; 2011; 2012; 2013, Holt 2012). Hence although research activity is significant in the field, it is as yet incomplete due to the limited research which addresses

comprehensively or intricately the form of 'challenging childhood', or the injustices which accrue because of it, an omission which I consider complicit toward the silencing initially referred to.

An example of research which does offer a holistic ethnographic approach is the work of Anna Carlile (2011, 2013), who skilfully illustrates not only the emotion and tangible impacts of school exclusion across the varied contexts youth inhabits, but the institutional systems which underpin its application. Although focused chiefly on the impact of race toward institutional propensity to blame and exclude, Carlile (2013) also remarks on the impact of neurodevelopmental disabilities on these young peoples social functioning. Of the scenarios Carlile illustrates, many were familiar, demonstrating eloquently the vulnerability of not only the young person, but also their families and interconnectedness to wider systems. The following excerpt illustrates the potency of this approach:

'They were boys who could often not read very much, who had often grown up with alcoholic parents or in the care of the local authority, who had problems with impulsive behaviour and who found it hard to make the right choice when someone more wily said, 'Hold this stuff for me for a couple of weeks, there's a good lad', or 'Just pick me up at the corner, don't worry, no one will know it was stolen.' And outside the cells were mothers and girlfriends and sisters crying tears of frustration. I began to think that these boys had complex stories that did not have a place or space to be told within the legal system. I thought that some of them may have some kind of learning disability, but I did not know enough about learning disabilities to find out. I wanted to be there earlier in their stories, to try to help them avoid the same mistakes' (pp 5/6).

This small excerpt introduces issues of domestic abuse/neglect, learning difficulties, peer abuse, familial despair and unjust treatment in a manner that is hard to ignore, but more importantly it emphasises links, the pathways that lead to a disadvantaged future. Nevertheless what this research found was that the formal 'seeing' of 'behaviour' was filtered through the sense and significance it held in set contexts aligned to specific purposes, be they diagnostic, pedagogical or social, and as all were equally one dimensional, they omitted the sense making possible from a multi-dimensional context. As a researcher I had the luxury of witnessing very different ways of 'seeing' and thus 'knowing', reinforcing belief that there was a need to forge connections between these differing context to enable a more detailed holistic 'knowing' of the child.

Carlisle's research focuses upon institutional racial prejudice, nevertheless I would seek to expand this and suggest that the indices attracting of prejudice are multi-

faceted and extend beyond racism. Toward extension I would argue that behavioural disabilities conjure unfavourable response in comparison to disabilities that do not impact on behaviour or which are physical in nature. Behavioural symptoms are also liable to objectification, giving impression that behaviour exists as a tangible variable. It is hence asserted that it is vital to step back and resist objectifying behaviour as a tangible classification in its own right, rather to consider behaviour as a manifestation of an underlying difficulty (Hardwood 2006, Greene 2008b, Cross 2011), one which impacts beyond the school gates.

Equally significant is how behaviour is 'read' and to what extent the variables of race, class and gender affect 'behaviour's association with disability in the dynamic of the moment (McGlaughlin 2002). Sacha's story offers pertinent example of how social status can mitigate against exclusionary sanctions, advantage which is not always of benefit in the longer term. The data generated through this study suggests that the effects of behavioural disabilities rarely respect position, education or experience. Although these variables impact on the resources parents can draw upon to limit behavioural effects, the drivers beneath appear random in their choice of host. Paradoxically such lack of social resources in the case of behaviour appears to compounds impression of deficit, which in respect of families managing challenging behaviours can be both negative and positive. As Sacha's story indicated, ability to cope seemed to result in less external support. This disposition is not universal as Mordre (2012) indicates, Norway in particular acknowledge the effect of neurodevelopmental difficulties across the life span and adjust social supports accordingly. Such approach is pre-emptive and acknowledging of the multiple sites impacted upon through disability.

Childhood behavioural disability was found by families to be constitutive, generative of identities which stuck. As Leanne noted schools formed diagnostic opinions which were used to make sense of the difficulties the child posed "It's just because school think he is just naughty". Yet this belief acted as a filter to interpret subsequent and historic actions. These propensities are similar to those noted by Carlile (2013), particularly the preformed knowing generated through formal documents. To demonstrate Carlile refers to a previous professional role as an inclusion panel member, to illustrate how educational organisations solidify identity through official

documentation; practices which can be linked to Foucault's (1977) writing on objectification:

"I was introduced to my new students when the class resident social worker showed me their case files. These files offered me the official view of the students, their categorised – diagnosed identities and constituted my first proper understanding of what Foucault describes as official documentations propensity to capture and fix" (Carlile 2013 pp 8).

Although such practices serve to formalise the individualisation of behavioural deficit, the classifications used also hold pre-existing identities and are generative of expectations which act to confer meaning to subsequent behaviours observed. I had experienced the power of these associations first hand, when during a peripheral conversation about my son's dislike of PE, our local SENCO announced that none of the autistic pupils liked PE. Although a harmless comment in the scale of things, it held more troubling connotations, particularly toward the nature of other truths. I was reminded of a conversation that I had during my volunteering placement in a local PRU, where in conversation one of the staff announced that a particular pupil had a personality disorder, which although as yet undiagnosed, was she believed likely to result in eventual imprisonment. Although this projected pathway may not have been too far from the truth, given the already discussed association between behavioural disabilities and offending, in the context in which this conversation took place it implied a fatalistic mentality which I felt contrary to the role of a PRU.

Disability truths are powerful diagnostic signals, yet are increasingly being questioned. Drawing upon the established association of lack of empathy with autism Carlile describes how skilful and observant personal engagement can counter this particular truth. Such phenomenon has also been observed by Pinchevski (2015), noting the impact of technology toward the former conception of autistic persons separateness, which is described as 'the transition from impaired sociability in person to fluent social media by network' (pp2).

Both Carlile and Pinchevski observe skills that are counter to the core indicators of autism, yet it is notable that these claims had been stated from within the autistic community decades previously (Sinclair 2005), although failed to capture the public imagination. Greene (2008) similarly seeks to reframe the sense made of behavioural difficulties, calling for engagement to be based upon a philosophy that asserts children are programmed to achieve. Such philosophy reframes behavioural

challenges from won't behave to can't behave and as such are indicative of a deficit, which is requiring of education and therapeutic intervention rather than sanction.

As ethnographic writing demands close and personal attention to both detail and emotion, its proximity can expose factors omitted from more segmented engagement. As such demonstrates without intention the difference between formal 'knowing' and more personal familial 'knowing'. Ethnographic writing hence has potential to enrich our understanding of behavioural disabilities and inform the supports needed to steer the young person to a productive adult hood, as similarly familial knowing does.

5.4.1 The illogical nature of accountability

It is paradoxical that alongside expansion of what are termed neurodevelopmental disabilities (APA 2013), both personal experience and research data indicates that the markers of these disabilities in terms of behaviour, prompt educative, legal and social digression away from rights and protection (O'Connell 2016). Favouring instead control, responsive to perceptions of threat and impact on community. Thus endorsing demand of restitution for the effects of medically endorsed behavioural disabilities. Most of the families who engaged with this research indicated desperate need for support and for help to salvage the children they knew. Nevertheless as parents shared their children's experiences, it became evident that support was not a priority. Systems remained responsive to individual acts, resistant to any 'knowing' of the whole, either the child that pre-dated adolescence or the adult they held potential to be. Some of these young people resembled what Bauman (2004) depicts as wasted lives, beyond the scope of remediation, requiring of management, not help as Louis's mum noted. "You are left wondering where the help is. There is a lot of talk about it, but very little actual action that has any really meaningful impact on your child's life".

Talking with other parents their knowledge and understanding of their children's disabilities was impressive, through these conversations a greater understanding of the unjustness of accountability was forged. Saz's comments in particular were pertinent and relevant not only to accountability, but to responsibilities owed to the child if indeed the spirit of a medical model is truly embraced:

“There is a psychologist Russell Barkley, he says that ADHD and I suppose it is also true for some other brain disorders, he says it is a disorder of performance and that you have to treat it at the point of performance. So it is not about what you know it is about implementing what you know. If the point of performance is the implementation point, then that is where you have to make sure you have the reminders in place”. [Saz]

It is therefore significant that the digression between social rights and legal accountability is found enshrined in law (Parsons 2005, Jull 2008, Caslin 2014, Jimenez 2015, O’Connell 2016), resulting in serious disadvantages for children and adults affected by neurodevelopmental difficulties, including disproportionate vulnerability to engagement within the criminal justice system and disadvantaged treatment by it (NACRO 2011, Talbot 2011, Hughes 2012, PRT 2013). Furthermore it is considered indefensible that accountability remains standard school protocol, despite many unwarranted behaviours being listed as diagnostic criteria, or known to derive as a consequence of such criteria.

For the young person at the centre of these scenarios there are a multitude of judgements from a wide range of professionals, despite their having a diagnosis of disability. Hence although the law covers equality, safeguarding and criminality, for young people with behavioural disabilities, it is the latter that emerges as the most frequent basis of professional concern, judgement and action. Although only when challenging behaviours exceed the boundaries of the family home, triggering a separation of the young person from the protections accorded by equality legislation with regard to disability. Equally so separating these young people from safeguarding protections which should be responsive to the vulnerabilities their disabilities incur.

These practices echo Giroux’s (2011) observation of the ambivalent relationship modern societies have with young people. Generative of practices which Giroux defines as the war on youth, ‘leading to a growing youth-crime complex that increasingly governs poor minority youth through a logic of punishment, surveillance, and control’ (Giroux, 2011, p. 6). Giroux (2009) also speaks of a reconfiguration of bio politics, leading to what he termed the ‘politics of disposability’. Political mind-set which appears legitimating of punitive response to presentations of youth which are considered to pose both societal risk and burden on health, welfare and educative services. Giroux’s writing in regards of society’s relationship with youth generally offers a rationalisation for contemporary practices which enforce accountability even

when behavioural challenges are attributed to a biological definition of disability (O'Connell 2016).

Of added concern is that accountability is found disproportionately directed toward mothers, as Runswick – Cole suggests, 'mothers of disabled children experience disablism directly and by proxy through their relationship with their disabled child' (in Curran 2013, pp 105). Indeed the material circumstances of childhood disability are considered a gendered issue, rendering mothers part of a 'marginalised group of women whose self-sacrifices are taken for granted' (Kingston 2007, pp15). Certainly within my own experience this has been my context, similarly so many of the mothers I engaged with, that said, neither I nor my respondents expressed gender to be a primary concern.

Unsurprisingly mothers are found to experience disproportionate disadvantage, economic, social and emotional (Kingston 2007, McLaughlin 2008b, Carpenter and Emerald 2009, Gallagher 2010). Disadvantages directly linked to their shouldering of a disproportionate share of parenting responsibility, impeding on not only ability to pursue employment, but equally ability to form or sustain effective social relationships. Reading about these disadvantages I was struck at their familiarity, more so when put in context during interviews with families, for example one mum out of the blue asked me "between you and me have you ever taken anything to get through"? Another mum whispered to me after telling me her child was temporarily staying with her partner "I know it sounds bad, but I really don't miss her, I love her, but it's just so nice not having the responsibility and the worry, it's better for her too".

By the end of my contact with families, there were two significant outcomes that seemed most common, the first was the separation of the young person from the family home when the family could no longer cope, and secondly for parents of younger children there was a determination to have schools view their child and the impact of the child. This is summed by Saz:

"It's just about understanding really, understanding about the lifestyle of a child with not just the autism just the whole range, understanding because your life just doesn't tick by like normal peoples do, it doesn't at all does it? It's very disjointed and an understanding, a better understanding really is what I hope for".

Partnership breakdowns were found to be common amongst my respondents, as were partnership tensions, this was found to further disadvantage siblings, as well as heighten the expectations held of them:

“Ironically it is my daughter that is causing me the most stress, I mean she is being really difficult, nothing major, but we have had a big fall out. And part of it is maybe that I think she is setting a really bad example for her brother of this arguing and fighting with me, and maybe I just expect her to be better behaved, because of her brother, and it is just really hard [chokes back tears] (Andy)”.

It is unsurprising that the effects of parenting a disabled child are found to have a deleterious effect on the physical and mental wellbeing of mothers (Dobson 2001, Eisenhower 2005, Greene 2007, McConkey 2008, Griffith 2010), effects which were alluded to by my respondents. One mum (wished not to be named for this disclosure) had succumbed to serious depression and ill health, whilst other mums spoke of lost careers, friendships and even the support of wider family. Notably medical labels were found heavily implicated in the experience of parents and children:

“It is just such a horrible label ADHD, it really is isn't it, and loads of people will instantly say 'there is no such thing, they are just naughty children', my sister is classic, she will say 'oh he is just naughty, won't do a thing I say, won't listen to me, doesn't matter what you say to him', and I mean the kids pick up on this that other people do not like them, that they are not liked as well and that is horrible” (Freya).

It is significant that amidst the life experiences shared although there were mixed emotions there was a unanimous acceptance of the children. None of the parents spoke of burden, rather they referred to need and sadly its absence. Sentiment which Green (2007) encapsulates in the title of her article ‘we are not sad we are tired’. By far the darkest fears exposed by my respondents and indeed myself is the fear of harm to our challenging children, both self-harm and harm done by others. For some parents these were abstract fears, for others such as myself they were situations faced. Irrespectively they serve to indicate that from a familial perspective, not only a mother's eye, these challenging children who become challenging adolescents and eventually challenging adults are also vulnerable, an identity which is in direct contrast to those conveyed through the sum of actions.

5.5 Concluding comments

So what does the experience of parenting a challenging child teach you? What are the emotions left long after the worst challenges have been faced, fought and

passed? Personally if I were to characterise the effects, I would say they weave their influence in subtle ways, occasional flashbacks linked to specific cues, times, places even smells, infiltrating the memory when it is unguarded. If I had to describe my main role within my son's childhood it would be as an advocate, long before any of the more pleasurable privileges of motherhood. But just as insider research has been found to hold emotional effects on the researcher, so too does being the parent of a challenging child. I spoke within the narrative of holding to the child I 'knew', yet challenging behaviour which is sustained over time is erosive, it destabilises and even though I can now see the son for the person he was before adolescence, there is always the waiting for it all to go wrong again. It is ever a journey into the unknown, for just as miscarriage may be said to shatter pregnancy innocence, so too does challenging parenthood shatter parenting innocence.

As a family we drew strength from numbers and supported each other when no one else would, yet even in this context there were casualties. Most specifically the loss of childhood, not only for my son who was challenging, but for his siblings in numerous subtle ways. In the immediate the trauma and drama as their brothers' difficulties escalated, in the intermediate as his identity began to taint their own, and in the longer term like me through the 'knowing' of the dark side of disability and the 'not knowing' if or when it might return. Pervasive neurodevelopmental disabilities are impacted on by age and developmental milestones, but their core effects are stated to be lifelong. Our family, like all others cannot predict the future, but the past can continue to extend its influence long after its moment has passed.

Neither my experience, nor that of my respondents was unique, as Carpenter (2013) found similarly, the dark side of behavioural disabilities remains in the shadows, behind closed doors. Silenced through shame and stigma, in direct contrast to the esteem the psychiatric profession enjoy amidst the professional hype of newly configured classifications. Such contrast raises uncomfortable questions around ongoing disability discrimination, social control and the un/inclusion of a population who emerge as problematic. It necessitates asking why in an age where so much is deemed to be known about behaviour as an indicator of psychological disability is there such barriers to its embrace socially as a bonifide disability. It further highlights

the hierarchies inherent within the disabled community and suggests that all disabilities are not equal, not in law or society.

Realising this and living this conjures feelings of anger and disappointment. Anger that having experienced these difficulties during a period which will be recorded in history as that which founded and championed inclusion, such inclusion for many was illusionary. Disappointment that others too continue to experience both the prejudice and barriers that we parenting survivors now look back on. Returning to the title 'challenging disability in childhood - the construction of a life trajectory. One can tease out the meaning implicit within. This chapter has sought to challenge the narrow definition of childhood disability and the absence of behavioural disabilities within it. It has also illustrated that 'challenging' behaviours effect major stress on families which trigger need for support not condemnation. Responses faced by parents intimate the trajectories drawn, yet these do not stem irrevocably from the challenges posed. Rather they are linked equally to systemic failures to erect effective supports in earlier childhood, pre-empting the heightened needs and excesses of adolescence.

Repeatedly parents spoke of failings to respond effectively in adolescence and where responses were made, these appeared triggered only when external risks were posed. At this point the young person is transformed from profile of vulnerability, to that of perpetrator. It is therefore my contention that the silence which surrounds challenging childhood needs to be broken if there is to be any opportunity for change. Effecting change however necessitates the breaking down of barriers exposing the realities of challenging childhood. For as was my experience, challenging children grow into challenging adolescents and adults, where risks posed are heightened and opportunities to effect change limited.

Responding to challenge as a symptom of disability rather than malevolent act reduces systemic inclination to offer support on the basis of the severity of actions. It places responsibility to alleviate symptomatic effect, in parity with those accorded to children who have the physical markers of disability. Thus if disability equity represents the mark of a civilised and developed society, it necessitates as a preliminary step equity within disability. The narratives shared within this chapter challenge such equity and hence the final comment of this chapter invites the reader

to consider how they might navigate similar challenges. Would they hope for dignity and respect, or accept the accountabilities so typically accorded? For parents such as myself there is no choice, worn by the realities of parenting a challenging child, there is limited energy for social lobby. As a result this chapter extends an invitation to remedy what I have previously referred to as the last taboo of childhood disability. One important step toward this would be to place the onus back to schools to educate all children, irrespective of difference, which would of itself necessitate the adoption of the Italian education system's mind set, which disavows exclusion as an option. Problematically however many of the difficulties parents faced were caused not by formal exclusion, but exclusionary practices within the mainstream. These practices, including late starts to the school day, early finishes, parental supervision at lunch times and segregation from mainstream classes in what are known as 'twilight' sessions (where a child attends school at the end of the school day for a few hours), were as disruptive as a formal exclusion was. Notably there is increasing recognition of these as illegal exclusions as is demonstrated by the findings of the 2013 children's commissioner's report (as discussed in subsection 3.2, point 3.2.10). Nevertheless these practices continue and disproportionately disadvantage families and children with disabilities of impact on behaviour. Although looking at the data from engaging families, it would appear that Nind's (2008) observation of the impact of class is further supported by my data, as notably parents such as Leanne struggle to gain any formal recognition for her son, she also struggled to negotiate any reasonable provision for her son, indeed the narrative shared with me suggested schools actively avoided such support. However in comparison Angie could be seen to draw upon her educational and financial resources and was able to fight for recognition of her child's difficulties. This different pathway suggests that it is not only a child's presenting difference which directs understanding by teachers. Rather it speaks of the differing habitus (Holt, Bowlby and Lea 2013) observed. Equally so (Bauman's) notion of surplus populations, and the means Freire (1996) suggests are employed to prevent recognition of disadvantage. It is at this juncture that considerations of the functions served by blame become most pertinent and potentially institutionally and professionally functional (Youdell 2011, Frigerio (2013)). It is therefore necessary to explore the knowing which underpins their orchestration, through an interrogation of the knowing which coalesces in the formal school domain. Chapter six now looks to formal knowing in the mainstream sector,

pursuing the question of whether all disabilities may be seen to be equally accepted, or whether ability and willingness to support link to wider priorities and responsibilities, beyond the remit of the child or family.

Chapter 6 – The shape of ‘formal ‘knowing’ in the mainstream – seeing from the outside in.

This chapter considers how childhood disability and challenging behaviours come to be recognised, and are ‘known’ by teachers and by SENCOs. A view which is described as seeing from the outside and refers to formal professional understandings that emerge and are employed in the school context. This is knowledge which I term ‘formal knowing’. The guise of ‘formal knowing’ emerges from data collected during this study, from teachers and SENCOs. Section one introduces the concept of ‘formal knowing’ and discusses processes identified in its generation which emerge from parental narrative. ‘Knowing’ emerges in this context out of the pursuit for answers to difference, a search which appears to irrevocably include assertions of blame, be they medical, familial or organisational.

Although data is employed from across the range of data sets, section two focuses upon the responses of SENCOs and teachers. This section explores what professionals consider they ‘know’ and the influences on such ‘knowing’. Teachers and SENCOs knowledge was found divided between ‘formal knowing’ which conceded to medical authority and ‘formal knowing’ which privileged pedagogical explanation. Pedagogical ‘knowing’ appeared eclectic and did not concede absolutely to medical explanation. It was found to be directed also by the expectations of pupil complicity, as well as externalised explanations for behavioural or learning failure. These explanations were based upon the child’s culture, parenting and motivation, although interestingly the nature of these attributions was mitigated by the individual teacher’s personal experience and interpretation of the teaching role as well as entitlements to inclusion.

Therefore the variability of attributions demonstrated a malleability which held important implications for how ‘knowing’ developed and was employed and specifically impacted on the sense teachers made of pupil differences. It is also notable that at times these two differing forms of ‘formal knowing appear incompatible, resulting within the school context, occasions where ‘pedagogical knowing’ effects challenge to medical explanations for difference. Nevertheless, irrespective of the forms of ‘formal knowing’ employed, schools indicated a dependency on medical diagnosis to support applications for additional funding to

support the child. Parents showed awareness of these practices and suggested that a lack of diagnosis led schools to have a lesser motivation to support these children. Additionally where the child's difficulties involved behavioural conduct, this placed these children at a heightened risk of both fixed and/or permanent exclusion.

Section two addresses four key questions which emerged from the ensuing discussion in section one (Chapter six, subsection 6.2). This discussion (and that which follows in Chapter 6) explores the contrast of 'knowing' between different educational settings, as well as providing an opportunity to compare 'formal knowing' between schools in the mainstream. It is through the collation of data generated in these multiple contexts that a more detailed picture emerges of the nature of 'formal' knowing. This picture challenges the notion that all disabilities are equally validated, including in respect of the child's rights as accorded by the Equality Act (Parliament 2010) and inclusion as a charter of educative rights (Parliament 1981, 2002, 2014).

Section three offers a discussion of the implications and functions of different forms of 'knowing'. This section argues for a move toward a more collaborate and holistic approach that can bring together both formal and familial 'knowing', that is in the child's best interests, both in the immediate and in the longer term. Parents repeatedly emphasised that schools 'just didn't get it' (Sacha). Parents also emphasised that they struggled to impress upon schools the seriousness of their children's difficulties, and the impact of school on their children. This exploration of 'formal knowing' aims to uncover the professional knowledges employed in schools, alongside their effect. This chapter concludes that the collaborative sharing of these differing ways of knowing, ('formal (medical and pedagogical)' and 'familial') offers means of 'seeing' the child in a multidimensional manner, which in conjunction with a heightened awareness of the implications of 'knowing', holds potential to challenge discriminatory responses in education.

6.1 Section one - why does it matter what is known?

In my personal experience the absence of common 'knowing' was inhibitive of a constructive school/parent working relationship. It was interesting to find that other parents had found similarly and that this experience was not always linked to behaviour, nor was it inevitable. Micha - mum to Hassam aged 9 (suspected learning difficulties) shared the difficulties she had experienced:

“For me the first three years in his school were not very good, they didn't say anything, they just said that ‘this is his level (ability), he is below average what can we do’? But this is not the same attitude this last two years. His previous teacher accepted him as a stupid child, ‘he is that way, I don't want to change anything’, I think she (teacher) thinks this is not her responsibility, this is the child this is what he is doing. But the current teacher she said, ‘no it shouldn't be like that, he is clever he is a good boy’. So now we are working on the same page. I was really happy, because I thought that here is someone who really understood what I had felt for years and we are now working together”.

Micha explained to me that her Saudi culture had instilled in her a deference to authority which she found hard to challenge. Such deference bestowed on school staff a significant power and responsibility which in this case led to an evaluation of Micha and her partner parenting competency. Nevertheless the power schools hold was revealed in differing guises, exceeding placement security and extending into the heart of the dynamics that punctuate the school relationship. Jules describes how power manifested for her, stating that, “a bad teacher is a year of misery isn't it”? This comment, although brief, emphasises how power exceeds singular acts or domination, but pervades the everyday. It is also interesting that in interview Jules intimates at conspiratorial ‘knowing’, through the addendum of ‘isn't it’. This comment in the moment resulted in an affirmative response, but looking more deeply its significance was more evident as I can concede that I too ‘knew’ such vulnerability and I might add this was a vulnerability that transcended the bounds of disability, but extended across the parent base.

Jules comment typifies how a dependency is produced in schools for both children and parents, through their reliance on compatible personalities to navigate the child's placement. This dependency speaks of the serendipity Leslie Henderson alluded to in interview (pp 470) and it is significant as its primacy appears to negate the levelling effects of ‘pupil and parental rights’. Such vulnerability was both heightened and revealed through the data my study generated as teachers displayed inconsistent and questioning attitudes to disability classifications, parental competencies and complicity.

Henceforth although teachers comments in my study were made in abstract; when placed in the context of school relationships, their potential impact is revealed, not only toward a pupils rights, but on the guise of the relationships developed. Additionally Jules comment, considered against the backdrop of her comfortable socio economic status, suggests that status does not automatically mitigate against the sway of individual personalities. Indeed Micha's statement (shown above)

extends this point, highlighting the inconsistencies that many parents find to be a feature of school life; a feature which alludes to the inherent unequal relations of power between families and schools. It is also noteworthy that Micha refers specifically to her son being described as 'good' and equates this with his school worthiness. Such comment not alludes to an unequal hierarchy between parents, challenging the notion of a simple us and them divide between parents and schools, it also suggests that the concept of a 'good pupil' is part of what Schutz (1973) determined 'the lifeworld', taken for granted knowledge that does not need explicit statement.

Unequal relationships between schools and families are found to hold worrying connotations in the wider field. For example similar evidence gathered as part of the SEN and Disability Information Review (Lamb 2009) suggests that there are systemic abuses of position and power in the following areas:

- a) 'Incompetence in schools and ignorance of the rights of the child' (Specialist Teacher/SENCO, pp103).
- b) 'Schools not using dedicated funding' (Parent of a child with ASD pp103).
- c) 'Dismissing parents concerns as 'over anxious', or 'blaming' parents for their child's difficulties. Especially for impairments like ADHD and Asperger's (Parent Partnership Officer pp 109).

The Office of the Children's Commission (2013) extends these concerns, reporting significant evidence of illegal school exclusions. The features of illegal exclusions are presented as an informal arrangement, brokered locally and rarely recorded officially, and as a result parents are not always aware that their rights and those of their children are being dismissed. Indeed illegal exclusions are often arranged voluntarily between school and the family, under a guise of benevolence, which is masked through the illusion of the school working with the family to avoid a permanent school sanction. Contact a Family (2013) state:

'70% (of illegal exclusions) are because the school suggests it is for child's 'own good' as he or she is having a bad day. Of these, 45% say it happens every day or every week' (pp 3).

Similarly the charity Ambitious about Autism suggest that exclusionary practices are often justified as a means of preventing 'punitive exclusion', alongside an intimation that the pupil's difficulties warrant 'respite' (AA 2014). To a struggling parent these strategies might appear reasonable, but they also serve to apportion unspoken accountability onto the family for the difficulties the child holds. I was personally

complicit to many such exclusions (at that time) unaware of their guise, indeed on many occasions it felt as though school were being understanding. It was only in retrospect I could see that the school was actually being manipulative. The parents participating in my study voiced similar stories, agreeing to absences which were often framed as part of meeting the child's needs. These took the form of a conspiratorial recognition that the child could not manage unstructured time, or changes to staff, or the school day. With the passage of time I realised these acts were signalling a more sinister meaning. In essence they amounted to an avoidance strategy by schools; a dereliction of their organisational responsibility to make 'reasonable adjustments' to include my son (Parliament 2010, Chapter 3.1.4, section 20)

The 2001 SEN Code of Practice introduced a requirement for all Local Authorities to offer a parent partnership service, between parents, schools, Local Education Authorities, health and social services and voluntary organisations. Nevertheless Todd (2003) cautioned that introducing mediating agencies into the parent/school relationship would foster greater not less distance. Additionally, although partnership implies equality, Reay (2008) cautions, 'parental involvement in schooling and parental choices are classed, raced and gendered processes' (pp. 643). Such an observation reflected the differing cultural resources parents within my study held, despite holding a common determination to make visible their children and their needs. This need was emphasised to Saz as a parting comment from her son's consultant before being discharged and who stated:

"The best thing you can do is to become an expert in your son's condition yourself, read everything you can, go to seminars and conferences, learn everything you can, and then you can tell everyone about it, because your son's greatest obstacle in life is going to be other peoples prejudice".

This is sound advice in theory, but in practice its discharge depends upon a variety of parental skills and coping resources. Resources which may be summed as social capital (status), socio-economic position (money) and education (intellectual abilities) It is nevertheless useful to gauge how others see our children, as such appreciation can also reveal the implications of externalised knowing, particularly the nature of its authority and the counter knowledge necessary to address any ensuing inequalities.

'Formal knowing' is central to the identities that children with disabilities develop, offering explanation for childhoods that deviate from typicality. It was found that

these explanations lent towards either a medical or pedagogical explanation. The latter at times challenged the accuracy of diagnosis and offered alternative explanations for difference that were framed around a nature versus nurture divide. At other times teachers 'formal knowing' shifted between contexts and was responsive to the type of difference presenting, in particular where a teacher had personal experience of a similar difficulty, there was a greater appreciation of the nature of difficulty. Irrespective of allegiances, additional funding for pupils with SEN was bolstered by a diagnosis and SENCOs alluded to the value of a formal medical diagnosis and a 'statement of special educational need' (at the time of conducting this research the educational statement was the legally binding means of identifying and securing a child's educative needs, this has now been superseded in the UK by the Education Health and Care Plan (EHC)).

I had personally experienced the uncertainties of childhood difference which had resulted in numerous negative school experiences for me and my child. Hence I felt it was significant that parents in my study narrated similar experiences. Having an opportunity to reflect on my son's childhood and the serious difficulties he has experienced and continues to face, I was only too aware of the impact of school toward the future life pathways open to a child. I was also aware that responsibility for these pathways was infrequently acknowledged by schools, finding more typically that there was an organisational disposition towards skilful deflection. Consequently I considered it important to explore why, despite a heavy reliance on medical diagnosis, some children appeared less welcome in school and were susceptible to school exclusion. Additionally, having faced challenge to the validity of my own son's diagnosis, I was also interested to explore the extent to which classifications of disability were equally validated by teachers, or whether my own experience was an isolated occurrence.

The spirit of inclusion as envisioned by Booth and Ainscow (2002), generates an impression that as inclusion as matured, presentations of disability and difference would have evolved to hold both an equal and respected status, although the extent of teacher training around disability classifications was at that point unknown. I was therefore also interested to discover the extent of residual knowledge that teachers and SENCOs held in regards to the spectrum of disability presentations. As many teachers gain their teaching certificates following a one year PGCE programme, I

was also determined to probe the level of training around disability classifications and the extent to which teachers felt competent in their knowledge. I was also keen to explore with SENCOs their professional development programmes and working protocols to support teachers knowledge around disability and SEN.

Working towards a more nuanced appreciation of the sources of formal knowledge, teachers in my study were asked to consider where their own understandings derived from. The sources of 'formal knowing' were broken down into three main arenas. These were; knowledge accrued from formal training and education: knowledge gained from popular sources such as media, TV and the community (local knowledge), and finally, knowledge gained from personal and professional experience. Knowledge in this latter instance was considered to straddle the familial and formal 'knowing' divide, as such was considered to offer the greatest insight into the potential of combining familial and formal knowledge, as a means of broadening disability appreciation in the best interests of the child.

Considering further the nature of 'formal' and 'familial' knowledge, my research findings suggest that formal knowledge is purposeful, is situated in the immediate and directed to issues of causation for pupil presentations that deviate from the typical. As one SENCO emphasised: "we are a very data rich school, this enables me to collate detailed information on pupils which staff if concerned can access with a few clicks", yet such a data base does not allude to individual nuances, strengths or weakness, it is factual, offering guidance on the appearance of disability classifications and considered best practice in response. 'Familial knowledge' in contrast, presented in my data as more complex, unsurprisingly there was an evident emotional connection, which led to a more intimate knowledge, which was punctuated by present and longer term concerns. These concerns exceeded the bounds of academic outcomes and enveloped issues surrounding social/personal development and wellbeing. The idea of knowing the child deeply surfaced most evidently during discussions of the merits of medication and it was at this juncture that the most overt references to 'familial knowing' were made, as Freya's explains:

"My family said that he was terrible medicated, not behaviour wise, just that he wasn't himself, he was unsociable. He was horrible really. I mean he is not quite right today, but he still tries socially. But not when he was medicated, he would just growl, but you see the teachers were quite happy with that, they were not really concerned about the effect on him, just on the teaching of him".

At times the guise of 'formal knowledge' exhibited by teachers digressed from a medical model, pitting medical causational factors against those of an external nature, most particularly familial and cultural deficit. Notably this 'knowing' failed to envelop any personal investment, thus as the above statement implies, teachers gave impression of pursuing 'knowing' for purposeful means, which by extension shaped any evaluation of interventions to address difference.

Bearing in mind the three types of 'knowing' revealed by my study (familial, medical and pedagogical), I considered it important to question whether all presenting disabilities (or suspected disabilities) triggered the same digression, or whether this was linked to the type of disability a child held. Notably although the parents in my study were drawn mainly from families managing disabilities which manifested as challenging behaviours, of the few families whose children did not exhibit such challenges, such digression was still apparent. Micha's story illustrates this, demonstrating the varied points of reference employed by school in their quest for formal knowing.

Micha's experience demonstrates that the quest for knowing serves to position teachers as experts and parents as lay persons, who until exonerated are considered accountable. Julie became aware of such suspicion retrospectively following the entry of Zac's younger brother Jon to school:

"When Jon started the school, the head teacher actually said, she said 'oh we always thought it was you but Jon's all right'. And she actually said that she thought it was me until Jon started the school, I never knew!"

This disposition to investigate the family as part of the process of 'formal knowing' was found by parents to be a common strategy, both by schools and agencies such as Child and Adolescent Mental Health Services (CAMHS), as Freya's response to my query about parental blame indicates:

"Oh yes, I mean we have gone through it time and time again, you always feel that it is your fault, that's why I think CHAMS do a good job in a way I think, because they are looking for parental neglect as well, and I think they get to the point where they will hold their hands up and say look it is not your fault, I think that is the point you are at when they indicate that they will put you through for the screening".

Parents shared how accountability for a child's difficulties extended even in regards to extra-curricular activities once the processes of surveillance are instituted and attributions made:

“They have been nasty, their whole attitude to me. We went round to the Halloween disco a year ago and their form tutor was on the door collecting the money and she actually turned around, because Alice wouldn't go in and she said 'if you weren't here she would be alright, it's because your here, she always cries when your here', and I thought I can't win” [Catlin].

Micha's story (below) illustrates that even when behaviour is not an issue, processes of surveillance to inform 'formal knowing' appear directed toward the family in the first instance. Although significant in their own right, these processes do not operate in a void, rather the suppositions drawn are known to be impacted upon by interceding variables known also to incur educational disadvantage (Rogers 2007c, Nind 2008, Tomlinson 2014). These divisions were echoed in the parents narratives and it was possible to map the divisions generated between respondents who may aptly be described as 'professional parents and those who were overwhelmed by the system. This left them little alternative other than to remonstrate their frustration verbally, which for Leanne and Catlin led to allegations of being verbally abusive and served to deflect attention to their very genuine concerns:

“There has been incidents where staff seem to wind him up on purpose, or they handle things badly and when he gets upset he is then in the wrong. But we find that staff are not always totally truthful they tell only parts of what happened, and they rarely listen to him. I mean I got chucked out of the school by admin, because when there was an incident I went up to the school and demanded to see the teacher involved and they said I was confrontational. Their cameras never work either, conveniently” [Rob, Leanne's partner].

“I started writing down things that she did. I have letters going way back, in some of them they say that I am a liar, basically because I was told that she [daughter] would be treat the same as a person with a statement, but she wasn't, she didn't get the concessions from the school. When I challenged them they said I was aggressive and hostile” [Catlin].

These comments also offer a glimpse of how 'formal knowing' appears to be led not just by the child's presentation, but by a wider evaluation of the child's familial background, itself fundamental to the types of 'formal knowing' generated. In contrast Sacha's story is a good example of how schools can effect discretion in the boundaries they set and as Sacha herself stated, it is who you are and who you know that brokers discretion (pp 369). I turn now to Micha's story to illustrate the processes instigated by schools in the search for formal 'knowing', processes which as Julie discovered, begin close to home.

6.1.1 Micha's story

Micha is a young married woman from Saudi and at the time of interview was studying at a local university. Micha suggests that as a couple they would both consider themselves high achievers, she also alludes to their status and wealth at

home in their native country. Nevertheless in the UK, as a couple their cultural resources did not appear to hold comparable value. Micha is worried about her son, he has failed to meet the national standards deemed typical for his age. Micha knows this and has been searching for an explanation. At first Micha approaches the school with her concerns and this is where we take up Micha's story, this is reproduced as narrated and at times reflects Micha's difficulties with English:

"For me during his playing I think he is a normal child, but when it comes to study and school and his normal grades I get a shock every time, when he gets any marks or when he is evaluated by his teachers. His teachers always complain about his lack of concentration, when even if he is given a task even for ten minutes he can stay in a daze for ten minutes he just his teacher told me many times when I ask ,why don't you just do the work, he usually says I am daydreaming'. So this just shocked the teacher, he says 'I have something in my head I am thinking of so I can't do anything'. So she asked me 'what type of thinking do you think your child is doing'?"

Micha tells me she takes on the role of testing her son at home, in an attempt to raise his grades, yet in school there is little progress:

"I feel he is a normal child at home, this is just what he likes, he likes playing so much, he has computer games and he spends a lot of time doing these things. I think this is just a normal outcome of what he is doing all the time. But sometimes when I do sit with him and try to explain for example, to try to pass an exam or something, he seems to have good marks. But when he is evaluated by the teacher, his marks drop down, dramatically, but sometimes when I examine him at home he gets 10 out of 10 or 8 out of ten in spellings and in maths. But the next day the same exercises, when she tests him he gets 3 out of 10 or sometimes 0. I am really shocked. I mean yesterday he has got a good mark, yet when he is evaluated by the teacher his mark is very low".

As Micha's sons grades fail to improve an educational psychologist assessment is arranged and for a brief period Micha believes her son has dyslexia:

"At first thought he suffered from Dyslexia, when I read about the characteristics of dyslexic people I thought my child is dyslexic, but when I talk to the psychologist, well they are not really a psychologist, she said he is not suffering from dyslexia. She says he just has a lack of concentration and needs to be evaluated by a person who is specialised in that area, so she recommended the psychologist to work with him for about two months, actually one and a half months".

Micha's story up until this point suggests that the school and parent were engaged in a common purpose of trying to find out why her son is not meeting standards.

Nevertheless it soon becomes apparent that there is an agenda behind the ways schools conduct the processes of 'formally knowing':

"They asked ...they were trying to find a reason, they thought there might be some family issues, so they studied our state and how the child is treated at home and they found everything is normal and everything is quite encouraging".

Micha continues to explain how the school and psychologist explore whether the problems were particular to the family:

“They thought he might have some problems in his private life and they asked him privately and I later found out about it, about his mums treatment and his dads treatment, is there any problems between his parents and if he doesn't like anything... It's all about the social situation, and they seem to find the results are that they are happy with his family and there is nothing wrong with his environment”.

It is interesting that Micha begins to engage with this evaluation of her family:

“She said she had sat with him and asked how he felt regarding his teachers and regarding his mum, by treatment of him, is it that which affects him? He seemed to be satisfied from the school and from the family as well and they register that his family... that he has a good environment, he is given and he's told in a very respectful way [sorry I do not know how to express it in English]. He has a very good environment for a child to live in and we do not suffer from anything as parents. There ask if there is something from his family? I told them, my husband sometimes he lacks the concentration for a long time. So at first I thought he is just like his dad, he doesn't concentrate, but either time I found that his dad usually gets good scores at school. His lack of concentration does not affect his progress, his child though his score is affected it is always below average”.

Ongoing enquiries result in Micha accepting the blame for her son's difficulties, blame which spills into her relationship with Hussain's father:

“We felt helpless, that we couldn't change anything, that this is the way my child is, I put all the blame on myself, about my way of treating him, this is my mistake because I am doing everything for him, they always told me that he was too dependent, that he doesn't like to do things by himself, even getting changed, he is always last, they said it was because I was doing things for him at home, that was why he doesn't like to do things for himself, even schoolwork, even his dad said to me, it's your way of raising him “.

A period of enquiry ensues, whereby Micha's family are scrutinised by school and aligned agencies, this involves teachers interviewing Hussain and his parents, alongside the cross checking of databases for evidence of any historically recorded concerns. It is only when Micha's parenting skills are deemed adequate that the discourse changes between the school and the family. At this point there is real consideration of not only the supports needed to move forward, but the family's entitlement to their support. It is at this juncture the social ostracising of children with behavioural challenges is illustrated most clearly as Micha herself states:

“School is now very supportive as my child does not have a bad influence on others or the school, so I think they want to help him just for himself, for the later effect in his life, they want to do things that benefit him later”.

Micha's story not only illustrates the mechanisms triggered when a child deviates from expected attainment and conduct, but also how a school have a tendency to consider the role of the parents as a preliminary stage in the investigation process. It is also interesting that discourses of 'deserving' and 'undeserving' surfaced unquestioningly in this discourse.

6.1.2 *The triggers for 'knowing'*

The search for formal knowing emerged to be a dual process of routine school surveillance and response to pupil presentations which were deemed to fall outside of normal expectations. The latter trigger was stated by teachers and SENCOs to be typically led by a child's impact on the class and his/her ability in comparison with peers. Nevertheless schools differed in the energies devoted to formal knowing and this appeared to reflect the value that schools placed on external expertise and its invocation as mitigation. The following two statements are illustrative of this point. The first made by a SENCO (Clare) in a large secondary school in a suburban area populated by a diverse population. We discussed the use and value of a diagnosis and it was stated:

"As you asked earlier 'is a formal diagnosis helpful?' Yes it is because then you can say definitely that they are diagnosed with that rather than having to just say that they are showing traits of this and therefore this is how you should deal with them. But staff are keen to learn more about it and as I say they are going out of their way to do the training".

Claire's comment alludes to the value placed on 'formal medical knowing' and intimates that school will concede to the management protocols as advised. In contrast another SENCO (Gill) discusses that a diagnosis is not always accepted unquestioningly by staff, nor is a diagnosis recognised as mitigation for sidestepping the dominant sanction code:

"Sometimes there are some kids that I think don't have it [mutual laughter], but they have a diagnosis, yet you just think it's just a naughty kid, but we have a very strict discipline policy here, and it is applied across the board...When it was introduced by the new head I did question those children who had disabilities and SEN, but I was just told well they deal with it like they would have to in the outside world, so they're all treated the same, they all have the same sanctions with a few minor exceptions we have managed to negotiate".

Gill confides that staff were informally creative in interceding in the 'all the same' policy of the school, but even in a senior management role, direct formal opposition was not a possibility, neither in deference to a medical understanding of difference, nor on the grounds of equity.

What Claire and Gill's statements signify is a polarising of the differing types of 'formal knowing': medical versus pedagogical explanations for difference. It was therefore unsurprising that the stance that schools adopted was directive of working practice, signalling the level of 'adjustments' made for a child and the sway of diagnostic mitigation. It was also interesting how the responsibility for 'knowing' was

both metered and collated. Whilst a few schools in my research indicated proactivity and mass screening protocols for incoming year seven pupils at the start of their secondary careers, others spoke of the responsibility of the primary sector for identifying and explaining difference. These attitudes were reflected in the knowledge teachers were seen to have and indeed were considered to need. As Gill states, “teachers really don't want to know in depth about it (medical/psychological conditions), they want to know how it manifests itself and how they can help, they don't have the time, energy or keenness to know in depth, they just want to know how it is going to present itself in class and how they can work with it”. Gills comments suggest a very selective form of ‘knowing’ is desirable, only that which holds pedagogical significance. This stands in stark contrast to the holistic ‘knowing’ parents emphasised and the impact they reported that school had in the home.

6.1.3 Priorities

By far teachers and SENCOs demonstrated that pupil management and consistent educational progress were prioritised. Challenging behaviours appeared the most difficult to accommodate and were heavily associated with exclusionary sanction (DfE 2014). Interestingly teachers rarely attributed exclusion to organisational failings, nor did they defend or explain the heightened vulnerability of pupils to exclusion when school difficulties were the result of disability. It was evident that when conferring disability accountability, the needs of all pupils and staff were implicit and unquestioningly assumed to supersede the rights of the pupil with a disability:

“I mean I have to say I think if we've got real severe behavioural problems our school isn't the place for them, we need to move them into a special school dealing with behaviour” [Steve].

Such a statement does not expand on why a mainstream placement is unsuitable, however, it does offer clear intimation of a concern for the school body as a whole. The status of behaviour as a symptom of disability rather than intent was alluded to by the SENCO (Jon) of a local single sex school for boys:

“I have tried to take the chaps who are on for EBD off the register if it is purely behavioural and they are not presenting any other difficulties, like social or emotional difficulties behind it, because I think that really is ambiguous, it is difficult to draw a definite line with behavioural difficulties and additional needs. But all the lads that I have taken off for that have really had no other needs other than basically being made to behave”.

Jon's comments not only speak of the status of behaviour as a symptom, they also introduce an assumption of perceived expertise, notably the ability to differentiate between real and faux disability as Jon confidently expressed "all the lads I have taken off for that really had no other needs other than basically being made to behave".

The surveillance triggers demonstrated in schools were presented as pedagogically purposeful, rather than holistic and child focused. This was considered by me and by some of the parents in my study to erect a barriers to parent/school collaboration. The impression teachers conveyed was that parents held a duty to support and facilitate the child's management in school, however, there was no reciprocal *quid pro quo*. This led to resentment for some parents and appeared to erect, rather than reduce barriers to a 'collaborative seeing'.

6.1.4 The nature of difference

Behaviour and the causes of behaviour appeared at times to be viewed as separate issues, rarely summoning understanding or recognition as indicative of a disability in the same manner physical indicators did. Macleod (2006) suggests discourses are separated between approaches of welfare or punishment. Some SENCOs also echoed such division particularly in relation to ADHD. Similar to the views of Jon previously, Christine (also a SENCO) stated that in relation to disability equity, not all disability classifications are accepted, when pressed as to which these might be she stated "ADHD I would have to say. Typical view is "naughty boy syndrome"... some parents are of the opinion that if you can get your naughty child labelled then that is taking the responsibility away from the parent or carer". Christine did not allude to whether this was her own view, but she did state that this is a sentiment that some school staff and parents exhibit.

The pervasiveness of these views have prompted wider calls for behaviour to be considered indicative of an underlying difficulty and not a homogeneous standalone entity (Hardwood 2006, Cross 2011). Such calls are reflected in the new SEN code of practice (2014). Sidestepping issues of etiology, Cross (2011) reframes EBD within a discourse of emotional literacy, as does Greene (2008b), in so doing affording behavioural difficulties both respect and logical lineage to rehabilitation and not sanction. Within my research the reasons for behavioural difficulties were

framed by teachers and SENCOs around issues of causation and self-control: “I think as a school we spend a lot of time working out whether its “cant’s or wont’s” [Claire (S)]. This endeavour supports Rafalovich’s (2001a) assertion that schools have carved out [credible] jurisdictions in an alliance with the medical profession, particularly psychology, thus positioning themselves as behavioural managers.

Nevertheless my data suggested that teachers ‘formal knowing’ divided between adherence to medical expertise and ‘knowing’ which was aligned to pedagogical practice, as at times these were incompatible. Nevertheless some of the school SENCOs indicated there was reliance on the diagnostic process to validate applications for additional funding to support the child. Both types of ‘knowing’ implied in the first instance that some disability types are amenable to self-control and behaviour modification techniques. Although such a view challenges deterministic neurological discourses which attribute neural flaws as explanation for some forms of difference, particularly ADHD, the action of exclusion by schools implies that for some, remediation through behavioural modification is not viable. Nor do teachers always feel confident that they have, or should have the skills to fulfil the role:

“It’s hugely outside of the remit of teaching [laughter], but as schools are becoming more inclusive and specialist schools are unfortunately in some cases being shut you are expected to have all of this expertise, except at training level before you actually start the job”[Jon].

Also as previously demonstrated, teachers differed in their willingness to concede to medical explanation of difference. In these instances teachers staked their claim to ‘formal knowing’ and strategic responses through a combination of pedagogical SEN discourses that spoke of strategies and ‘special’ interventions, these discourses ran parallel to intimations of familial accountability as the following comment from a teacher in the ISS illustrates:

“I’m not convinced by ADHD...they say some of our pupils have it but I don’t think so...it’s one of those conditions that can be misinterpreted... I think a lot of those kids just need to have consistent boundaries, its where there is a lack of consistency that their behaviours get out of control” [CT ISS].

This teacher offers a challenge to the disability classification ADHD and simultaneously the adequacy of her pupils parenting skills, followed by a strategic explanation of both the problem and ‘the solution’ to the difficulties the child

presents. Although unstated, there is clear intimation that the school is the intermediary that can compensate for 'poor' parenting:

"We are their stability us, they don't have any routine in their lives, Friday is the worst day, they get difficult because they don't want to go home, there's no consistency there, they can act out here it's safe, but at home they can't".

Whilst a therapeutic response is congruent with a medical conceptualisation of disability, exclusionary sanction in the school context is not. It speaks of culpability and an implication that some pupils cannot respond and are therefore beyond reach. Such sentiment is (as previously noted) reflected in the criminal justice system (Bishop 2008, NACRO 2011, Hughes 2012, Pfeiffer 2015) and often employed to justify incarceration and denial of rehabilitative programmes. It is at this juncture where exclusory sentiment appears to be enshrined in the practical implementation of the law (O'Connell 2016).

6.1.5 It's not my fault! – How blame shapes the nature of 'knowing'

Although SENCOs emphasised systemic limitations, these were frequently levelled as beyond theirs, or their institution's control and were typically rationalised as the result of the failing of others. These failings were attributed to governmental finance cuts and their impact on both children's diagnostic services and school SEN budgets:

"We are expected to deal with all this and where is the support? It's difficult enough to get CAMHS involved for support, so we are expected to manage these behaviours in the classroom. At the same time that we are managing everything else and we don't consider ourselves to be the experts in that area. So we need the support from agencies, and we just find that things are being cut left right and centre in the current economic climate. I think there is a lot of concern over money and budgets and this is clouding all other issues" (Christine).

The statement above was made by a SENCO who was employed in one of the city's more affluent areas and it is interesting that despite an 'economically comfortable' catchment area, the school appeared stretched to provide the services it felt were required. As a result this led to a strain on not only staff morale but also the practicalities of contemporary inclusion.

Parental accountability took many guises, ranging from overt challenges as has been previously indicated, to more subtle 'positioning' comments which suggest an unequal relationship between parents and schools based upon what is 'known'. The following statement is illustrative as even when parental expertise is recognised, it is

simultaneously undermined, through the intimation that parental expertise is unanticipated:

“The hardest conversation isn't necessarily the one we are having surrounding the labelling of pupils, it is having that conversation with the parents. Sometimes using formal terminology with the parents is difficult, but also surprisingly they, I think, understand more than we do” (Marie).

External attribution for support failings was also used at times to support exclusion, not as a punitive action, but as a recognition that the school could not meet the pupils needs due to its own lack of support. This served to deflect accountability from the school and rendered it a political issue. It was therefore notable that neither teachers or SENCOs acknowledged the possibility that power disparities in the school system may be an interceding factor shaping the ‘formal knowing’ of a child’s difference (Graham 2008a, Bailey 2009, 2010, Holt 2010b, Youdell 2011).

Nevertheless as was suggested in the familial narratives, the child’s background appeared an active variable mediating what is ‘known’. In this case it is cited to be a contributory factor to a child’s likelihood to display challenging behaviour as Marie (SENCO) states:

“Well this area is classed as deprived, so I think we are very aware of some of the difficulties the children may have at home. So if their behaviour is not spot on we are understanding, we know the families well, and understand that irrespective of any other conditions why at times they don't behave”.

At first glance one might interpret this statement as caring and appreciative of the difficulties of an area, yet it also serves to position the school in a benevolent position and by extension its recipients in an indebted or deficient role: a population made allowances for. Such accommodation is however not benign, as Liasidou (2012) has cautioned, the pedagogical gaze hones in on ‘students presumed deficits’ (pp 171), which in this instance is mostly a family’s socio-economic status. Indeed as I discussed in Chapter three, the socio-economic status of families whose children attend Marie’s school, (using the indices of free school meals provision) are known to be disproportionately disadvantaged and currently 69.2% of pupils on the school roll are eligible for such support. It is interesting that in the first instance Marie makes attributions for behaviour drawing upon socio-economic background as an explanatory framework, rather than one drawn from the medical field.

Looking more closely at teachers ‘formal knowing’ it was also interesting that although they were critical of the demands made upon their profession, they were

not critical of the form of mass education generally. Nor did they indicate that the perceived it to be contributory to the appearance of behavioural and academic differences. Nevertheless there is a body of academic material which suggests that the form of contemporary schooling is itself contributory toward the appearance of some childhood disabilities and disengaging behaviours (Macleod 2006, Campbell 2009, Robinson 2011, McCoy 2012). Robinson (2015) in particular emphasises how mass education evolved in symbiosis with the workforce requirements of a rapidly expanding industrial system and retains many now defunct practices, serving to foster disengagement and the appearance of behavioural difficulties.

Youdell (2006) similarly draws attention to how pupils bodies are problematized in education, as does Graham (2007b; 2008), finding schools to be constitutive of the conditions they identify, through structural inflexibility and rigid discipline codes. Such inflexibility is, however, not axiomatic as the data from SENCOs demonstrates, it varied according to the leadership of individual schools and the extent to which medical 'knowing' was accepted as the best means of 'knowing'.

Pedagogical 'knowing' has also been accused of such fluidity, for example Waterhouse (2004) shows that schools through behavioural conventions define 'typical' and 'normal' behaviours, not only institutionally, but individually during classroom engagement, which are referenced against cultural norms and school identity. These sentiments support the assertion that the expansion of formal labels to describe difference may have less to do with medical advance and more to do with context, and the needs these contexts trigger. Schools may thus be seen to foster the climate for difference to be heightened and the teaching profession in alignment with other 'experts' the licence to intercede (Illich 1977, Tomlinson 1985, 2012).

6.1.6 Change the context not the child?

Youdell (2011), similarly to Robinson (2011; 2015) describes how altering pedagogical responses can provide spaces for pupils to move beyond negative identities and role. Such observation supports the assertion that pedagogical practices can generate barriers and create an illusion of difference. Although Youdell's observations were based on teaching practices in a PRU, they emphasise how adjustments at an institutional level can affect the appearance of disorder and

disability, similar in nature to how the ethos of a school impacted on acceptance or resistance to medical forms of 'knowing'. Notably there have been calls for a radical reshaping of mass education, involving more critical consideration of the role of school systems (schools) toward the appearance and 'knowing' of difference (Greene 2008b, Robinson 2011; 2015).

These calls challenge both the logic of current modes of mass education and also the underlying assumptions that teachers bring to the school context in regards to the motivations of children (Greene 2008b, Robinson 2011). Robinson (2015) states 'everyone has creative capacity...everyone has inner brilliance. We need to recognise and value that and find ways of tapping into it. If you can do that, you'll maximise your opportunity to develop a culture of engagement, belonging and creative capacity' (pp 243) and by default minimise disaffection and disengagement. Calls for change demonstrate that 'formal knowing' of difference is reflective of the context within which it is embedded. As neither teachers nor SENCOs made reference to these key debates this was taken to indicate a level of disconnection between 'formal knowing' in the academic arena and that of teachers and SENCOs operating practically in the school context. Henceforth it is now possible to suggest 'formal knowing' differs in at least three arenas; the medical, the pedagogical and indeed the academic arena.

These bounded knowledges contrast markedly with the broader 'knowing' that families expressed. Not least their assertion that there were disabling barriers in mainstream schools which heightened their child's appearance of difference. These barriers were attributed to the nature of school life, most specifically the sanction code which is a core organisational feature of mainstream schools in the UK, limited disability awareness amongst teachers and wider school management and their child's heightened visibility. These observations are substantiated by Cologon (2016) who states that families were disposed to an interconnected understanding of the difficulties their disabled children faced. Hence despite families search for a medical explanation for difference, they were equally aware of the additional social and organisational barriers that heightened or compounded its effects.

It is interesting that the barriers identified by parents in relation to the accessibility of services and resources were not dissimilar to those expressed by teachers and SENCOs. They digressed on account of the lens each party adopted in the first

instance and this was linked to their specific priorities and expectations. The priorities of teachers and SENCOs were bounded by the impact of the child on learning and learning progress, whereas for families the child's emotional wellbeing appeared to be their main priority, focused on longer term social and educative needs, as Saz is recorded to state:

“The schools approach was not about how does this impact on xx and how can we support him, no it was how does this impact on us, can we cope with this, can we deal with this in school”.

These concerns are echoed in the wider literature and indicated that parents hold tendency to wider priorities than schools, focused on a broader and deeper 'knowing' of their child's difference and needs. There is also an indication that the narrowness of 'formal knowing' is at times recognised (Knox 2000, Kearney 2001, Green 2003, and King 2006) as Derbyshire (in Curran 2013) states: 'I realised then that it wasn't x's additional needs that would be detrimental to her, but other peoples ill-informed and low expectations' (pp 33). This type of sentiment has been echoed by the families in this study and supports my assertion that collaborative 'knowing' could redress the barriers that are erected through narrow 'formal knowing' which is channelled by contextual priorities. To address more closely the content of teachers and SENCOs 'formal knowing', in section two I explore in greater depth the constitution of teachers 'knowing' drawing upon the central research questions and topic guide detailed in Chapter One.

6.2 Section 2: Exploring teachers and SENCOs 'formal knowing'

Areas of foci:

- Are all disabilities equally validated?
- Why are some children more vulnerable to exclusion than others?
- Teacher's residual knowledge (level of training, confidence in the classroom and continuing professional development programmes, plus school SENCO protocols). Teachers were also asked to consider where their knowledge was gleaned from (multiple sources, academic/training, personal experience, professional experience and popular sources).
- Are all disabilities subject to a nature/nurture debate?

6.2.1 Foci one - are all disabilities equally validated?

Disability equity is the cornerstone of both the equality act and the educational doctrine of inclusion. Nevertheless it emerges within the literature as illusionary: predicated upon a disadvantaged position within the legal system (Borsay 2005, Boyd 2012, O'Connell 2014, 2016); qualification in the educational domain (Allen 2006, O'Regan 2010, Graham and Slee 2011, Tomlinson 2014) and the object of mirth, challenge and sensational indignation in popular media (Kirkland 1999, Lupen 2009, Goldberg 2011, Walker 2011). Having personal experience of both inequity and challenge and set against a backdrop of persistent pupil exclusion rates which indicate association with 'behaviour' (DfE 2013b, 2015b) I felt it was important to explore teacher's opinions toward disability classifications and to test the extent to which all disabilities were considered equal.

The logic of inclusion and equality legislation in the UK suggests all disability classifications to be equally protected and of equal validity (Parliament 2010b). However in practice both are found wanting (Dunne 2009, Runswick – Cole 2008, 2009, 2011, Jull 2009, Barton 2013, Rogers 2013, Caslin 2014, Heeney 2015, Kulz 2015). The diamond ranking activity particularly suggests that it is not only in practice that such inequalities are found, but also extend from pre-held opinions which are reinforced in both criminal and educative law through qualifications to entitlements (Parliament 1981, 2001, 2010b). These are found to be based upon impact and are generative of a division between rights and responsibilities (O'Connell 2014, 2016). It was therefore less surprising that the majority of teachers who participated in my research were not only willing and able to rank, but also articulated explanations to support their decisions. Only a small number of teachers felt the exercise contrary to the spirit of inclusion and emphasised their position by declining the invitation to rank on the basis that they considered all classifications of disability to be equally valid.

6.2.2 Explaining Inequality

The pervasiveness of inequality within both the educative and legal systems demands address of its rationalisation, such address is viewed as an essential step toward effective challenge. Within the medical profession internal debates centred on classificatory validity and the re-configuration of criteria for diagnosis are standard practice, appearing as one of the central mechanisms driving medical knowledge

forward. Problematically the checklist diagnostic protocol as introduced by Spitzer (1992; 2001), rather than acting as a check on clinician subjectivity, has delivered into the public domain the former secrecy surrounding classificatory delineation. This has intimated a simplicity which is disavowing of clinical practice and the rigorous cross referencing of clinical observations that Newsom (2003) has indicated precedes the introduction of any new classification. The processes surrounding revision of the main classificatory manuals are illustrative of contested debates (APA 2013), yet transparency has fostered challenge. Most typically assertions that some neurodevelopmental disabilities amount to little more than professional constructs, serving to perpetuate professional status through the medicalisation of normal human variation (Conrad 2000, 2005, 2007, 2010, 2014).

In light of such contrasting sentiment it is interesting that none of the respondents in my study claimed in-depth medical knowledge to support their ranking choices, nor did respondents talk about an awareness of opposing constructivist arguments. Most typically answers were influenced by the frequency of exposure and practicalities a disability posed in the classroom and, although informally, teachers indicated their personal experience outside of the classroom to be of significant impact also.

Teachers indicated that behavioural disabilities were subject to the greatest contestation as the following annotation indicates, linking their use to the functions they serve:

“Dyspraxia – I have this. ASD – son has this. SEBD, ADHD, ODD = labels that children live up to, children/parents like these labels, social workers encourage children to accept these and not to accept responsibility for behaviour” [r.36].

This teacher not only indicated an active interest in the evidence base available to support the legitimacy of disability classifications, but interestingly showed concern that these were being manipulated to excuse poor academic performance or behaviour. This was not untypical and represents a commonly expressed sentiment as the statement:

“ASD – is becoming more prevalent. Again medically substantiated, a lot of students not diagnosed exhibit ASD traits. Physical disability – This tends to have a medical evidence background and therefore cannot be argued as incorrect. Dyslexia, dyscalculia – a definite condition, however many students with learning issues are ‘diagnosed’ [especially when parents pay] when they only need more targeted appropriate teaching from specialist teacher. SEBD – A huge number of students exhibit these. The reasons for these behaviours are huge, e.g. Home background, disaffection etc.” [r.15].

The above statement skilfully introduces the notion of parental and cultural failings, parental manipulation and the primacy of medical evidence. Despite being a brief comment it illustrates the complex way teachers form opinions and 'know' their pupils. Teachers in this study displayed conflicting attitudes to disability classifications and at times a broad scepticism to the medicalisation of 'behaviour'. I would therefore suggest that these varying opinions, if mirrored across the profession may offer an explanation for the stratification of emotional responses to students with disabilities that Cook (2001) recorded across the four dimensions of attachment, concern, indifference and rejection. Grieve (2009) nonetheless cautions against such generalisations stating that pupil presentation and the attributions made are unstable as expectations vary across contexts, impacting on not only behaviour but academic performance. Cassady (2011) offers a more general explanation for teacher's varying responses, indicating that teacher's reluctance is directly linked to their professional confidence and concern that they do not hold the requisite professional skills to include complex medical conditions.

Notably Gibbs (2010) and Elliot (2014) argue persuasively that the employment of medical categorisations in education are unhelpful, impacting on teachers belief that they can manage disability diversity. In resolution they suggest a call is made to respond individually to presenting educative need, embracing a pedagogical not a medical lens, thus boosting professional efficacy. This approach was most evident to me in the PRU setting (as will be discussed in Chapter six) where I found 'formal knowing' in this context was responsive to 'behaviour' as it was presented 'in the moment'. This then enabled work-based practice that freed the teacher from any requirement to meet medical protocols and as such was fostering of an individualised response, whilst also of positive impact on professional autonomy and self-efficacy.

Teachers and delegates at the conference demonstrated repeatedly they held concerns toward classificatory legitimacy. However they also extended challenge to the diagnostic process itself, suggesting it to be unreliable and at times abused by parents and notably schools to satisfy other pressing responsibilities:

"ADHD – some over diagnosis exists – schools pressured to explain failure to meet standards. Categories of SEN are an explanatory factor" [r.35].

It is interesting that physical disability was considered self-confirmatory and was less implicated in the discourses of accountability in the mainstream as the statement below demonstrates, although again there are concerns raised toward diagnostic practices:

“To me physical disabilities are included, they are automatically most accepted however considering conditions such as ME it is not so clear. I think autism is also contested at times, considering Romanian immigrants many are over diagnosed with autism but cause of symptoms is suggested trauma. I subscribe to a social model of disability but categorisation is from a medical framework” [r.3].

The detail embedded within these responses suggest that concerns raised were well considered and formed part of an ongoing dialogue of evaluation as is demonstrated in the following two comments:

“Physical disability – most obvious, ASD – much more awareness and acceptance, ADHD – so often misused and wrongly diagnosed, leads to questions over validity” [r.37].

“ADHD over diagnosed and can be used as an excuse for poor behaviour, other disabilities should not be ranked” [r.47].

Looking at these responses I could picture where my own child would have been situated, ‘Atypical Autism’, ODD and ADHD are a heady cocktail and one that does not fit well into the stereotypical representations common in the public domain. Indeed similar discourses emerged during my son’s time at school as there was confusion toward the meaning of ‘atypical’ and also that my son did not match the conventional portrait of autism. In the teachers own words: “there are many aspects of Dom’s behaviour that do not fit comfortably with the diagnosis and I would welcome a further assessment” (year 6 class teacher). This statement although directly related to my own familial circumstance was written in 2008 and it indicates that the passing of time has not reduced the tendency to question an individual diagnosis, nor reliance on ‘typical’ presentations of a classification of disability as Sacha herself indicated to me when discussing her experiences as an SEN governor before her son left his mainstream school:

“Some of the times there was a couple of members of staff who talked about autism as something that kids could switch on and off, and I was just a bit disturbed by this. I mean I have actually heard them say it. And I have responded by saying ‘I beg your pardon’? And she (a teacher) would say ‘oh that wasn’t autism that was just naughtiness”.

6.2.3 Foci two - why are some children more vulnerable to exclusion than others?

Statistics indicate that pupils with a disability/SEN are at an increased risk of both formal and informal exclusion (OCC 2013, DfE 2016aa). As wider statistics attest,

exclusion is most commonly substantiated on the basis of unacceptable behaviours, for example, low level persistent disruption, aggression and acts of non-compliance (O'Regan 2009, 2010, DfE 2013b, 2015b, 2016). Paradoxically however, parents indicated there to be occasions where exclusion was resisted by school, an action which parents felt detrimental to their child and also their family's well-being. Such reluctance raises the question as to why, particularly as teachers ranking choices appeared to be led by classroom impact, rather than detailed medical knowledge. Teachers also indicated concerns around resources to support pupils with disability in the mainstream, suggesting in principle that all disabilities are equal, but are made less so by the way government has reduced funding for children with less easily defined difficulties:

"I would want to list these all at the top, in alphabetical order. I believe in inclusive education 'for all'. The training required to 'equip' staff into knowledge, resources and understanding is the issue perhaps!!"

It is therefore as important to also question why exclusion may be resisted, when as Sacha (Ch5) indicated, the ability to access appropriate supports is impeded when a mainstream school claims they can cope. As I had also faced a similar dilemma, with disastrous consequences, the significance of the question was heightened, particularly as the parents in my study indicated similar frustrations, particularly Leanne, who as indicated, considered mainstream school retention to be a barrier to her son's progress.

Processes of exclusion may be seen to be wedded to 'formal knowing' as inevitably the bureaucracy involved necessitates the delineation of attributes to support the contention that an individual is incompatible with the school context. Such contention locates the central cause to the individual, even where a school resists or rejects a placement on the basis of an inability to meet needs. Nevertheless 'formal knowing' may also hold potential to support, as it may be shown to be the function 'formal knowing' is used for that is questionable, alongside the organisational culture of which it is a part, not the exercise per se.

The writing of Graham and Macartney (2012) illustrate the potential of 'formal knowing' through a re-visioning of how inclusion could look, if emphasis on mainstream placement was replaced by emphasis on equitable educational provision. This vision of inclusion involves as central, appreciation ('formal knowing')

of the pupil needs and learning dispositions. An insight which is considered vital to effect equitable differentiation of teaching approaches. Paradoxically Graham and Macartney contend an equitable, but differentiated education underlay the original tenets of inclusion, rather than has developed, whereby inclusion has association with notions of equal treatment and right to mainstream placement. Indeed Graham and Macartney argue that in approach inclusion resembles more closely an integrationist approach, which is underpinned by an expectation that the pupil will 'fit', albeit with support, the school system. Markedly the ability to respond flexibly to difference is considered the key factor which demarcates inclusion from an integrationist approach.

Considering the notion of differentiation, one can see how inclusion was envisioned to concede to difference at the level of an organisation (Booth 2002), whereas integration was founded upon shift at the level of the individual. In working practice inclusion - as it has evolved - appears to operate on individualised integrationist principles, thus where there are 'difficult differences' (Rogers 2012, 2013) or an inability to 'fit in' or be 'fitted in', this legitimates exclusionary reaction, not organisational change. The practice of 'formal knowing' is heavily implicated in these processes and one suggests in the current climate they are manipulated. Nevertheless the former statement of educational needs and the current EHC may also be seen as the embodiment of 'formal knowing'.

Analysing data collected from teachers ranking choices towards explanations for a disposition to exclude, it was notable that although their ranking choices varied, ranking patterns (i.e. positions) were consistent across both research contexts (conference and in-school). These patterns indicated a greater legitimisation of both physical disabilities and autistic spectrum disorders and a lesser validation of 'behavioural' conditions such as Oppositional Defiance Disorder and imprecise classifications such as Pervasive Development Disorder (see stacking bar charts in appendix). Teachers annotations also suggested that ranking choices were not solely based upon medical evidence, but to an equal extent the disability's impact on the teaching role. Indeed as the following field notes from the NUT conference detail, teachers appeared uncomfortable at being asked to evaluate disability classifications, preferring to consider professional impact:

“It seems not to be a teachers place to question validity and most delegates struggled, perplexed by the thought and that the task appeared hard. Many revealed their choices were based on which types posed greatest difficulty in the classroom and when asked about their own personal opinions, this appeared alien. One delegates stated that she had never been asked to think like this before and was unsure as to whether it was professionally acceptable. This appeared to mirror wider teachers concerns about professional agency and government intervention in the profession generally” [NUT conference].

As teacher’s concerns tended toward ‘manageability’ and access to appropriate supports, exclusion would logically appear to indicate a failure to procure the supports identified. Nevertheless teachers also indicated very definite opinions toward causal factors, introducing the notion of accountability, primarily toward parents and culture. This supports the contention that what is termed inclusion, is in practice integration, and resides upon expectation that the child is able to be ‘fitted in’ with support to the mainstream. ‘Formal knowing’ in these instances is directed to addressing the reasons for failing to integrate, and it is identifying the supports necessary to include. Practices of separation were suggested by Baroness Warnock to be inevitable, as the following statement suggests:

“I think that all children are entitled to is education, and sometimes they can't be educated at a mainstream school, they would be deprived of what they are entitled to, therefore I do not believe that every child is entitled to be educated in a mainstream school, unless you count as being educated in a mainstream school where there is a unit or some other way of withdrawing a child”.

It is clear from my interview with Baroness Warnock that she privileges the mainstream as the default provision for the majority of children, leading to what has been defined as the ‘dilemmas of difference’ (Minnow 1990) in respect of how one identifies and explains difference.

The use of medical labelling to determine educational entitlements was most clearly evident following the introduction of universal free secondary education (Parliament 1944), which despite an outer appearance of benevolence, in practice was highly metred for all children, and configured upon the notion that there were three types of mind, (academic, technical and practical). At this point in history disabled children faced segregation not only on the basis of medical labels, but academic labels as well, which in combination determined a child’s educative pathways (Tomlinson 2005).

The use of labels persists and although controversial (Florian 2008) extends means of common ‘knowing’, in a manner reminiscent of what Moscovici (2000) defined as social representations. Nonetheless as Voelklein and Howarth (2005) indicate there

is insufficient attention given to the strength of consensus implied in any common term, similarly to the power differentials which may distort representations. In addition what constitutes 'formal knowing' may be standardised in classificatory manuals, but found to be responsive to wider social variables, particularly those associated with disadvantages, thus as Aneshensel (2013) cautions 'knowing' cannot be neutral, nor can it correspond to truth, as it is embedded within a wider system of social relations:

'The influence of social forces...is perhaps most evident in the aftermath of the onset of mental, emotional or behavioural problems. Here we see that individuals with essentially the same disorder often follow divergent sequences of societal response which determine (at least in part) the course of the disorder' (Aneshensel 2013 pp. x).

Culture and socio-economic status has been implicated in the determination of what is 'known'. In particular pupils from disadvantaged school contexts have been identified to be at greater risk of being labelled as having behavioural disorders than specific learning difficulties, compared to pupils from more advantaged school areas (Croll 2002, Riddell 2011, McCoy 2012). Looking at my data there were subtle indications that social status was a factor that directed 'formal knowing'. This was more obvious in the mainstream where explanations for difference were often undetermined and evaluated between the axis of a nature versus nurture continuum. In these instances social cues were implicated as part of the discernment process and were embedded within discourses of blame. These discourses were contextually responsive and it was at this juncture that social variables were most influential, serving to establish both the social position of the family initially and also the child.

Notably in the special sector, 'knowing' preceded the pupil cohorts and was revealed initially through the population it catered to. Staff at the PRU and the ISS reinforced this 'knowing' informally in conversation, although its substance was implicated in the formal sense making processes that surrounded individual pupil presentations. Staff at the PRU 'knew' that their pupils mainly stemmed from disadvantaged backgrounds, just as staff at the ISS 'knew' their pupils were disabled. Such 'knowing' served to reaffirm to staff their position as experts and emerged in differing guises. In the PRU, staff took pride in being experts in loco parentis and engaged mutual affirmation that their expertise offset familial deficiencies. In contrast staff at the ISS projected an expertise in the management of childhood disability by virtue of context, role and academic credentials. Through informal conversations it became

clear that claims to such expertise was underpinned by the dissemination of blame most frequently but not exclusively towards the child's family.

In the PRU it was notable that staff erred from conferring accountability onto the pupils, tending instead to deflect blame toward the both parents and culture. In contrast in both the ISS and the mainstream, blame where individually metered was divided between the child and the family, although there were intimations of blame being directed toward external support organisations as well. As a result it was predominantly in the mainstream that demographic factors filtered how behavioural 'difference' was interpreted, typically as either an indication of disability or malevolence (Molloy 2002, Faraone 2003, Polanczyk 2005, Mah 2007, Paivi 2008, Begeer 2009, Tomlinson 2014).

The impact of external social variables emphasise the interconnectedness of 'knowing' and hint at how 'knowing' is both produced, pre-existing and not unequivocally referenced against the individual. Gabel (2008) describes this process as the manner 'in which numerous discourses together create multidimensional experiences, complicating notions of how people come to know and understand their lives' (pp. 470). As a result the certainties around 'formal knowing' are destabilised and emphasise the importance of exploring what teachers consider they 'know' in relation to disability classifications and also 'challenging behaviour'.

As Graham and Macartney caution (2012) labels hold a tendency to develop pejorative meanings in the popular domain, forming part of common vernacular, which has discriminatory implications. The term 'special educational needs' is illustrative and despite initially being an attempt to move from medically informed 'knowing' to pedagogical knowing (Warnock 1978), in working practice the labelling system based on special educational need, relies upon medical knowing to inform not only on the type of special educational need, but also to prove entitlement to funding and resources.

Lupton's (2012) contention that 'medicine' exceeds delineation as a profession and resembles more a culture, directive of dominant ways of thinking about illness, is equally applicable to the systems of mass education common to industrialised nations. Thus even though mainstream schools continue to justify the exclusion of significant numbers of pupils, a trend (Adams 2015) notes has risen in the primary

sector, and educational rights are qualified where need is 'difficult' (Rogers 2013), mainstream schooling remains the default means of educating young people. As such serves to marginalise alternative provision to an identity of 'special' education'.

Looking at the detail of mainstream schooling, Hart (2004) cautions that contemporary education systems generate a culture of self-fulfilling prophecies, through reliance on ability testing. Reliance, which, in conjunction with wider social variables is directive of teachers expectations (Cook 2000; 2001; 2004, Klehm 2014). Henceforth the marginalisation of pupils considered unsuited to mainstream schooling, may reflect as much the current climate which positions a continuum of provision as unthinkable in terms of 'normal range', as it does the nature of individualised difficulties. As such reinforces demand for a move toward a continuum of educational provision (Norwich 2008, Graham and Macartney 2012). A provision which can respond to individual dispositions, need and ability, outside of notions of success, failure and thus stigma. Currently as Robinson (2011) observes, educational success is wedded to the age referenced developmental markers of academic performance and social development, stifling potential for other visualisations of educational provision and hence 'knowing' (Robinson 2014). For as Greene (2008b) asserts the 'formal knowing' teachers consider directive of professional practice has major ramifications for their response. In particular the logic by which sanctions and exclusions are metered as consequences' to encourage or emphasise the cost of non-compliance.

Nevertheless Greene persuasively suggests a shift in teachers assumptions from the stance that children need to be 'made' to behave, to the position that children 'want to behave' is sufficient to reimagine how schools could be. Greene offers the example of teachers 'seeing' and 'knowing' behaviour to be a skills deficit, which in turn alters the integrity of exclusionary or punitive responses. Just as 'knowing' children to be truly heterogeneous outside of reference to an arbitrary 'norm', enables the removal of 'special' from the range of educational provisions needed to cater to a diverse pupil population.

It is therefore important to consider not only the 'what' of 'formal knowing', but also its linkage to wider ontological assumptions concerning the nature of human being. This study found that differing forms of 'knowing' were inextricably linked, and it was

found that parents and teachers drew eclectically on a variety of sources to inform their 'knowing'. These sources extended beyond the familial and the professional, embracing wider popular discourses of questionable validity as the following statement from a mainstream teacher indicates:

"Diet is a huge issue, my form all eat chocolate/crisps/sweets and drink energy drinks from 8am onwards. Home life also, I mean social development is a huge factor in mental health issues. Other factors include diet during pregnancy, family problems – divorced/single parents can lead to mental health issues/self-esteem...sorry I can't think of any more".

It is notable that whilst this respondent does not specify neurodevelopmental explanations for childhood disabilities, there is a range of social explanations offered for the appearance of behavioural difficulties. This expansion in a professional context undermines medical explanations and introduces doubt, which by default legitimates attributions of accountability as the following annotation made by a teacher at the NUT conference illustrates:

"SEBD, ASD, MH, ADHD, ME and PDD, although some students genuinely suffer from these, I believe many use them as to excuse their behaviours in class".

Looking more deeply at this statement it is possible to project how in the routine of everyday professional engagement, the dissemination of these views can foster wider uncertainties that may serve to undermine a child's diagnosis, or indeed referral for assessment. Where behaviour is of issue, as the classifications listed above suggest it is, the corollary of disability as an explanans is that the child is acting from a position of intention and is therefore accountable, as also this teacher suggests are the adults surrounding the child. Such logic where developed institutionally to the point of common taken for granted culture, explains how schools are able to claim inclusivity whilst simultaneously executing exclusionary sanctions.

The strength of challenge toward medical explanations for behaviour was explored further in the final questionnaire that was distributed amongst teachers and was strategically designed to request simple agree/disagree responses to controversial statements. In response to the statement 'some types of disability are used as an excuse to explain bad behaviour' a substantial majority indicated agreement. Similarly in response to the statement 'some types of disabilities are less credible than others' just over half of the total number of respondents agreed.

The answers returned were considered to offer a useful snapshot of contemporary opinion, particularly as they were recruited from across four separate secondary

schools in the North East region following an open invitation. It is interesting that despite such scepticism, teachers when asked to agree or disagree the statement 'the expansion of types of disabilities reflects greater understanding within psychology', thirty out of thirty-nine respondents agreed despite the cautions stated toward diagnostic intent. These cautions offered a partial explanation for the negative experiences that the families had expressed. In particular the use of behavioural modification techniques as illustrated in Chapter five, which implied behaviours were not organically driven, but were rather learnt or culturally derived (hence amendable).

Problematically the strategies that parents described in Chapter five appeared to effect limited function in regards to learning, nor were they a fixed term punishment with clear boundaries. Rather they spoke of containment: the exigencies of having behavioural diversity within a system that defaults to conformity and the norm, which effects significantly how a child is 'seen' and eventually 'known'. As was expressed by both SENCOs and teachers, the extremes of behaviour act as the juncture where exclusionary discourses begin and are rationalised outside of a disability frame. Nevertheless, as Leanne's narrative which is discussed in the following section indicates, schools are also required legally to be inclusive and to demonstrate an ability to cope with a range of pupil diversity, including challenging behaviours. Yet as NASUWT (2012ab) and (NFER 2012) found that poor behaviour impacted negatively on ability to cope and was for some teachers a catalyst to leaving the profession, rather than failing in their legal and professional obligations.

6.2.4 Being in but wanting out

School exclusion as shown in Chapter five was not axiomatic, and for some parents, retention in the mainstream resulted in restrictions that defined their child negatively. Such restriction was alluded in Sacha's story and was also intimated by Leanne, who told of the ever shrinking and restrictive provision allotted to her son in the mainstream (see pg. 386). The nature of these restrictions resonate with the public concerns raised by the Lamb report (2009) and the Office of Childrens Commissioner (OCC 2013), illustrating practices which are considered illegal. Paradoxically the price of inclusion in the mainstream was for some children, a heightened vulnerability to at its best, creative 'internal' exclusions' (separate

teaching, restricted social time and hours of school attendance), and at its worst recurring fixed and eventual exclusion.

The escalating restrictions Leanne described resemble punitive actions and certainly that is how Leanne saw them. Nevertheless they may also be seen to serve a different function for the school, serving to demonstrate compliance with the responsibilities accorded to schools under the 2010 Equality Act and the charter of Inclusion as defined by the DfE. Thus the restrictions described by Leanne, could also be seen to be the manifestations of 'reasonable adjustments', signalling a determination to avoid exclusion: for just as exclusion typically speaks of child failing, it also speaks of school failing, which has itself attracted scrutiny (CAF 2013, Gazeley 2013, OCC 2013, AA 2015).

Nevertheless a restricted curriculum (however well intentioned) brings specific inequalities as I found personally. It heightens a child's visibility, impacts on their self-esteem and separates the child from his/her peers. It also impacts heavily on the child's family, most frequently the mother (Jackson 2004, Kingston 2007, Rogers 2007a, McLaughlin 2008b; 2016, Gallagher 2010) as Leanne explains:

"We went to meetings and they said that they could cope and that they could deal with him, but then they phone up every two minutes and tell us to come and get him, or they ask us to keep him off. I mean he has missed nearly a full year now, he hasn't been there full time since Oct".

Leanne continues to explain how the school resisted supporting an alternative placement for her son in the special sector, through the levelling of blame toward her son:

"When he first started to get chucked out they were talking about putting him into a special school for behaviour, but the SENCO said no, because he was too bright for that school and there's kids with Asperger's Syndrome there and she said he would end up picking on them". I still think that the EBD school would be best for him, they have smaller classes and he likes that, it would be ideal, he likes outdoor activities, they [EBD] school go out a lot and do lots of practical things.

At this point the various discourses operating in school begin to reveal how uncertainties toward possible diagnosis and practical issues of management can lead to the 'seeing' of a child as naughty and the family as deficient. Whilst in tandem the conflicting demands of inclusivity and requirement to reduce exclusion statistics (Gazeley 2013), juxtaposed against government demand to raise standards (OFSTED 2014b), has spawned practices (out of necessity) which are often described as 'internal exclusion' (Leslie 2008), and illegal exclusions (OCC 2012,

CAF 2013, AA 2013). The outcome of mainstream resistance to exclusion is the use of segregation to support a placement in crisis, yet this locks families into a placement stalemate which they have little control over as Leanne states:

“You can't get in though (special school) because you need a statement from the LA, but as long as the school are saying they can cope what are we supposed to do, but he is not in lessons, they are not coping with him, but they just keep saying that they are. I really don't think they have done enough, I think there is a lot more they could do.

The double bind presented in this situation, further emphasises the need of schools and parents to communicate openly and for schools to listen and respect the concerns of parents. However as has been suggested schools have wider responsibilities which exceed the individual and it appears to be these which paradoxically act to inhibit any formal acknowledgement of inability to meet the child's needs. Teachers in my study indicated strong opinions towards particular types of pupil difference, most typically difference which involved disruptive behaviour. These opinions whilst wedded to a medical model in principle, also embraced causal scepticism in some cases and erred in favour of individual and environmental factors. These differing opinions were significant toward the nature of accountability and also the nature of response. Subsequently this study explored what teachers felt they knew, as well as the main influences on their knowledge.

6.2.5 Foci three - teachers residual knowledge

Teachers indicated both knowledge and concerns about their knowledge. This was most generally emphasised in the annotations teachers provided alongside their completed ranking activity. A direct enquiry was also made to teachers (in-school) as a ranking exercise inviting teachers to express the greatest and least influences on their knowledge of disability from a broad ranging list. In addition the final questionnaire distributed in school, requesting participants to indicate familiarity to a list of commonly identified disabilities along a five point continuum (as contained in my appendix).

Three main areas of concern emerged in my data which allude to the overall knowledge base teachers felt they held and also felt they needed. These were; familiarity toward specific types of disability; issues of management (the confidence teachers felt when engaging with pupils with disabilities and classroom impact) and finally the potential of diagnosis to be used in an excusatory capacity. This third

concern was by far the most concerning, as it was an issue that occurred many times, yet was rarely expanded upon beyond anecdotal suspicion, which was typically levelled against the child's family.

Familiarity: Teachers expressed concerns toward their level of familiarity, particularly toward classifications that were less frequently encountered. This was a recurring theme, noted in my field notes: "Personal experience and professional exposure seemed most influential on opinions expressed; however few had sufficient time to follow wider research and debate irrespective of desire" (FN/NUT). The last part of this illustrated record was considered especially significant as across all of my data sets, 'knowing' was the main factor that impacted not only on confidence, but also disposition to challenge individual diagnosis and validity as a discrete classification. Teachers related to the classifications listed in terms of familiarity as the following annotation illustrates:

"ASD – personal experience, Mental health problems –family members have suffered, Physical disability – Have taught a wide range of students, ODD – I am Head of year and have come into contact with many pupils with this diagnosis, ME – unsure as to whether this is real, Atypical autism my feeling is it is deeply psychological" (NUT/49).

Personal experience was indicated to counteract lack of and medical knowledge, as this respondent illustrates in relation to ME "I used to think it was fake illness, but then my friend's daughter got it and I realised how wrong I was" (T/in school [1]). Although teachers were keen to share personal familiarity, professional experience was also indicated to strongly influence perceptions of confidence, yet in this context knowledge was structured around issues of pedagogy, which suggested a very partial 'knowing, the following teacher examples:

"Dyslexia: Easy to help/cope with, doesn't physically or mentally frustrate you. SEBD – common. ADHD can be handled. ASD – forgetful. Atypical autism – can learn, but needs help can find learning hard. Physical disabilities – restrain you a lot. ODD – impossible to teach, mentally cannot learn" (T/in school [1]).

Familiarity did not however always lead acceptance, to the contrary it frequently signified a greater willingness to be critical and to transfer causational attributions onto an external source. "I do tend to blame parents for unidentified/unlabelled behavioural issues – not fair I know but too easy sometimes (T/in school [2]). Equally familiarity through exposure was found to foster increased questioning as this teacher indicates. "ASD – many people are diagnosed with ASD but may not

have the condition but a collection of symptoms that are akin to ASD – so I always question!”

Cook (2001) concluded that teachers opinions are responsive to the severity or obviousness of a pupil's disability, hence distortion is most likely pupils presentations permit a level of ambiguity, as I personally experienced with my own children. The propensity to challenge disability may be seen as a side effect of the increasingly complexity of disability classifications, yet whilst such complexity is ineffectively disseminated amongst secondary professionals, the propensity for doubt and to act on that doubt is significant. As a family we discovered to our cost the longitudinal effects of doubt, not only in terms of our son's academic performance, but also in terms vulnerabilities held that were unrecognised by ourselves and by school. Our son was deemed a health and safety risk by school and schools solutions to our son reflected this. Yet the absent factor in the conversations which determined future educational provision omitted the vulnerabilities our son held as an autistic teenager. As Klehm (2014) found the expectation teachers hold toward their pupils is of major impact on achievement levels, not least because the expectations teachers hold direct the shape of future educational provision. For our son this was a financed move to a further education college for older students, which ended with serious safeguarding concerns, yet in retrospect speaks of how at that point in our son's life he was 'known'.

The responses teachers made in relation to disability classification equity suggest that all disabilities are not equal and that some are more vulnerable to challenge than others. It is thus unsurprising that Cook (2004) suggests need to facilitate greater knowledge about mild disabilities, particularly EBD in order to enhance recognition of 'challenging' behaviours as evidence of disability hence reducing propensities for blame. Nevertheless as O'Connell notes punitive response to behaviours which offend or harm is entrenched within the legal system and similarly as exclusion figures suggest schools.

As a parent disability doubt was personally unsurprising, but as a researcher the generalisability of the data giving rise to doubt is uncertain, as Grieves (2009) notes teachers conceptualisation of what constitutes 'difficult' is uncertain, hence it is reasonable that teachers discernment of familiarity may be equally unstable. What is

infinitely more concerning is the repeated tendency to accord accountability and doubt, in relation to disability effects and the reliability of individual diagnosis.

Training: Issues of training reflected most clearly the gaps teachers perceived in their knowledge and was a consistent issue in all three rounds of data collection. At the NUT conference, respondents appeared most at ease questioning both initial training and pre-qualification and that offered as continuing professional development (CPD) by their current school. Lack of training around disability was highlighted to be a major issue. These concerns are mirrored in wider literature, for example the NFER's (2012) survey found that a significant number of those surveyed (41%) felt teacher training in basic pupil management to was poor or very poor, in conjunction with (60%) who stated they had not received any CPD in the previous year.

SENCOs also expressed these concerns as the following comments indicate:

"I did a PGCE and it is only a year to learn how to be a teacher and how can you fit everything in to one year? I think it should be more enforced within schools and I think there should be people who can come and deliver the training days and it should be maybe more of a legal requirement that every however many years you have a specific training on ...for your staff ..."[Marie].

"I think the PGCE should be a two year course; there is an implicit expectation at the moment that in relation to disability and SEN that you will learn it on the job" [Jon].

The expectations that are demanded in the new code of practice (DfE 2015a) intimate need of a depth of 'formal knowing' that teachers suggest they don't have. This knowledge gap renders problematic the stated demand that teachers offer an 'anticipatory' response, rather than reactive sanction to children, requiring 'thought in advance to what disabled children and young people might require and what adjustments might be made to prevent that disadvantage' (DfE 2015, para 6.9, pp 93). Problematically teachers in my study appeared far from objective as the following comment emphasises:

"Labelling can be offered as an excuse in an educational setting for some conditions. This is my opinion and does children a disservice in terms of preparation for adulthood. E.g. ADHD, ODD as their behaviour traits are 'managed' but not challenged" (teacher/in school).

Twin attributions: It is also possible to detect in the previous comment both evidence of disability challenge and intimation of accountability, through the under defined nature of what constitutes reasonable challenge. The tone of this comment also implies belief that behavioural conditions can be 'challenged into submission' and

that it is teachers who are entrusted to teach their pupils such control. This is a position nevertheless that does not correspond to the description of disability as it is defined in the Equality Act (2010). Indeed it is hard to imagine the same comment being applied and substantiated in relation to a physical disability. However differentiation between physical and psychological disabilities were emphasised by teachers on several occasions, one teacher even suggested that “disability suggests physical impairment”.

Teachers ranking choices reflected such sentiment and suggested teachers felt confident that they ‘knew’ physical disability, yet despite indicating similar confidence in regards to ASD and ADHD as discrete conditions, there was recurrent concerns stated towards the legitimacy of individual diagnosis. As one teacher stated “physical disabilities are most obvious”. This brief comment underscores the basis of challenge toward psychological disabilities. Most specifically physical disabilities leave little room for doubt and may be seen to correspond to physical presentation. Whereas the psychological disabilities are sufficiently intangible and hence leave room for doubt and alternative rationalisation. Thus the nature of ‘formal knowing’ opens spaces for challenge and problematically the training offered to teachers during both training and in employment is insufficiently rigorous so as to combat the doubts that are inherent to less obvious disability presentations.

It is reasonable to suggest that it is impractical to upskill all teachers with in-depth knowledge of all the disabilities that inhabit the classificatory manuals. Rather it is suggested that it is more helpful to address with serving and training teachers their assumptions towards difference and indeed their role in heightening and exacerbating difference. Graham (2008) suggests that increased training around types of disability is secondary to need to encourage teachers to consider the relationship they hold generally to presentations of difference. This sentiment is heavily reinforced by Adams (2008) in relation to ADHD, stating that ‘if educators are to understand their relationship with and to ADHD they should appreciate that they themselves are part of the process that constructs ‘the disorder’ (pp 123). It is however also fair to suggest that teachers by virtue of role and as a primary gatekeeper to assessment services also are part of the process or sorting. Essentially as one SENCO stated, “it’s knowing who can and should behave”.

Troublingly this judgement if one accepts medical explanation is not professionally within teachers and SENCOs remit.

Processes of sorting are also complicated as Boyd (2012) notes by liminal state between disability and non – disability, which is increasingly being recognised. Although Boyd speaks of fluctuating illnesses (punctuated by periods of wellness), which are problematic for official disability status, the notion of fluidity is equally relevant to behavioural disabilities, which as Baroness Warnock suggested to me in interview are heightened by context. Indeed considering the incongruence of my own sons in relation to intellectual capacity and social functioning, this fluidity was both evident and unrecognised by school. Teachers in my experience anticipated a child with a disability to exhibit classical traits of that disability consistently, yet during periods of calm at school, with conducive teacher/pupil relationships, the appearances of disability were dulled. This fluidity of presentation was a prime juncture that substantiated disability doubt. However alternatively spoke of the primacy of context and relationships, as such supporting of Grahams (2008) claim that teachers need introspect on the relational aspects of their role as a contributing factor to disability presentation. Disabilities that impact on behaviour are found by their nature to conjure challenge and at times hostility, Cook (2000) observed the negative impact abrasive personalities had on teachers disposition to respond within a disability frame, similarly Rogers (2013) notes 'difficult' difference attracts an uncomfortable response, which separates it from the range of other acceptable responses to disability. Looking at my data these tendencies were evident: teachers indicated abstract challenge to both a pupil's claim to disability and also parental motivation to seek diagnosis, these challenges within this research emerged as a dichotomous opposition framed between issues of nurture and those of an organic nature. The implications of these judgements however, was for the families interviewed and myself personally life changing, enduring in impact long after the name and incidents were forgotten by teachers.

The excusatory capacity of disability diagnosis: By far the most troubling data returned was the often blatant accusation that parents sought diagnosis is a calculating manner to exonerate themselves for their children's behaviour and their inability to control it. Teachers both in-school and at conference however expressed these concerns and looking across the data, outside of personal experience, it was

evident that these tendencies were highly significant, opening not only spaces for accountability, but justification for accountability.

Blame is found to be embedded in disability theorising as Thomas (2007) indicates, finding a divide evident within the social sciences. Thomas notes that whilst disability studies has viewed disability from a lens of social oppression, medical sociology has adopted a social deviance perspective, which has altered in integrity disability rationalisation. Considering my own experience of disability response in schools, traits of these pathways resonate, not only with my experience, but with the data this research collated. Talcott Parsons (1952) rationalised disability from a functionalist perspective, determining that disability per se was a form of social deviancy, circumventing of the normal social responsibilities all individuals were charged with. Whilst acknowledging of the concerns levelled towards the functionalist perspective particularly from the perspective of power relations (Foucault 1980; 1982), and that of human agency (Winch 2008), the reciprocal responsibilities Parsons identifies to accrue from the sick role can be seen to hold a contemporary relevance in relation to the relations and expectations between parents and teachers in contemporary schools. In brief Parsons identified two rights and two responsibilities. The former being exemption from the normal duties of everyday life, consolidated through exemption from blame or punishment for failing to fulfil normal social obligations, the second being exemption from blame for being ill. These concessions however are counterbalanced by corresponding responsibilities, these are detailed as demand to ensure swift recovery and secondly to seek professional input to facilitate this recovery, including adhering to medical advice (pp 436-437). Looking at the locus of blame in schools, in the first instance, blame appears to accrue from contested claims to the 'sick role'. Secondly blame was also detected in relation to how parents respond and manage their child's disability, most particularly how astutely they are seen to respond to medical advice, in particular their willingness to medicate (Taylor and Houghton 2006, Whitely 2014). This responsibility was commented on by parents who contributed to my study and was the subject of serious concern for Freya:

"My family said that he was terrible medicated, not behaviour wise just that he wasn't himself, he was unsociable, he was horrible. Normally he tries socially, he will at least try. But not when he was medicated, he would just growl, but you see the teachers were quite happy with that" [Freya].

This statement clearly implies that the effects of medication were for the benefit of school, not the child and certainly not the family. Farah similarly encountered such partiality of concern, “so the doctor said I will listen to the professionals and if he is not causing problems at school we won't give him anything”. “But then he did start to become more difficult in school so they [doctors] thought”, “oh well we will medicate him”.

These comments allude to the priorities held between professionals and also the expectations of these professionals for parent to concede to professional priorities, which if not delivered are themselves attracting of condemnation. They also intimate less savoury opinions held toward the causes of behavioural difficulties as the following comment made by a respondent teacher indicates:

“SEBD, ADHD, Behaviour = Diet/nutrition – link to autism? Media/TV, lifestyles – related to family, family beliefs, decline in respect for others/family, welfare state dependency, low aspirations, environmental issues”.

Like many other responses, this respondent lists what are considered to be the causes of behavioural decline and excepting autism, all are identified as being linked to life style and attitudinal choices. These attitudes are however not limited to teachers but are reflected in governmental statements concerning standards in school and in particular the need to improve behavioural standards as well as the consequences for poor behaviour (Party 2010, OFSTED 2012). Although seemingly disconnected from discourses and issues surrounding disability, the data generated in this study suggests otherwise. The ongoing debates conducted by teachers in relation to the legitimacy or indications of disability is illustrative. Yet as teachers indicate, they are not sufficiently knowledgeable to make such deductions, thus their determinations are subjective, however with real life consequences as the families in Chapter five indicated.

Similarly the accountabilities intimated by teachers is disavowing of the very real challenges faced by parents, which as Rogers (2011) observed may paradoxically impede ability to cope and to engage seamlessly with professionals, causing further discord. Nevertheless as Gill (2011) suggests, unless one has experienced the strains of parenting a disabled child, it is unreasonable to Judge and despite being a simple sentiment it speaks very clearly to the challenges shared by families in Chapter five and begs the question of how would anyone else cope. Certainly from

my own experience and that described by parents the contingencies faced were not anticipated, nor were they sought. Thus despite being positioned as feckless and complicit, myself and the families who engaged with this study spoke of the life sacrifices made, the indignities faced and the ongoing challenge to manage disabilities that were only partially understood. Yet unlike other disabilities were fully accountable for their effect.

6.2.6 Foci four – the pervasiveness of the nature versus nurture equation

Teachers and SENCOs indicated that the ‘formal knowledge’ they held was shaped by their determination of the cause of pupil difference and that this was directional of not only their response, but also the relationship between school and the family. The most evident example of this is Micha’s story, shared in section one, yet this was not an isolated example as Leanne and Julies narrative also indicates. Looking at the data gathered from teachers and SENCOs it is possible to see the threads of the nature/nurture divide. At times these were subtly stated at others there was a bold questioning about the reasons for a child’s difficulties as the following comment indicates:

“Sometimes disabilities may be blamed when children are naughty when poor parenting skills may be the cause of bad behaviour” (teacher in-school).

One of the ranking exercises in-school asked teachers to state what they felt were chiefly responsible for pupil differences, and it was this exercise that reinforced to me that understandings of the causes of pupil differences and pupil behaviour were divided between organic or environmental factors. The following answers are illustrative:

“Genetic, Diet –pre and post birth, background/economic - this feeds into some others in the grid, but I’ve chosen to list them separately. Transitory nature of family, family breakdown, bereavement, traumatic incidents in childhood, peer groups”.

“Organic, culture, environment. Organic tendencies i.e. child might not develop it, but does in certain environments, such as lack of support from parents/teachers. Culture/environment to do with poor nutrition and fast food (lots of kids in school with SEN eat very poorly all day) suggesting parental neglect”.

“Depending on type of school, parents can see a label as a means of obtaining help, emotionally or financial, or conversely it can also be a stigma. ADHD is most commonly recognised, but often can be due to lack of parenting skills”.

Teachers also intimated that their ‘knowing’ of disability was linked to issues of proof that they themselves were able to observe. Not unsurprisingly, physical disability

was considered 'obvious', whilst other diagnoses attracted doubts toward their legitimacy as the following teacher states:

"Physical disability – This tends to have a medical evidence background and therefore cannot be argued as incorrect. Dyslexia, dyscalculia – a definite condition, however many students with learning issues are 'diagnosed' [especially when parents pay] when they only need more targeted appropriate teaching from specialist teacher".

The statement above is highly interesting as it alludes further to how medical labels are viewed generally and this statement shows clearly the tension between what was termed in section one as 'medical' and 'pedagogical' knowing. The teacher cited above makes distinction between a 'learning difference' which is considered a pedagogical jurisdiction and 'dyslexia' which is termed 'a definite condition'. This statement speaks to the mind-set of teachers generally and the jurisdictions they consider they hold. It would appear that 'formal knowing' in the pedagogical sense is purposeful and actionable, whilst that of a 'medical nature' is directed, as such inhibiting of professional agency. Looking back at section one and how one SENCO described her role as choosing between the 'cannot's and the won'ts frames the potency of the nature/nurture divide. It may also be seen to be disempowering, particularly given the previously stated concerns towards external funding and wider agency accessibility.

Gibbs and Elliott's (2010) challenge to the status of dyslexia as a diagnosable disability status, details how not 'knowing' can be outside both the teacher and the pupil's best interest. In essence they suggest that 'dyslexia is falsely reified and indistinguishable from the generality of other reading difficulties' (pp 3). In addition Gibbs and Elliott argue that medical labels can stifle not only a teachers self-efficacy and intuitive teaching, but it can also lead to the exclusion of some pupils from support if they are not officially diagnosed.

These concerns conjure a reasonable question as to why a medical diagnosis should be viewed by an aligned profession as a necessary tool to inform their own professional 'knowing'. In answer it would be reasonable to argue that an official medical label may be considered a reliable source of insight and support, yet teachers indication of additional doubts, is also found to give rise to disability challenge, which is inhibitive of effective support. Baroness Warnock during our interview suggested that particularly in relation to dyslexia, the rise in diagnosis, reflected financial incentives (on the part of schools as well as parents) to seek a

formal label. She also suggested that the reliance on medical validation, left some children at a disadvantage as she felt it was parent proactivity and ability to obtain a private diagnosis that had led to dyslexia being termed 'a middle class disease'.

Certainly SENCOs in this study appeared concerned with how additional supports were to be financed in the absence of a diagnosis. Florian (2008a) highlights three main policy concerns that emanate from disability classification, linked to considerations of causation, these centre on cost; adoption of services and their allocation. Indeed the idea of allocation of resources has been viewed historically as central to the utility of medical labels in education (Hobbs1975).

By far the greatest indication of an ongoing debate around nature versus nurture was in relation to 'behaviour'. A cognitive activity found conducive to not only who is ill behaved, but what constitutes poor behaviour generally (Waterhouse 2004; Araujo 2005; Macleod 2006; Begeer 2009, Bailey 2010). Additionally unlike debates around learning competencies, which divided between 'pedagogical knowing' and 'medical knowing', issues of behaviour introduced a second dimension to 'pedagogical knowing'. This dimension involved the attribution of blame and accountability, conjuring with it, justification for reasonable address which in school take the form of sanctions. My data suggested that it was this juncture more than any other that was an impetus for parents to seek diagnosis. Not to excuse, but to cement disability rights. As Leanne's narrative indicated, without a formal diagnosis, many teachers continued to consider her son's behaviour simple 'naughtiness', which legitimated unfavourable treatment and sanction. These judgements were not uncommon as Gill expressed in relation to ADHD:

"Sometimes there are some kids that I think just don't have it [laughter], but they have a diagnosis, but you just think it's just a naughty kid. Not that it matters too much at this school we have a very strict discipline policy here, and it is applied across the board regardless of disability".

Nevertheless it is also at this juncture that parental ability to seek and secure a diagnosis interrupts the vision of an objective and neutral diagnostic playing field. Interestingly my data suggested awareness of disadvantage as Christine (SENCO) states:

"It tends to be those parents with greater education who are more articulate who will come in, and then there are parents who are less articulate who are less inclined to come into school, and it is more likely that their children will not necessarily be put forward".

Such observation adds a more sinister dimension to the ongoing culture of parental and environmental blame, as it is those children with the least effective advocacy who are most liable to be labelled 'naughty', or equally in the case of learning difficulties less able. One would hope that reliance and deferment to medical labels would close gaps created through inequality, yet the data in my study suggests that 'formal knowing remains wedded to the wider intersections of disadvantage that have been classically identified (McCoy 2006, Russell, Steer and Goulding 2011, Liasidou 2012, Tomlinson 2014).

6.3 Section 3 – Discussion - Wider agendas

To appreciate more fully the dynamics between the parties that comprise the school context, it is useful to borrow Francis (2013) micro politics framework. This frame poses the following questions; 'who are the relevant social actors? What are their sources of power? What are their vested interests? Whose definition of trouble prevails, in what contexts and why' (In Ribbens McCarthy ed. 2013, pp 85)? Looking at the composition of the social actors, teachers, parents and pupils would appear to be the main players involved. However as noted, teachers and parents rely for understanding, (their 'formal knowing') on wider professionals. It is equally important to remember that this 'knowing' transcends description or explanation; it is also definitional, particularly in the school context where supports are visible (Beardon 2008), particularly as the child relies upon his/her peers to affirm an identity and sense of belonging. As Freya indicates below, the practical implications of 'formal knowing can serve to highlight the child within his/her peer group, with deleterious effects:

"Well he (son) came home one day and asked what a 'retard' was; he couldn't even pronounce the word, but I knew what it was. I panicked and I said to him, oh it is not a real thing, it's made up, there is no such thing, did they not mean leotard? I tried to make a joke of it, but I just went off and cried".

Freya's comments remind us that 'formal' knowing is firmly wedded to issues of identity and pupil assimilation. Indeed these factors above all else were found in a former study to be prized by children (Watson 2010).

Identifications of difference serve differing functions, most specifically in regards to the conferment of accountability for 'difference's' impact. There are however distinct inequalities in relation to the sources of power each player holds to sway

determinations of accountability. Huws (2011) states presence or absence of voice to be indicative of such power; adopting such measure it is clear that teachers hold a very definite power, both in relation to classroom protocol and through their relationships with their pupils and parents. It is thus noteworthy that what are determined as behavioural challenges are disproportionately associated with social and economic disadvantage. As Propper and Rigg (2007) observe, children in low socio – economic groups are eight times more likely to present as behaviourally problematic. Similarly Begeer (2009) cautions that ethnicity is also a factor which channels how difference is labelled.

The picture which emerged from my data in respect of difference is most aptly described as a mutual search for answers and a parental fight for theirs and their child's recognition, embedded in these exchanges is both the conferment and resistance of accountability. 'Formal knowing' is indeed central to these endeavours and bestows on schools immense responsibility and power. It is therefore telling that 'the power of voice is less developed in the field of behavioural, emotional and social difficulties, where there is no equivalent (self-) advocacy movement' (Nind 2012). Indeed none of the teachers or SENCOs who participated in my study indicated any linkage between what they did and how the pupils felt or saw themselves; and where behaviour was the issue, there was little address of triggers at the level of systems. To the contrary as Jon (SENCO) implies, the issue is one directional involving and involves "being made to behave" (pp 421). Thomas (2005) cited in Caslin (2014) summarises the position of the 'challenging' pupil thus:

'The process of understanding children to be not only irrational but also emotionally disturbed effectively condemns them to voicelessness. Being seen as irrational (rather than simply stupid), is particularly damning, for it means that you are deemed unworthy even of consultation about what is in your best interests' (pp 164).

What was found to be of impact however was both the expectations generated from parents cultural and educational capital; and its expenditure as an impetus to 'formal knowing'. These resources may be viewed as guiding not only on the 'formal knowing' teachers formed, but the guise of sources consulted to gather that 'knowing' (either psychological or behavioural). The brokered guise of 'knowing' was also found by Beardon (2008) whilst canvassing the educational experiences of young adults with disabilities: whereupon it was emphasised that parental support was considered a vital asset, not only in navigating educational systems but toward

being 'known' 'If I didn't have a mother willing to fight my cause, I wouldn't have been where I am now' (pp7).

The medical profession through their licence to diagnose may be seen to intercede between the differentials of power identified in the educational context. Parents and teachers in my study indicated a diagnosis of disability to be welcome; not only informative but also viewed as an evidence base to support additional funding requests. Additionally for parents a diagnosis conferred very definite legal protections to the child and family (Parliament 2010) mitigating against accountability and placing strict obligations onto schools. The most obvious embodiment of 'formal knowing' in school is the statement of educational need (now the education health and care plan). As several parents indicated to me, this was the passport for additional support, recognition and entitlement to move their children into the special sector. Schools similarly alluded to the currency of the 'statement' and implied that its issuing was being resisted at a wider level, as Gill states: "with funding actually cut from schools. It's notable that you don't get as many statements as you once did".

The pursuit, issuing or denial of a statement or diagnosis was found to interrupt the power dynamics between teachers and parents, as well as between the child and the teacher. As I, similar to Leanne had experienced; schools presented as less motivated to understand or rationalise 'behaviour' without a formal medical label, preferring instead to manage 'behaviour' through a sanction led approach that was denying of the logic of disability as a causal factor. This emerged as the prime juncture where accountability accrued. It also opened spaces for wider insinuations, most specifically suggestion that parents and children were abusing the diagnostic system to exonerate themselves from accountability.

Troublingly children are least placed in the formal arena to exercise power, they are also vulnerable to being made additionally visible by supports offered in school. Which as Benjamin (2002) found may lead children to exercise power in the only way available, through the adoption of counter identities (Black-Hawkins and Rouse 2008). In addition Beardon (2008) found in a study of post school adults indication that the supports adults feel are helping, may for the child be a social and identity hindrance. As such inhibiting of further acceptance of educational support in their

later educational lives, as this young man stated; 'If you think I am going to go and get any more special needs, you can get lost... it ruined school for me' (Beardon 2008, pp 9).

It is practical to suggest that the 'knowing' of a child involves the interplay of vested interests. For teachers there are multiple accountabilities, not least as previously noted those framed around standards and inclusivity (Parliament 1988, 1998, Gillborn and Youdell 2000, DfES 2005, Ofsted 2014b). Teachers are obliged to evidence pupil progress and therefore are motivated in their own professional interest to get results. The implications of this was intimated by the headmaster (acting SENCO) of the PRU, offering more sinister undertones in relation to who is excluded and why:

"I think it is the pupils who can blend in that do manage, because if you take any school with about 300 pupils in a year group and they are struggling all they have to do is exclude 3, or in multiples of three, say if you have 300 because that is 3 out = 1%, 6 out =2%, 9 out =3% and so on, now those schools may be 1 or 2% below flow standards, and if they are desperate to get above flow standards to stop them having to become an academy for example or a category such as special measures, they are going to put those kids out"[Len].

It is evident from the above comment that accountability for the level and choice of exclusions, extends beyond the individual pupil and indeed school. Diagnosis may therefore be seen to act as discrete evidence, deflecting accountability from both individual teachers and schools. Parents similarly benefit from a diagnosis, what has been termed a label of forgiveness (Slee 1995, Lloyd 2003, Ryan and Runswick-Cole 2009).

Although teachers 'formal knowing' is generally bounded by the school context, where behaviour is an issue, the issues and concerns these raise may transcend the school context and lead to 'knowing' being informed by unknown persons in aligned professions. As I detail in Chapter six; in the ISS and the PRU, the role of these 'other' professionals is aligned to the discrete remit of the specialist context. In the mainstream however wider allegiances are less obvious. Hence they are often faceless and unknown to the parents concerned, yet are present and effect influence in the unfolding of 'formal knowing', As Foucault states:

'Discursive practices are not purely and simply modes of manufacture of discourse. They take shape in technical ensembles, in institutions, in behavioural schemes, in types of transmission and dissemination, in pedagogical forms that both impose and maintain them' (Foucault in Rabinow 2000, pp 12).

Schools and the agencies aligned to schools may be seen to represent these 'technical ensembles', dedicated not only to teach, but to deliver wider responsibilities. As has been indicated previously, schools have a duty to be seen to be inclusive. This formal accountability requires supporting evidence to substantiate any exclusionary response to be reasonable and proportionate. It is also necessitates being seen to be inclusive, making all 'reasonable adjustments' needed to retain in the mainstream.

Hence school motivation to retain pupils who need significant constraints may be alternatively viewed as the means necessary to maintain identity as an inclusive school. However this vested interest in practice is unilateral, privileging the school rather than the child, as many of the parents attest. Similarly so, the OCC (2013), who found schools tended to frame disadvantaging exclusionary actions as benevolence. Therefore when considering disability positioning and indeed the process of teachers 'knowing' it is vital to retain an appreciation of the interconnecting agendas and responsibilities which may themselves be directive toward not only the shape of knowing, but the desire to know.

6.3.1 Scratching beneath the surface

At face value teachers and SENCOs held varied opinions toward disability types, and notably there was significant concern toward disabilities which impacted on the operation of the school as a learning environment. These concerns appeared heightened in light of economic uncertainty and accountability as Mark (SENCO) states:

"I think the attitudes that teachers have is that we are expected to deal with all this (children with a wide range of disabilities) and where is the support? It's difficult enough to get CAMHS involved for support, so we are expected to manage these behaviours in the classroom, at the same time that we are managing everything else and we don't consider ourselves to be the experts in that area, so we need the support from agencies, and we just find that things are being cut left right and centre in the current economic climate. I think there is a lot of concern over money and budgets and this is clouding all other issues".

The above comment offers a very clear view of the multiple tensions teachers and SENCOs consider themselves to be faced with. It also alludes to how the teaching profession views itself relationally; as both reliant on and answerable to the medical profession. At conference many delegates mentioned that it was a novel experience being given permission to be critical of disability classifications, as most often such input is unwarranted and outside of their professional jurisdiction. Such professional

distance was found mirrored in relation to formal training, as teachers, particularly at conference reiterated knowledge gaps; gaps perceived by teachers to be limiting of their ability to fully assess and respond to pupil difference.

The mixed opinions suggested through teachers ranking choices destabilises the notion of unequivocal disability equity and indeed delegates at conference indicated concern that there was no forum for such debate. Nevertheless teachers are positioned professionally as intermediators and although they input informationally to the diagnostic process, the final jurisdiction resides with the medical profession. SENCOs on the other hand indicated they considered themselves to be in a position of greater familiarity with the finer nuances of disability classifications, and indicated that they were entrusted by role to disseminate this expertise to both staff and parents. It was interesting that in interview SENCOs did not allude to any doubts about classification validity, although they were open and candid about organisational barriers and economic constraints. Similarly SENCOs discussed the role of parents both as a contributor to difference and as an advocate, indicating mixed opinions as to the efficacy and utility of parental input.

The causal attributions intimated by teachers and SENCOs and also as narrated by parents, emerged as the output of relational and negotiated engagement between home and school, rather than as a considered individualistic assessment. Overall although both SENCOs and teachers stressed the primacy of the medical model to their understanding of pupil differences, they equally indicated that other factors were implicated in the nature of particularly behavioural difference, most specifically those of a cultural or parenting nature. Indeed it was at the interface of these two discourses (Nature/organic versus nurture) that the conferment of accountability was rationalised. Unsurprisingly where nurture was implicated, teachers indicated the greatest professional agency and appeared most confident to meet the demands of difference. Professional agency is a factor addressed by Elliot and Grigorenko (2014) and considers the utility of a medical label for pedagogical purposes. Overall it is suggested that medical explanations in the school context are superfluous in regards to pedagogical practice, serving to inhibit and generate perception that there is need for an expertise that exceeds the teaching role. Thus although Elliot and Grigorenko emphasise challenge to the utility of medical labels in schools, they also stress that this does not imply challenge to the legitimacy of

particular classifications per se, rather addresses the implication of 'pedagogical knowing' being informed by 'medical knowing' .

Although teachers emphasised insecurities around expertise, the most pressing concerns were practical and focused on how to respond to a wide range of diversity in the classroom. It would therefore be plausible to suggest that teachers concern themselves with the craft of teaching, rather than acting in a pseudo medical capacity. But there is an interface between both professional arenas (Medicine and Teaching) which necessitates a basic level of familiarity and competency. Cross (2011) states professionals working with children and young persons with EBD and mental health problems are insufficiently trained, leading to a lack of recognition in the first instance and inappropriate response in the second. As parents indicated, particularly Sacha's story, there were real life implications which transcended clear professional demarcations and demanded a wider and more fluid knowing.

Teachers difficulties were also stated to be made more difficult as a consequence of interconnecting tensions that led from government directives and financial constraints. This research found that it was a combination of all of these factors, not just an assessment of the legitimacy of disability classifications that shaped teachers 'formal knowing'. It was thus concluded that although teachers indicated varied opinions toward disability classifications and that this was taken to intimate that all disabilities were in fact not equal, overall 'formal knowing' was the output of relational engagement and this was informed by more subjective factors, including appraisal of parental status. Nevertheless there also needs to be caution offered in regards to the level of connection teachers generally hold between 'behaviour' and disability. This study introduced disability classifications as a primary focus, looking specifically for areas that could explain challenge. In contrast the NASUWT (2012) survey, questioned teachers opinions more generally and found that 'ninety-four per cent of school leaders believed that poor pupil behaviour was caused by both poverty and a lack of parental and pupil aspiration' (pp 11). Similarly participating teachers displayed a similar disconnect between disability and 'behaviour'. Interestingly NASUWT also found that eight out of ten teachers (84%) indicated that they did not feel they were empowered or respected as professionals to deliver the best outcomes for their pupils'(pp18). Thus despite the concerns towards medical labels indicated by Elliot and Grigorenko (2014), teachers suggest that insecurities were led

predominantly by the following factors: constant change; a culture of blame toward teachers; lack of understanding of the realities of the role on a daily basis and a lack of respect for teachers professional judgement. Supporting further the claim that there is a disassociation between disability and behaviour, which opens spaces for accountability to logically flourish.

6.3.2 Diagnostic expansion

The increase of diagnosis was an issue for many teachers in my study and was implicated in belief that such expansion was indication of a lax system, open to abuse, as the following teacher suggests: “ADHD – some over diagnosis exists – schools pressured to explain failure to meet standards (T/in-school 35).

Certainly prevalence and diagnostic expansion were issues of concern which teachers and SENCOs felt reflected deeper motivations and agendas. Yet as Eyal (2010) argues, new and expanding medical categories may equally reflect wider social factors, as much as they do medical advance. Thus generating appearance of expansion rather than actual expansion in terms of presentation of difference. Eyal indicates this to be the case in regards to the so called autism epidemic, which is alternatively explained as resulting from a combination of factors, rather than simply increased numbers. The reasons cited include: the policy of de-institutionalism, a greater public awareness of autism and also a relaxing of the criteria for diagnosis. Taking Eyal’s argument forward, if medical expansion is responsive to deeper social change and processes, one might posit that the expansion of neurological explanations for ‘behaviour’ may also be a by-product of wider social discourses, in particular those concerning issues of social justice and inclusion. What this argument also does is highlight the interconnectedness of attributions for difference, widening beyond medical debate explanations for difference and accountability of difference.

6.3.3 ‘Knowing’ – paving the way for marginalisation and accountability

Many parents indicated concern that they and their children were being marginalised by schools, and were ‘known’ only partially. Such ‘knowing’ was considered by parents to be at times distortive and damaging as Chapter five indicated. Teachers confirmed such contention through open challenge to certain types of disability presentation, which of itself served to marginalise particular types of pupils. Such marginalisation is not however specific to contemporary times, as the history of

education and indeed disability shows. The 1944 Education Act in particular established a framework for sorting prospective pupils into life pathways, it also detailed how children were to be sorted in relation to 'disability', drawing upon medical categorisations of ability and need. Of greatest significance was the invoking of the criteria delineating 'ineducability', signifying a body of disabled pupils deemed so impaired as to be considered unsuitable for education (Parliament 1944).

Disability is not however the only criteria for separation or omission from mainstream educational provision. Issues of behaviour both in and out of school historically and contemporarily have served similarly to legitimate exclusionary processes. This has most recently been complicated by an ongoing expansion of type and prevalence of neurodevelopmental disabilities, leading in contemporary schools to a blurring of which is disability and which is not. There has been nevertheless an ongoing protocol for segregated educational provision; and in the case of 'behaviour' this is historically linked not only to health services, but also rehabilitative and punitive sectors.

The establishment of the Borstal system in 1902 is a prime example of how youth rehabilitation evolved to be inextricably bound up with systems of education, separated from the mainstream. Notably the 1944 Education Act recognised the category 'maladjusted', as a descriptor for those pupils considered or known to be liable to disrupt the classroom and was also an accepted classification warranting of segregation. Currently, despite a dissolution of the prominence of medical classifications in the education context, modern names appear to have replaced former nomenclature, offering impression of progress and inclusivity, yet in reality the meanings invoked remain the same. Caslin (2014) proffers an overview stating that 'professionals construct perceptions of how young people with BESD are to be understood. The young people become marginalised as they are deemed unfit to mix with peers' (pp164). Indeed my data suggests that it is both perceptions of unfitness to mix with peers and the accordance of accountability that drives forward exclusionary response, negating educational entitlements, both in and out of the mainstream.

The criteria invoked to discern between disability and SEBD (maladjustment) may be viewed both historically and contemporarily as the basis of 'formal knowing'. Yet

despite shift to medical explanations of difference, the basic divide that channels entitlement from non-entitlement remains the same and is founded upon notions of accountability, which is itself derived upon perceived or actual impact on self or others. Hence as Jull (2008) argues, impact on others in education circumvents diagnosis as a valid mitigation. Caslin (2014) notes similarly, stating that a diagnosis which holds implications for behaviour, far from being one of forgiveness, can act to the contrary, leading to negative perceptions and exclusionary response.

Similar circumvention is noted by O'Connell (2016) and toward explanation it is suggested that a "'brain-based' framework is not as neutral as it appears. Specifically how the law regulates the brain-based subject when they present in the form of a badly behaved child, is determined by how law conceptualises the brain" (pp1). O'Connell notes several positions which can be divided into a simple binary, those that see the brain as malleable and amenable to interventions, and those that deny flexibility. Either pathway has potential to be detrimental to the individual concerned, as both speak of control and 'normalisation', the very antithesis of diversity and inclusion.

Consistently accountability appears in education (Jull 2008, O'Regan 2009, Caslin 2014) and indeed the legal system to be determined on the basis of impact; determination that has been embedded consecutively in legislation. For example the Salamanca Statement (UNESCO 1994, para 9, pp7) states segregation is justified 'where it is clearly demonstrated that education in regular classrooms is incapable of meeting a child's educational or social needs or when it is required for the welfare of the child or that of other children'. The criteria of impact as grounds for accountability is similarly embedded in UK legislation (Parliament 1981, Parliament 2001) and formalised most recently in the Children and Families Act 2014. Section 35 (b and c) of the afore indicates two criteria that justify exclusion, these being where a pupils attendance compromises 'the provision of efficient education for the children with whom he or she will be educated' or where such attendance is not considered an 'efficient use of resources' (Parliament 2014). Thus one can see that despite disability challenge appearing to derive from a rapid expansion of classificatory types, the forgiveness previously referenced by the conferring of a medical diagnosis, may in working practice be impotent, rendering superfluous claim that diagnosis is sought for exclusionary purposes.

6.3.4 *'Deserving' and 'undeserving'*

Despite the rise of, and qualifications to equity that have been identified as accruing from neurological explanations for difference, a chief systemic (and indeed parental) motivation for 'formal knowing' remains entitlement to support. Nevertheless the processes of determination may reflect wider intersections of discrimination, as much as medical evaluation (Russell, Steer and Goulding 2011). To further our understanding it is useful to return to Giroux (2009; 2011) and the argument he posed in relation to the position of youth in the United States. Giroux builds his argument around the claim that (certain types of) youth are increasingly distrusted and marginalised, and that this distrust is founded upon racial discrimination. Although the situation in the UK and indeed that of the North East is fortunately more tolerant to racial differences (although recent developments following the EU referendum may challenge this assertion), other more subtle social prejudices produce similar impacts. In particular divisions based on socio-economic status and SEN, continue to be factors implicated in vulnerability to educational exclusion and social marginalisation (DfE 2015b; 2016). In education these are legitimated predominantly on a narrow range of reasons, not least of which is persistent disruptive behaviour (O'Regan 2009; 2010, NASUWT 2012).

The teachers union NASUWT (2008, 2012b) found from members surveys that the fear perceived from out of control youth was a constant; responses indicated concerns around discipline and considered lack of jurisdiction to curb poor behaviour as a main reason for demoralisation and exit from the profession. These concerns have spearheaded educational reform, justifying teachers greater powers of restraint and sanction (Parliament 2011). Nevertheless less stated is the impact of these insecurities on how young people are viewed. However as Caslin (2014) suggested, behavioural labels can act to trigger a mind-set of threat drawing association with malevolence and lack of control. Such association leaves specific types of pupils vulnerable not only to 'behaviour challenge' by virtue of disability, but liable to segregation on the basis of perceptions of what they might do. Thus amidst a climate where theirs and their families voices are silenced, there is little means available to satisfy wider systemic insecurities.

Wills (2007) nevertheless observes, propensity to 'other' and to mistrust youth to be historically a constant disposition. Willis notes that each generation has laid claim to escalating dangers from uncontrolled youth, based on a spurious nostalgia for former times which is disavowing of the social factors which induced fear and suspicion. Nostalgia which impacts heavily on public perceptions as well as educational and legal policy, thus inducing a sense of urgency to re-establish control (Cox and Dyson 1971, Birbalsingh 2006, Haydn 2007; 2010, HCC 2011, DfE 2012d, OFSTED 2012). Such contention begs the question of the utility of medical diagnosis, yet as is discussed in the following section, medical labels are employed to inform teaching practice, although the degree of dependency was found to fluctuate between schools and was itself responsive to both social and systemic factors.

6.3.5 Medically informed pedagogy

The mainstream teachers in my study indicated reliance on medical explanations for difference, this mainly took the form of indicating difficulties accessing specialist agencies such as CYPS. Such dependency was also expressed through the concerns teachers expressed in relation to their preliminary training. Teachers suggested that it did not prepare them fully for the diversity of the classroom. Similar concerns were levelled against the quality and range of ongoing professional training in employment. Nevertheless despite such concerns, the majority of teachers felt comfortable ranking in relation to issues of classification legitimacy, even though the perceived insights was stated by many teachers to impact on their own confidence to manage their classroom. These concerns, echoed those presented by Gibb (2012) and Elliot (2008, 2014), who suggest medical expertise is not essential to pedagogy and can act as a handicap to professional efficacy.

Nevertheless the expansion and legitimation of medical explanations for 'behaviour' (Conrad 2007; 2014) has resulted in a corresponding turn to medically informed educational provisions. Yet these provisions are suggested to have little to do with pedagogy and more to do with control. Holt (2010b) suggests that although a medical discourse has prompted the development of separate provisions (albeit attached to a mainstream school) for some pupils, in essence they constitute 'geographies of normalisation and are tied to the specific policy context of the educational inclusion of young people with SEN' (pp4). Indeed Holt privileges

'normalisation' as a pre-requisite for placement entitlement, a position supporting of Graham and Macartney's (2012) stance that despite claims to inclusion, educational provision remains tethered to an integrationist mind-set, a mentality that is foundational towards 'formal knowing' and more importantly the responses which lead from such knowing.

Looking more closely at these assertions, particular facts support not only the contention that processes of normalisation are an integral part of educational sorting, but that they are also implicated heavily in respect of placement entitlement. For just as the historic 1944 Education Act established a framework of sorting, so too has the contemporary period of educational inclusion, led by the concept of 'educational need', rather than medical category (Warnock 1978, Parliament 1981, UNESCO 1994, Parliament 2001).

Thus educational and learning needs are contemporarily the cornerstone to the allocation of educational resources, and as discussed, can be foundational to the negation of mainstream entitlement, where need and capacity to meet that need are incongruent. Problematically the medicalisation of behaviour has blurred the formally simpler distinction between 'disability' and 'behaviour', demanding protocols that can discern which is which. These protocols however are themselves responsive to wider tensions, particularly those of a financial nature as parents in my study indicated. Leanne's case is illustrative, offering example of a family caught between differing explanatory discourses, which as Leanne recognises have serious implications in terms of accountability, resources and identity:

"I don't think the school know enough about the different types of disabilities, I don't think they look into it properly, I mean they know our son has been identified as having a developmental delay, but I don't think school see that as important as something like Asperger's, they just see him as naughty. Also if they can't get funding for it, they don't seem to want to help, I mean developmental delay isn't a big diagnosis, I think the schools seem to look better on some conditions than others. Even the support worker keeps asking if he has ADHD, but he's been tested for it every year since he was three, but because he is borderline he doesn't meet the funding criterion" (Leanne).

It appears therefore that although the explanatory frameworks rationalising marginalisation and exclusion have been led by shifts in medical political and social vision, the constraints of the economic core serve to undermine these. The support for vulnerable persons, both in and out of education was found wanting, considered by many to be responsive itself to a Neoliberal culture which prioritises individual

responsibility and by default accountability (Roulstone 2015; 2015, Tomlinson 2005, Garthwaite 2011, Hirschmann 2016). Welfare and its denial appear to operate in synchronicity with the peaks and troughs of the global economy, underpinned by the ethos of a capitalist market economy. This ethos according to Tomlinson (2005) has rekindled 'human capital theory' resulting in the commodification of the individual and the demand that the individual 'invest in themselves' educationally for academic currency that can be exchanged for employment (pp 3). This emphasis not only devalues learning as an activity of itself, cognitive enrichment, it also devalues those who are unable to participate, leaving them vulnerable economically as well as accountable.

6.4 Conclusion

'Formal knowing' in the mainstream was indicated by teachers to be inconsistent in relation to unconditional acceptance of disability classifications per se, indeed these were found to be highly responsive to personal experience, training and work based experience and wider tensions and responsibilities. Of great concern was the effects of 'formal knowing' in particular the disadvantages bestowed onto certain populations, most typically in the form of accountability and exclusionary response. Although vulnerability to exclusion was found to be mediated by the resources parents held, overall it was the impact of a pupil's difference which appeared to cause teachers greatest concern. Notably teachers rarely indicated concern toward the reasons for 'challenging behaviour' but limited their concerns to the practicality of managing 'behaviour'. On the whole teachers and SENCOs tended toward a contextually bound understanding of the pupil and the differences displayed. Looking back at participating parents narrative, one can trace the impact of such responses and the communication gulf it engendered.

Although teachers indicated awareness of negative factors that were considered contributory to the appearance of behavioural difference and challenge, there was very little awareness of any systemic factors which may also be contributory. This was taken as further indication that schools were operating on an integrative model rather than an inclusive model. For example despite schools employing strategies to retain a pupil, the onus for change remained firmly on the pupil and his/her family. Neither was parental or pupil 'voice' indicated to be a source of 'formal knowing',

despite judgements about the pupil and the family being central to such knowing. Thus the evidence informing 'knowing' was brokered predominantly through professional lenses. A partiality which appeared to deter any holistic appreciation of the familial impact of behavioural difference, or the efforts families made to ameliorate their effects. As such there were few effective channels open that were able to effect a credible challenge to the tendency to accord accountability, mirroring the voicelessness that Thomas (2005) in Caslin (2014) identified. This review now turns attention to 'formal knowing' in the special sector to determine if the same tensions and responsibilities actively shape the nature of 'formal knowing', in a context where all are 'special'.

Looking at the opinions expressed by teachers it would appear that formal knowing is directed by wider factors than child presentation. Certainly resources are found to be an issue, as are a limit to practical contingencies to manage 'difficult difference' (Rogers 2013, pp 132). Returning to Arnold (2009), the impact of these contingencies resonates with the acknowledgement expressed by an Italian teacher to Arnold that even though there is no protocol under the Italian system for exclusion, the contingencies faced by the teaching profession in the UK would, if introduced into the Italian system make necessary similar responses. Mindful of this sentiment it is possible to step back from the primacy of attitudes to medical labels and begin to form an alternative explanation for schools intolerance to behavioural disabilities.

From the responses generated amongst teachers, it is also possible to detect a level of frustration at the inability of mainstream schools to provide adequately for the pupils who require significant support. It is interesting that some staffs began to suggest that the special sector was the most appropriate sector to place these children in. For at these junctures one can see that parents and teachers appear to agree. I would argue however that such faith is misdirected and would be better employed addressing the root causes of resource scarcity and indeed the priorities mainstream schools are being harnessed for. In summation it is concluded that the knowing in the formal sector was not only led by presenting difference, it was directly referenced back to the implication of that difference on the other presenting tensions teachers in mainstream schools are subject to (Tomlinson 2005, Youdell 2011, Slee 2013b, Runswick – Cole 2014). This observation also offers a different perspective from which to view the propensity of schools in the mainstream to issue what are

termed 'illegal exclusions' (OCC 2013, AA 2014). For it may equally be seen as the only means by which a school can retain a pupil and also met the wider responsibilities levelled.

This position, not only stems from the awareness of parallel professional responsibilities, it extends from the engagement I have had with schools as a parent, where indeed I found the capacity for greater leverage extended where there was willingness of both parties to engage in open and honest dialogue that is acknowledging of the practical realities faced by schools and by parents. What is notable from parents narrative is that once a mutual position of defence is established the potential for productive dialogue is impaired, leading to a culture of blame which serves to further disadvantage a child. As both parents and teaching staff in the mainstream indicated faith in the special sector to manage more efficiently the needs of children with serious behavioural differences, it is pertinent to now direct attention to this sector. Chapter seven discusses the types of knowing expressed by teachers and observed by myself during my observational placements in two discrete school contexts; an independent special school and a pupil referral unit.

Chapter 7: The shape of ‘formal ‘knowing’ in the in the special sector

In this chapter I share my personal experience of the ‘special’ sector including the observations recorded during two volunteer placements, the first in an Independent Special School (ISS), and the second in a Pupil Referral Unit (PRU). Section one outlines my personal experiences of the ‘special school/college’ context, and suggests that even in the special sector there were qualifications to placement entitlement observed for pupils exhibiting behavioural difficulties as well as evidence of parental accountability. I explore what is ‘special’ about the ‘special’ sector and offer a rationale as to why engagement in the special sector was a core aspect of my research. Section two introduces the ISS and the PRU, whilst section three explores the implications of these observations on ‘formal knowing’. Section four concludes with a consideration of what was deemed special in these two differing contexts, suggesting that in the context of the ISS, all and none of the children are special. However in direct contrast, in the context of the PRU, I observed specialist pedagogy. This, I argue, offers a feasible alternative to the current sanction led system of control commonly employed in mainstream settings. A system which results in cumulative consequences for children with behavioural differences, which serve to legitimate a negation of their educational rights as laid down by UNICEF (1989).

7.1 Section one: Drawing upon personal experience of ‘special education’

The parents I interviewed expressed significant faith in the special sector and it was considered the solution to failings and discrimination they had encountered in mainstream schooling. These failings were related to not only how their children were ‘formally known’, but also how they were received. Of particular concern were lack of friendship opportunities and selective acceptance by staff, pupils and other parents. I too was swayed by these concerns, yet I was dissuaded at the eleventh hour from accepting the special school route for my son at secondary level. This decision continues to raise doubts. Nevertheless, following several occasions when my son’s mainstream provision was suspended and eventually deemed untenable, my son attended a disability specialist college at the age of sixteen. This was a placement we invested great faith in, yet it left us with a sense of disappointment. Why? Because despite its

claim of inclusivity, tailored for young people with autism, exclusory practices were as evident there as in mainstream school. Equally the understanding and social opportunities that we anticipated did not materialise. My son was what is termed 'high functioning', and was too able intellectually to assimilate seamlessly with what were a majority of less able peers. Subsequently he found the experience traumatic and demoralising, stress which rapidly impacted on his behaviour.

It became apparent that there was no dedicated provision for this group of learners. I also found that neither the manual on ASDs, nor the Masters programme the college was involved with had led to an appreciation of 'atypical' autism. It quickly became obvious that atypically may act as an indicator of autism, but as a condition the diagnostic protocols and ensuing expectations surrounding a classification rely heavily on the dominant criteria specified. Essentially 'formal knowing' of my son's condition was dependent on that pertaining to professional diagnostic manuals, other professional experiences and the stock of what each professional thought they knew. My son was essentially not a typical 'atypical' person and in almost all contexts of his life, he was neither 'normal', nor typically autistic as is commonly understood outside of the medical profession. It felt at that point that the worst scenarios of labelling theory were being reaped upon us as a family, yet despite the concerns toward medical and SEN labels (Dyson and Kozleski 2008, Slee 2013), what was less readily considered was the impact of challenging a label medically given.

7.1.1 Hopes and reality

Following several 'incidents' or more aptly 'allegations' my son was excluded from this 'specialist college', only returning following an informal appeal to senior management, who serendipitously I had forged professional connections with in a different context. Nevertheless on returning it was soon apparent that neither the college staff nor my son were comfortable with the placement's continuance. Facing the onset of a new academic year, the offer of attending a local college chaperoned by a teaching assistant from the specialist college was made, and accepted. This lasted less than four weeks, due chiefly to the high visibility my son as a supported student had. This visibility caused such distress that my son refused to attend, turning his back on education. I might add at this point in his life he had never completed an academic year in either mainstream

or the special sector. It was at this juncture that I came to appreciate the untenable position he and others similarly placed were in. Looking back at how these difficulties were resolved three aspects in particular stand out.

Firstly looking reflexively at my role as a parent, in retrospect I could identify that my actions resembled those observed by Nind (2008) and Holt (2010a): the ability and motivation of suitably skilled parents to reduce the disadvantages disability and behavioural difficulties can effect by drawing upon their own skills and connections. Personally, despite an escalating concern that all educational placements were similar, rendering my son and others similar in disposition potentially uneducable, I sought and secured another placement for my son in a neighbouring college.

At that time I was driven to resolve the situation faced, yet looking back I can see how fortunately I was positioned. I had little dependency on aligned professionals to advocate, held the ear of the local authority and was hence in a position to make arrangements with a neighbouring institution in my son's best interests. Leslie Henderson in interview spoke of pockets of good fortune, often when least expected, but which she and other parents found they could not depend on. It was also told to me that it was the lottery of provision that was an impetus to offering services. This idea of inconsistency and unanticipated support was demonstrated to me, when in desperation we approached a local Further Education college as a last resort and it transpired to illustrate Leslie Henderson's point. Unlike our past experiences at more prestigious colleges this Further Education College uncharacteristically inclusive. This college enrolled my son without undue chaperoning, claiming an ability to manage diversity as standard. Over four years they have demonstrated this ability, yet rarely advertise their approach to be a skill. Nevertheless over the course of this research I have been humbled by the many families that were not so fortunate: who through limited resources to effect influence, had to accept outcomes for their children that were less than ideal and certainly not just.

Secondly, re-visiting the extreme visibility my son had experienced I was minded of Goffman's (1968b) writing on stigma. In particular the suggestion that all societies and social collectives within, categorise the attributes of 'ordinary' (or more simply in-group attributes) as a means to determine group membership. Such action irrevocably opens spaces for identifying the absence

of such attributes. Indeed Goffman suggests it is the absence of identified attributes, which legitimates a person's diminishment, rendering them 'tainted' and 'discounted' (pp 12). Following Goffman's logic, it would appear then that exclusion is an inevitable part of social life. For my son this manifested as a tainted educational and disability profile, one which was cumulative and thus enduring.

Thirdly, seeking understanding toward the resistance and challenge to my son's diagnosis of 'atypical' autism (as detailed in Chapter one), rather than being founded on an informed medical basis, such challenge appeared founded on a diagnostic expectation and the inability of my son to meet that expectation. As such it was reminiscent of Rosenhan's (1974) infamous study 'being sane in insane places'. Rosenhan's study, although a classic piece of research, illustrates how once a deficit label or tendency is identified, it can act as an explanatory filter, colouring all other observations and effecting a resistance to movement beyond the identity it engenders. Rosenhan's findings elucidate how a diagnosis sets in motion a chain of expectation, which is directional of 'formal knowing'. Hence where presentations are incongruent with such 'formal knowing', this acts as an impetus to individualised disability challenge, rather than classificatory challenge.

7.1.2 The search for explanations

Looking back at my son's childhood, his differences not only contrasted against others 'sameness', leading to judgements around implication, but also from the ideals of 'sameness' within a disability classification. My son's ability and indeed disability label was compatible with the type of student an inclusive mainstream school and college is qualified to admit. The underappreciated side effects of his diagnosis - 'behaviour' (Vargas 2013, Berg-Dallara 2014) set him apart in the mainstream, just as his functioning ability set him apart in a special school. Both contexts led to incongruent 'knowing', which did not lead to cognitive adjustment or 'special knowing', it just served to fuel individualised and familial accountability where failings to conform to type frustrated the professionals involved in his care.

Scholars of group dynamics focus on the subtle ways membership is brokered (Tajfel, 1982) and suggest that it is 'membership' commonality and predictability, founded upon group norms that foster cohesion, serving to 'other' those who do

not fit. Hence even without a medical label to explain difference, it is likely my son would have remained an outsider. Indeed the philosophy behind group dynamics challenge the contention that it is labels themselves which typify and generate expectations (OFSTED 2010, Slee 2013, Goode 2014). Boyle (2013) cautions the 'overuse of labels depersonalizes the individuality of each person who receives a label' (pp2). However theories of group dynamics suggest individuality may function to typify 'sameness', fostering a commonality which is essential for group cohesion. Indeed Goodley and Runswick – Cole (2016) suggest difference to be a consolidating force for sameness and is fundamental to their current theorising around the differing forms that dis/ability take. Pinchevski (2005) argues similarly, suggesting that the boundaries of autism serve to define communicability. Such sentiment highlights further the collaborative and constructed nature of what is or is not acceptable difference. It thus offers an alternative way to think about disability challenge outside of a medical framework.

Looking at the core tenets of social representations theory, I was struck at the extent to which a disability diagnosis resembles the form social representation are imputed to hold. This observation is based on Moscovici's (2000) two main contentions, the substance of which resonated with experiences I had personally experienced, most notably in relation to the expectations which ensued from my son's diagnostic labels. The first contention is the claim that social representations (SR) 'conventionalize the persons, objects and events we encounter, they give them a definite form' (pp23). Thinking specifically of neurodevelopmental conditions such as autism - which lack organic markers - their form appears best typified as a social representation, particularly as it is this 'formal knowing' of the label which binds it as an entity. Hence Moscovici's second contention that SRs consist of a 'structure' ... 'which decrees what we should think' (ibid pp 23) would also appear appropriate toward these classifications of disability and also offers an explanation for their fluidity and vulnerability to challenge.

7.1.3 Discrimination?

If the tendency to categorise and group is an innate human inclination can these processes be viewed as discriminative? Looking at the history of disability and the injustices which have been levelled and justified on the basis of difference

(Stiker 1997, Armstrong 2003, Borsay 2005, Foucault 2006)? I believe so. This is particularly so where social tendency to secure group unity results in the marginalisation of those deemed 'different', in spite of such an outcome being considered morally reprehensible as it is contemporarily. Modern equality and anti-discrimination legislation is illustrative of how a developed society guards against such processes (Parliament 1995, 2001, 2010), yet it is less clear what solutions can be sought where this legislation factors in criteria which operate to legitimate the segregation of a given population in a manner which is the very antithesis of its core tenets. Thus despite O'Connell's (2016) contention that 'the legal protection of equality rights is potentially transformed as social explanations of disadvantage are replaced with biological ones' (pp2). Such change has not only failed to materialise where behaviour is of issue, the expectations which coalesce around behaviour can serve to generate expectations which act to further discriminate and consolidate negative identities.

Thus as O'Connell finds 'the turn to a brain-based approach to identity is creating new forms of stigma and inequality for the child or youth with behavioural disabilities (ibid). Such disadvantage is hard to rationalise within a medical model, yet is progressively recognised in the area of criminal justice. In this context it is increasingly found that offenders with neurodevelopmental disabilities are considered less suited to rehabilitation programmes. Such exclusion may be seen to stem from the 'formal knowing' that surrounds certain disability classifications; 'knowing' which serves to position some disabilities to be unamenable to rehabilitative programmes. 'Formal knowing' in this context sets in motion a chain of determinism which has major ramifications for individual liberty (Loucks 2007, Bishop 2008, Hughes 2012, NACRO 2011, Wasik 2015). O'Connell charts the locus of such determinism to professional contentions about how malleable or not the brain is, commonly termed plasticity. As such this 'formal knowing' serves to negate any mitigating benefits that may arise from an ongoing association between the structure of the brain and behaviour. Thus even where accountability is medically negated, it has wider ramifications in respect of control, which the logic of medical science by default legitimate. The deterministic logic of O'Connell's observation, expanded my own understanding of my son's ineducable status for the vast part of his

secondary education. It also emphasised to me the value of pedagogical flexibility and open mindedness in the formation of 'formal knowing'. Such creativity was finally found in a mainstream college: this college held itself to be highly inclusive and both promoted and supported teachers to develop individual pedagogical strategies, based their own 'knowing' of their pupils, rather than being guided by medical or learning labels. This approach circumvented the 'negative truths' that had dogged my son's school career, inhibited any real inclusivity in all the other contexts, including the special sector.

It is useful when thinking of 'formal knowing' to consider it in the plural and to visualise it as at times competing discourses. This is reminiscent of Foucault's (2000) theory of the relationship between truth and power. For Foucault, 'truth' was not a singular tangible discovery; rather it emerged from the interplay of relationships of power:

'Truth isn't outside power or lacking in power... Truth is a thing of this world: it is produced only by virtue of multiple forms of constraint. And it induces regular effects of power'... Each society has its regime of truth, its "general politics" of truth – that is, the types of discourse it accepts and makes function as true' (pp 131).

A contemporary example is the nature/nurture divide teachers expressed in my study's data. A further example is the dual discourses in education of the problem of behaviour resultant from poor discipline (Birbalsingh 2006, HCC 2011, DfE 2012d, Ofsted 2012, 2014a) and that resultant from disability (CEBRA 2013, BIBIC 2005; 2011, DfE 2015a). Both channels of knowing is considered by its protagonist to be a valid truth claim: and each is productive of a stock of 'formal knowing' which is definitional of the individual. For example this teacher makes broad claims to 'knowing', which at face value suggest 'truth', but at closer inspection, may be considered mere opinion:

"My form all eat chocolate/crisps/sweets and drink energy drinks from 8am onwards. Home life, social development = a huge factor in mental health issues, diet during pregnancy, family problems – divorced/single parents can lead to mental health issues/self-esteem".

Claims to truth are significant toward both 'knowing' and future 'knowing', not only in respect of their content, but of the responses to difference which are sanctioned in their name and the tensions these ensue. Smith (2015) indicates that tendencies to confer familial accountability challenges the certainties of neurological claims, whilst conversely O'Connell cautions that neurological

explanations for behaviour serve to detract from social disadvantages with which they are disproportionately linked.

Looking back at my own experience I could identify these dual discourses in operation. For example my son's conduct in school was not only driven by a combination of autism and ADHD, it was also channelled by the social disadvantages he faced, not only in respect of peer relations, but also pupil teacher engagement. Nevertheless in formal meetings, explanation for 'incidents' focused predominantly on the medical labels he held and the 'formal knowing' that surrounded them, thus deflecting any organisational failing.

The acceptance of a particular frame of knowing was also indicated by parents to inhibit other forms of explanation for difference. Parents told that where schools considered that they were 'the problem', this 'knowing' was a barrier to the pursuit of potential medical explanations. Overall the tensions and processes between differing frames of 'formal knowing' is most clearly illustrated by Micha's story (pp, 416), as it shows how differing 'truth' frames can operate in conjunction and indeed determine the nature of surveillance. Notably the protocol in Micha's instance appeared to be guilty until proven innocent.

For myself the resolution of these competing discourses resulted in our (familial) exoneration. However it left my son 'formally known' as a risk that was for most of his educational providers just too great. Paradoxically these calculations were based not only on misdemeanours he had caused, but on ones he 'might' cause. This emphasised further how 'formal knowing' can be flexible and vulnerable to inference. Paradoxically the outcome for my son would have been better if as a family we had been viewed accountable, but our exoneration added weight to a deterministic medical lens. In the context of a childhood and the right to education (UNICEF 1989), the combination of 'behaviour' exhibited, 'behaviour' that 'might' be exhibited and intellectual competency rendered in our case our son devoid of any suitable educational provision, or educational context. He was essentially too 'special' for mainstream and not sufficiently 'special' for special school. To interrogate further this seemingly irreconcilable incompatibility I resolved to explore in more depth the context of the special sector.

7.1.4 Moving forward in a research capacity

Personal experience has suggested to me that the special sector held the same qualifications to placement security as the mainstream. I was therefore keen to explore more fully the basis of its claim to specialness, not as an outsider or a parent, but from within. This was particularly pertinent as during my son's placement at a 'special' college, parents were rarely permitted to spend time in the college unchaperoned. Hence although I was familiar as a parent and aware academically of ongoing arguments which both defended and condemned the continuation of specialist provision, I was keen to situate myself in the settings as a researcher – thus offering a different perspective than that of a parent.

Having interviewed both the head and deputy head of the ISS as part of a Masters Research project (see Chapter one), I drew upon these connections to facilitate access as both a volunteer and a researcher. I was less familiar with the PRU, knowing it only through reputation; typically as somewhere the 'naughty' children were sent. The PRU is positioned as the last resort and operates in an advisory capacity, not only to determine needs, but to broker a move to an appropriate permanent placement. As the location of choice for pupils when all other educational options have failed, I wanted to experience the PRU as a working school. I particularly sought to explore what types of 'formal knowing' surrounded its pupils and the extent to which their behavioural difficulties conjured any association(s) with disability.

Significantly although my son's challenges presented in school as 'behaviour', he held several diagnoses and a statement of special educational need. This made him incompatible with the assessment remit of the PRU. Thus my son's 'behaviour' jeopardised his mainstream school placement and also 'inhibited acceptance into a special school like the ISS. Whilst paradoxically disability recognition rendered him incompatible with the PRU and other local schools for pupils with EBD. He was a poor fit in all sectors of the education system and the recognition that this position was not unique to him was foundational to my assertion that the category 'ineducable' still exists, albeit informally in relation to pupils who through a combination of academic ability, disability and behaviour are a poor fit in all sectors of school provision. It was at this juncture that the implications of incongruence between academic ability and social ability is most obvious, as they emerge as equally essential for successful school progress,

yet as Green (2008b) emphasises, the former does not necessarily imply the latter and there appears to be no educational contingency plan to compensate.

7.1.5 Unanswered Questions

Many of the challenges my son faced (as noted in Chapter 5) were similar in constitution to those that teachers in mainstream settings expressed. These included not only challenge to particular diagnostic classifications, but also to the reasonableness of diagnosis and indeed motivation for diagnosis. Hence having been advised during the primary years by both teachers and the SENCO to seek placement for my son in the specialist sector, then having being dissuaded from doing so by staff at his eventual secondary school, it remained an unanswered question as to whether my son would have been differently understood as a younger child in the special sector, altering the life trajectory he eventually followed.

To explore 'formal knowing' in the special sector from unfettered observation, rather than mediated by a formal research structure, I offered my services as a classroom volunteer, firstly at the ISS and secondly at the local PRU. I entered both schools with the intent of observing in a working environment, not only the understandings that accrued around disability and behaviour, but also how these understandings were negotiated during daily school routine. I thus devoted one day a week and fully engaged with this role across two and a half academic years (one year at the ISS and one and a half years at the PRU). The placements were chosen to offer a contrast of provision given the very different populations they cater for.

I considered there was opportunity to gain a more natural impression of the special sector as a 'hands on' volunteer, as this particular approach circumvents the pressures and interruptions which are inherent to more formal data collection methods (Bryman 2008). Spradley (2016) describes ethnography to be 'the work of describing a culture' (pp3) and indeed this was my ambition. I aimed to view and generate an understanding of the cultures of 'knowing' that permeated the special sector.

7.2 Section two: Introducing the ISS and the PRU

The ISS is part of a wider charitable foundation which enjoys an esteemed profile both within and without its locality. It caters for both primary and secondary students ranging in age from 3 – 14 (lower school) and 14 – 19

(upper school). This stands in direct contrast to the PRU, which I was informed by staff is the subject of local complaints, intimating a negative profile in the locality. The PRU is described by the local authority as a maintained special school, catering for pupils aged 5 – 16 years of age. The legal remit under section 19 of the 1996 Education Act, is ‘to provide education to children of compulsory school age, who on account of illness, exclusion or for other reasons, are unable to attend mainstream school’ (Bureau 2011 pp 5). Despite this broad remit, the PRU caters mainly for and is associated with, pupils who have been excluded from mainstream schooling.

The ISS hosts two pupil populations, broadly divided between physical and developmental disabilities, totalling 160 pupils. It also hosts a small residential unit offering respite care with provision for 18 boarders. Students in the ISS are grouped according to these disability divisions until Key Stage Four, whereupon grouping is based on accredited course participation. In contrast the PRU groups pupils according to key stage development, and although it does not offer single year classes, it maintains the curricular structure of mainstream schooling. Notably the PRU does not have capacity to offer respite facilities, which given the strains parents in my study outlined seemed questionable. Nevertheless it did explain why a group of parents I interviewed had organised between themselves a rota to provide informal emergency respite services as was noted in Chapter five (pg. 383).

Deficiency was a theme echoed by Leslie Henderson who stated “I found there was a lack of any joined up support network readily available to families at often crisis point, and this was the chief impetus to the founding of the trust”.

Teachers and parents in my study also spoke of ‘lack’, most specifically for teachers lack of wider agency support and lack of in-class support. For parents, lack manifested as both tangible and emotive. Specifically lack of understanding of their child and their needs, as well as lack of practical help. For both parties it was a test of resourcefulness, stretching parental and pedagogical skills.

Nevertheless parents and teachers were affected differently, lack for parents was personal and spoke of impact on their children and for those parents who were able, ‘lack’ was an impetus to adaptability and proactivity. For less skilled parents, lack became all-consuming and engendered further dependency.

Teachers on the other hand experienced ‘lack’ in relation to impact on their

professional role and perceived ability to support all pupils. These effects appeared heightened in the mainstream where there was an expressed indication of pressure to deliver all demands placed upon the teaching role, with insufficient resources as Marie's comment illustrates:

"I just think there should be more in the actual initial training, more in the way of awareness, and I think there needs to be more ongoing professional training/development. Unfortunately where that falls down is that there are already so many pressures coming in from here there and everywhere, so any training needs, you know you have your government agenda, OFSTED, you know you have all of those things which tend to be prioritised, before any address of individual needs in the classroom sadly and it means that some children are disadvantaged for the benefit of the majority".

Klehm (2014) found that the expectations that teachers have of a pupil were a major variable impacting on pupil outcomes. These expectations were found linked to what teachers believed to be the cause of the child's difficulties difficulty. Klehm's research suggests that 'formal knowing' extends in impact beyond simple reference ('knowing'), but is engaged with by teachers and parents in a manner which is generative of outcomes congruent with such 'knowing'. Teachers and SENCOs offered impression that their confidence to retain a pupil and to take responsibility for their own pedagogy was linked to the level of dependency they had on medical explanations, and medical solutions to difference. It was also notable that teachers in my study indicated professional and personal familiarity with disability classifications to be an important factor in their confidence to respond effectively to the presenting difficulties that children displayed.

For parents, the personal and educational resources they held, in terms of education, school networking and wider connections not only impacted on their adaptability, but as Nind (2008) observed, impacted also on the rights parents felt their children had. Similarly parental resources had an impression on teachers and as Cook (2004) found coloured teachers perceptions of not only the cause of the child's difficulties, but also the entitlement of the child to be retained in school (Cook 2001, 2004). Parents in my study unsurprisingly indicated a reliance on medical input during the diagnostic period, yet unlike teachers in the mainstream showed a lesser dependency on medical input once an initial diagnosis was made.

Although these differing responses and dependencies are guided by the role and contexts of the differing parties, their ensuing interaction can usefully be

viewed as the building blocks of 'formal knowing'. Yet as is shown for teachers in the mainstream 'knowing' is shaped as much by wider variables as well as the individual difficulties presented by the child. In contrast in both contexts of the special sector, a subtle difference of confidence was detected. Teachers exuded an air of specialist knowledge, they were unfazed by the extreme behaviours and medical needs the children presented and indeed such confidence appeared expected. Teachers in this context indicated great pride in their ability to educate children that the mainstream could not, thus informally such competency appeared to be a pre-requisite of the role in the special sector. This taken for granted ability was subtly expressed during informal conversations. These frequently revolved around teacher and institutional failings in the mainstream, which were contrasted against the practices held to be 'special' in the 'special sector'. These process of comparison was a source of great pride for staff in both the ISS and the PRU, offering spaces for mutual affirmation of the alternative educational provision both schools were offering.

7.2.1 Characteristics

The ISS resided on two sites, both situated within densely populated urban areas which hosted pockets of social and economic deprivation. Catchment, however, was not geographically determined as children were admitted on the basis of disability/learning need and frequently lived outside of the locality. All pupils within the ISS held a statement of special educational need (now known as an EHC) and funding was most frequently provided by the pupils own local authority and based on the calculation of need and ability of the school to meet that need. There was also a precedence for private fee paying, as I observed during my research, as a consequence of the placement funding being disputed by a family's local authority.

The PRU in contrast was situated in an area of significant economic disadvantage: a location which appeared to add to the ambience of disaffection. PRUs are funded by and cater for pupils largely from within the local authority of the child's residency and cater for disproportionate numbers of pupils who have been excluded from mainstream school on account of negative behaviours. These are rarely stated to derive from a disability and it has been estimated that 75% of PRU pupils nationally have SEN and of those 62% hold long-term unresolved EBD (Bureau 2011). These figures are congruent with the profile of

pupils deemed vulnerable to mainstream exclusion and the association of exclusion with 'behaviour' (DfE 2013b, 2015b, 2016). Nevertheless the introduction of a new SEN code of conduct (DfE 2015a) may change these demographics as it exacts new responsibilities of schools to aim to attribute 'behaviour' to an underlying driver.

During my time at the PRU there was a notable absence of association between 'behaviour' and disability, which I was keen to explore, particularly as disability and SEN are known to impact on behaviour (CEBRA 2013). I was interested to know to what extent the PRU actively sought medical explanations for conduct, or whether other discourses were dominant. Notably the nature of discourses operational in the context of a PRU is also intimated by the National Childrens Bureau (2011), stating that the main source of pupil difficulties in PRUs extend from a combination of environmental causes, particularly a lack of adequate parenting and trauma consequent upon loss or bereavement. Such claims further suggest that disability and SEN are not considered primary drivers in this context, raising the question as to whether its absence was because environmental factors were deemed primary, perhaps deflecting a motivation to seek medicalised explanations.

The PRU I attended drew a disproportionate number of pupils from the immediate area, many of these were 'pupil premium' children, a term used to describe pupils considered 'disadvantaged'. This is based on stated criteria and involves 'looked after' children, pupils in receipt of FSM over the previous six years or those who have a parent serving in the armed forces. Yet although pupil premium extends across a wide range of disadvantages, the characteristics of children in the PRU I observed were mainly pupils entitled to FSM.

There was notably an absence of 'advantaged' children, either in terms of disposable income or cultural abilities. This necessitated questioning as to whether behavioural difficulties were less frequently occurring amongst more advantaged children, or being managed differently through effective parental and professional advocacy. Certainly several parents in my study indicated that they had positioned themselves strategically to effect influence. This was most clearly evident in regards of Saz's training initiative (pp 383), whilst a similar motivation was indicated by another parent Andy:

“It’s hard because I don’t have a lot of contact with his teachers, I don’t go into school much, I have just started going in a bit more really. I have become a school governor, that’s a way of getting into school a bit more, otherwise I don’t get in”.

Parental proactivity was not a presence I observed either in the ISS or the PRU, nor was socio-economic or cultural advantage visible in the PRU. Notably when I raised these disparities informally with the class teacher (CT) at the PRU, there was broad agreement, although the CT did stress, “we do have a few middle class brats, Toby’s mum spends a fortune on clothes etc., and so does Lee’s”. I found this to be an interesting association of class with spending tendency, particularly where there was little spoken of education, attitude or overall culture. It appeared that a deficit culture was assumed, as another teacher stated “we are the kids stability, they don’t have any at home. You can see that on a Friday when they know they are home for the weekend”. Such a statement whilst sweeping, intimated the nature of taken for granted ‘formal knowing’ that appeared to be unquestioned in the PRU.

In contrast, parents at the ISS held varied backgrounds, education and socio-economic status. Hence one would have reasonably assumed a varied level of involvement as was evident amongst the families I interviewed. Nevertheless parental involvement appeared limited and unbalanced and parents appeared to concede to staffs ‘expert’ status. The demographic differences between contexts appeared significant and further suggests that ‘behaviour’ is linked to socio-economic and environmental disadvantage, whereas in contrast ‘disability’ cuts across all social groupings.

The randomness of disability is however challenged as demographic factors are found implicated toward both the prevalence and types of diagnosis recorded (Begeer 2009, Gould 2011, Heilker 2012, Miller 2014). Nevertheless in the context of admission to both these schools, it appeared that vulnerability to permanent exclusion was a more significant factor in terms of PRU entry, whilst medical evidence remained primary in respect of the ISS. These different admission criteria suggest ‘formal knowing’ precedes admission, making the stock of existing informal ‘knowing’ within the institutions highly significant. It also rendered pupils who have entered and left mainstream, dependent on their previous teachers ‘formal knowing’, the nature of which may as suggested in Chapter five is liable to be complex and potentially partial.

Conspicuously ISS policy restricted admittance of pupils with behavioural difficulties. As many of the speech and language children (SLC) held challenging behaviours, this policy appeared contradictory and raised questions about how determination of suitability was made and why. I was informed of this policy by the Head, who was not entirely clear, but did appear to associate certain disability classifications with 'behaviour' more than others:

"We can't cater for pupils with behaviour problems here, it's not suitable. I'm not saying that they don't deserve a suitable placement, but we could not accommodate them. We do have a speech and language sector, but the pupils there are predominantly autistic, we don't really offer provision for conditions such as ADHD etc". [HT ISS].

The PRU in contrast appeared to deal exclusively with behaviour, yet notably less so with the identification of disability. Although there is no stated admission criteria per se, referral protocol suggests a vulnerability to permanent exclusion is standard, based predominantly on behavioural issues. Funding was not an issue at the PRU, not in respect of pupil fees. This is unsurprising as the PRU is under the jurisdiction of the local authority. The PRU may be seen to provide other benefits as well. It reduces not only the appearance of disorder in the mainstream, but fulfils the statutory duty on the local authority to find alternative provision for those pupils permanently excluded. These were considered practicalities that could not be dismissed in relation to how 'formal knowing' develops.

7.2.2 Introductions and impressions

The lower school of the ISS extended across a significant space in a desirable residential area, situated directly adjacent to the local church which it maintained close links with. The building was set on two levels and maintained to a high standard. Nevertheless the first thing I noticed upon entering the ISS was the smell, it was dramatically different to the traditional smell of a primary school. It was hard to define, a clinical smell reminiscent of the geriatric wards at our local hospital. I found this disconcerting, it was not the normal smells of childhood and this featured on its own as highly poignant. A further feature was the lack of noise and bustle, the ISS hosts pupils with both physical and cognitive disabilities and the bustle typical of a mainstream school was absent.

I found joining the school as a classroom volunteer a huge role shift, being accustomed to entering schools as a parent and most particularly an advocate.

"Being in this school has conjured up mixed emotions, emotions that can be

traced to my own decision to educate my children in mainstream, despite advice to the contrary” [Personal observation records]. I was acutely aware of these emotions and wanted to guard against them, so they did not colour my observations, but during those initial impressions it was a challenge.

In contrast the PRU was contained in a one level semi modern flat-roofed building, situated on a council estate known to have significant levels of deprivation. At first glance the building appeared innocuous, although there was a group of ‘rough’ looking young people hanging around the exit in the yard. On arrival I was informed of building work to the roof and advised that incrementally students would take issue and climb onto it, similarly that the school was vulnerable to vandalism when closed. Staff jokingly referred to these works as ‘pupil proofing’.

Despite obvious reference to challenging behaviours, I was drawn to the proud exhibits of pupils academic work, there was also significant space devoted to life skills and wellbeing, appearing to emphasise a progressive forward looking approach which was a denial of the preconceived identity the PRU had locally as a ‘dead-end school’. The school corridors hosted displays of key staff, not only academic and pastoral, but external staff from the community. These included the nursing service, the local youth offending team, school counsellors and the visiting psychologist; emphasising the agencies most involved with the school. Indeed where the ISS had multi-agency medical support, the PRU had multi-agency social support. The wall displays contained various references to future careers and life pathways, and were situated amidst displays that reinforced school expectations and a need for good decisions. Particularly striking were the art exhibits which were of a calibre that would have befitted top set in mainstream, yet contrasted markedly with the failed school careers the artists held. I was intrigued, having considered the PRU a punitive environment, the impression gained on entry conveyed the exact opposite and suggested not failure but hope and second chances.

It appeared that the localities of these very different schools reflected the functions and clientele that they typically served, although assumed a likely coincidence, it felt significant. Nevertheless later in my placement its location appeared less random and most definitely reflective of the social position the parents and pupils held. These suspicions led me to ponder as to whether the

PRU serves to reflect failed school careers, existing as a vital link in the reproduction and maintenance of social and educational inequalities? Youdell (2011) addressing similar concern, states education is neither neutral nor benign. Rather it is metered on the basis of judgements made, official knowledges which serve to legitimate and perpetuate inequalities. The PRU as a discrete sector of educational provision is a prime example. Pupils are admitted on the basis of what is already determined, thus the notion of it being an assessment centre for the further generation of 'formal knowledge' is somewhat challenged. Notably the identities created by attendance at a PRU are also enduring, reproduced with every job application, further education enrolment etc. Thus forth, the acceptability of separate provision outside of a mainstream context is further jeopardised.

At the ISS there were seven male pupils in my class with speech and language disabilities, none had mobility issues although I was informed at least three of the boys had additional medical complications. The boys vaguely acknowledged me, but only as I was in their physical space. I noticed that one of the boys had 'one to one' support and appeared primarily the responsibility of the learning support assistant [LSA]. The other six boys appeared managed by the class teacher [CT]. My first impression was that there was no way that any of these boys could have managed successfully a mainstream placement, either socially or academically and essentially this militated against a completely common education system. Hence although Croll and Moses (2005) intimate the deliberate marginalisation of particular types of pupils from the umbrella of mainstream inclusion, it is premature to assume this to be a sinister rather than practical move. Indeed there is a steady support for the (pupil) benefits of separate and 'special' provisions (Warnock 2005, Cigman 2007) although Norwich (2008) visualises an integrated continuum of provision, rather than discrete sectors which holds promise to consolidate the expertise of both sectors.

Having alluded to mixed feelings about separate provision I remained drawn in both directions, yet troublingly my opinions began to change after a few months at the ISS. I became increasingly concerned at the opportunity for both emotional and physical abuse, which was unchecked due to the limited intellectual and communication skills of the pupil population. At times staff

indicted an impatience which as an outsider I considered unwarranted, yet despite the presence of other staff, this did not appear to raise comment. It was at this point the issue of vulnerability from separate provision really revealed itself.

Both the ISS and the PRU may be described as multidisciplinary organisations, the ISS offering therapeutic services as well as education; the PRU mainly social supports. These impacted heavily, but differently on classroom management and jurisdictions. At the ISS there was a more obvious presence and this interrupted not only the autonomy of the class teacher, but the shape of what was 'formally known', such knowing appeared mediated and at times incongruent and it there was a notable tension at given times between professionals in regards to the 'right way' to engage with the pupils. This was most obvious in relation to the involvement of the speech and language therapists [SALT], engendering an overlap of input within literacy and English provision.

Having been exposed to classroom politics from the perspective of a parent it was interesting to observe from a different stance the impact of different personalities and more importantly, individual teachers interpretation and enactment of their schools codes of conduct around issues of culpability and behavioural attributions. Hence whilst the disadvantaged population of pupils in the PRU reinforced Riddell's (2011) claim that disproportionalities promote and reflect wider economic and social inequalities, there was further suggestion that individual personalities distorted the interpretation of school protocols within the institution (Waterhouse 2004). Untypically in the ISS more than the PRU differentiations were observed which disturbed the notion of a unitary code of conduct. The same behaviours exhibited by different children resulted in varied responses, which supported a growing suspicion that it was each teacher's stock of 'formal knowing' which guided attributions and responses. These understandings linked very clearly to the relationship that teachers felt they had with the children's parents and it was telling that teachers were less tolerant toward pupils where there was ongoing tensions with parents. One boy in particular in the ISS was considered to be a trouble maker and accused of telling tales to his parents, even though he did not have the cognitive skills to do so. I observed on several occasions how staff were more ready to scold this boy

and indeed imputed wilfulness to many actions, which they did not hold other children accountable for.

The adherence of both the ISS and the PRU to the structure and requirements of the national curriculum defied their identity as 'special' in terms of teaching content. At times the determination to evidence that given areas had been delivered bordered on absurd and suggested that neither context fully appreciated the realities of pupils they catered for. For some pupils this was at times to be demeaning and disavowing of the pupils difficulties.

One instance in particular stood out and involved a project on India. This project was a timetabled part of the national curriculum and common across all schools within the learning key stage range. The lesson involved a video on India, which the children did not watch or really understand. This was followed by highly guided work sheet exercises which the staff practically completed for the children. I was curious as to why this lesson appeared so important and was shocked to find that the reason was that it was earmarked for inclusion in the 'evidence file', yet other lessons were more ad hoc and at times abandoned.

Observing this lesson conjured mixed emotions, particularly as few of these children could conceive of another continent and culture; and even less would probably ever experience it first-hand. It brought to mind all of the future experiences these children would most probably never know and I felt it unjust to conduct a lesson in this manner solely for pedagogical 'evidence' when it was clearly of no interest or benefit to the children in the class.

Notably I had argued for many years that my son needed an individualised education that was tailored to the shortfalls we as parents had detected and I had until this point believed that this was more likely to be possible in a specialist environment. However on reflection I determined that there was more potential for differentiation in the mainstream, where differences were more noticeable.

The communication concerns identified in the ISS stood in stark contrast to the vocal abilities observed in the PRU. In common with the ISS, class sizes are equally small, yet unlike pupils at the ISS, my presence was immediately noticed, I was greeted with suspicion and curiosity. The classroom is a large square shaped room with desks in rows at one end; directly adjacent is soft

seating, known as the social area, in the adjacent corner are three desks that house computers, alongside a series of cupboards containing games and general stationary supplies. It is 'social time', the pupils, all boys are expected to be seated and engaged with each other, what they are doing is fighting, shouting and leaping on and off the sofas. Taking a deep breath I ask if this is for my benefit and am told maybe, but that they are often like this. First classroom impression is of the noise, disproportionate to the number of children within. I am also struck by the physicality displayed, the boys seemingly oblivious to each other's personal space, or any social niceties. I was initially sceptical to what extent engagement in this unit could socialise pupils into typical school behaviours and this initial display confirmed my scepticism to be well founded. Pupils gave the impression of 'feeding' from each other's energy, rising to and issuing peer challenges, rendering impractical the observation remit as described by the Head. The following diary entry is illustrative:

'Social time' involved drinks and biscuits, this was a flash point, the first of many. One of the boys felt short changed, which stimulated an immediate reaction. His cup was thrown contents and all and an outpouring of expletives followed. I was a little shocked, although no one else appears to be. 'Staff continue to drink their tea and discuss the days schedule amidst this interruption; these behaviours would result in an immediate reaction and possible exclusion from a mainstream school' [Phone note entry 04/12].

Because of my own personal experiences with challenging behaviour, it was hard to form an objective assessment of this outburst, or the staff's apparent unfazed attitude toward it. However over time, similar incidents served to demonstrate how the PRU left issues in the moment and in so doing enabled pupils to salvage positives from intervening negatives. From the beginning I did not detect any real blame accorded to the pupils, rather it was directed at the family, positioning the pupils almost as victims.

I broached the issue with a class teacher of why not only teenage but very young pupils find themselves failing in school and it was at this point that parental blame was first introduced as shown below:

R: "You've got to wonder what causes children so young to be this full of anger".
CT: "It's bad parenting and environment"

R: "There appears a lot of evidence to support the physical existence of behavioural conditions"

C'T: "It's the parents every time in my experience".

These assertions challenged the PRU's assessment remit as described by the Head, "although we are a pupil referral unit, part of the remit that we have developed here is to assess the kids". It quickly appeared that staff had a blueprint of 'formal knowledge' which acted as a conceptual map, reminiscent of Kelly's (1963) personal constructs, except in the context of the ISS and the PRU, these constructs were collectively negotiated and refined, forming part of a taken for granted 'formal knowledge'.

In both contexts the realities of management defied theory and was responsive to the primary needs the schools catered to. Teaching approaches and additional skills reflected these needs and this additional knowledge was something which might be termed 'special', but only through its absence in the mainstream. Hence whilst ISS staff were well equipped to respond medically to emergency situations, PRU staff were skilled in the art of diffusing situations.

The need of containment was reinforced by the pace of events that typified every session I attended in the PRU; it was intense and erratic. Staff had to be responsive in the moment and this rendered impractical the ability to deliver pre-planned lessons, as each session mutated at the direction of the pupils mood. In contrast the pace in the ISS at times was beyond slow, particularly as each pupil appeared equal in pace. I found this to be generative of a malaise that reduced not enabled momentum. This was another insightful moment as I considered the dynamics and diversity of the mainstream, whereupon 'formal knowledge' emerges from the interplay of differently able peers. There was a stilted atmosphere in the ISS and I felt more able peers may have encouraged momentum from the pupils. Similarly the combination of troubled behaviours common to the PRU left me unsure as to its advisability. In many ways it was an apprentice for the younger children, in an undesirable way and was by design distortive of any personal 'knowing' of the pupils, as in combination they affirmed the negative behaviours that led them to the PRU in the first place. As one staff member stated to me "this isn't education, it is barely containment"... [Staff comment/staff room].

7.2.3 Institutional identities

I wanted to explore what was special about the 'special' sector and why its evaluation was linked so fiercely to the support and challenge of inclusion (Clough and Corbett 2000, Barton 2005, Warnock 2005, MacBeath 2006, Leslie 2008, UNESCO 2008, Ferrer 2009). Paradoxically from the outset there appeared nothing pedagogically special (in terms of teaching approach) about the provision offered in the ISS. Although medically, the school met the needs of its pupils through multidisciplinary input which was factored in to the school day. Nevertheless in regards to teaching, bar pace and limited differentiation to academic ability, little specialist pedagogy was observed. There was in essence no magic wand, teachers were less intolerant to the difficulties the children exhibited. Indeed difficulties were expected, but there was no obvious teaching expertise that was different from mainstream teaching competencies. Indeed if anything the teachers in the ISS appeared to be under less pressure than teachers in the mainstream, as there were very small class sizes and a high adult to child ratio.

At the ISS I came to the conclusion that when all children are special, none are special. I had anticipated a heightened appreciation of disability effect, yet I noticed that staff were de-sensitised to disability type and effect. For example in my class there were seven boys of differing ages and acuteness of disability. Yet their difficulties did not appear to generate sympathy, or even empathy. In fact there seemed to be a lack of wanting to understand the realities of these boys lives, staff exuded an air of indifference and at times irritation. This contrasted markedly with my experience of mainstream schooling, where my son's differences rendered him 'untypical' and eligible for reasonable adjustments. In contrast pupils by virtue of being on roll at the ISS appeared to have been given the ultimate 'reasonable adjustment', simply by being given a place in a special school. Also it became clear that pupils were expected to fit into the routine and protocols of the school. Indeed during my time at the ISS, the concept of 'reasonable adjustments' were never raised, which was a stark contrast to my experience of the mainstream, where in principle such adjustments were the substance of many review meetings.

At the ISS staff considered themselves to hold expertise in the management of disabled pupils and there was a notable academic impetus amongst staff that

exceeded internal professional training, the school supported many of its teachers to pursue wider academic qualifications: and many senior staff had completed or were completing Master's level qualifications/training in disability related programmes. This supported staff claims to expert status and their right to inform 'formal knowledge'. In combination the pre-existing status of the ISS and their staff's credentials served to legitimate the ISS's way of doing things. As on-going training was obligatory for all staff, expertise was a legitimate staff position, yet it also functioned to position parents as the recipients of such expertise, not equal contributors to it.

At the PRU, pupils were understood to be challenging, rather than disabled and disadvantaged through a combination of poor environment, questionable associations and insufficient parenting. Interestingly staff were rarely judgemental of the pupils, despite their high levels of criticality toward parents. Indeed on several occasions staff suggested that to work in mainstream with 'good pupils' would be boring. Staff referred to their pupils as 'spirited', yet it was rare that medical notions of disability would inform the 'knowing' of the child or the locus of difficulty.

In the PRU even where disability was known it did not automatically lead to a shift of understanding about the causes of 'behaviour'. Indeed it was observed to be resisted. Notably staff in the PRU, unlike the ISS, appeared less comfortable responding to disability effects and tended to focus on the outward manifestations (behaviour) with only occasional reference to the core disability identified. (Discussed further in section 6.2.5 looking at differing identities).

Unlike the ISS, the PRU appeared more pragmatic in its pursuit of the national curriculum and prioritised behavioural adjustment in the first instance as the following excerpt shows:

R: "They [pupils] don't appear to worry about consequences"

C/A: "They're not, they've so much crap in their lives, seen and done so much that this doesn't matter"

R: "If you don't catch them at this age though [KS2] there'll be no hope when they hit their teens"

C/A: "I'll catch up with some of them in a mental institution '] in a few years".

This type of conversation occurred regularly and suggested to me that the 'formal knowledge' of staff at the PRU extended beyond an educational remit: resembling in breadth more fully, a 'familial' way of knowing, centred on the

child's current and future prospects. Staff also exhibited a considered responsibility to divert future outcomes, as parents had also intimated. This expanded and finely nuanced interpretation of the teaching role appeared to me to extend beyond the boundaries of the teaching role as experienced in mainstream. It was further considered to support the contention that there was a 'specialness' to this particular special sector, which had been lacking at the ISS.

7.2.4 Issues of design

The physical design of both the PRU and the ISS reflected the types of 'knowing' associated with its 'typical' pupil cohorts. The interior of both buildings appeared designed to cater to the extremes of behavioural and medical emergencies. This served to reduce the need for phone calls home and also for school exclusions. These contingencies were also considered 'special' by me and indeed by the staff as indicated previously. It also exemplified a practical attitude to the realities of both schools pupil base, although by necessity the detail of contingencies varied. In the PRU classroom, doors were routinely bolted to keep both pupils in the classroom and other pupils out, but in times of severe behavioural emergency a senior member of staff would remove the child until calm. This dedicated member of staff was skilfully selected; benefiting an imposing physique, combined with a calm and gentle manner. During my time at the PRU I observed his infinite patience toward many of the city's most disturbed children.

In contrast at the ISS there was by necessity a lot of dedicated medical equipment and medical expertise. Staffs were unfazed by sudden fitting episodes or complicated medicine regimes. Nevertheless the most useful contingency I observed in both the ISS and the PRU was a dedicated 'calm space'. Unlike at the PRU where a member of staff would remove a pupil to a safe room, at the ISS this space was a low sensory room with crash mats and wall padding. It was host to numerous students experiencing extreme emotional episodes, yet notably was a solitary room. The door had a glass observation panel allowing staff to close it, whilst remaining vigilant whilst they waited for the pupil to calm down and indeed it was in constant use. It was unsettling to witness pupils in such a heightened state and I questioned their solitude. However over time I reasoned that this small practical adjustment enabled

pupils to remain on the premises and avoided the infamous phone call home. This utility was viewed by staff as purposeful, a statement that there was a contingency for the majority of eventualities, signalling a preparedness that set them apart from the limited coping skills that mainstream schooling was known for. As one of the longstanding psychologists at the ISS explained:

“I think it’s mad in mainstream that they [the school] accept pupils with known difficulties, get funding to support them and as soon as there is any problem they ring home and make the parents collect them. When they come here, most of our parents comment about how nice it is to know that they are unlikely to be called to the school and that we can cope with their children” [Psychologist ISS].

I concluded this small accommodation alone was grounds for asserting the ISS and the PRU to be special. Yet this was not something that required specific ‘expertise’. Rather it represented a structural adjustment linked to the ‘formal knowing’ of the pupil base, specifically that pupils were liable to have ‘incidents’ and that when these were during school hours, they were the responsibility of school.

This ‘knowing’ contrasted sharply with that of mainstream settings. In this context ‘typicality’ was defined through heady social and academic prescription in relation to conduct, dress and achievement. Yet when considered in relation to the number of pupils with an SEN statement and those subject to exclusion, ‘typicality’ appears less typical. It is hence reasonable to suggest that these prescriptions act to define typicality, rather than deriving from it. This is an observation which holds serious implications, as identification of SEN confers a negative learning profile, just as exclusion is generative of school failing.

This contrast in ‘knowing’ and expectation, emphasises how a change in priorities and expectations can reduce the need to meter individualised responsibility. So although the special sector may claim ‘specialness’ due to the ‘knowing’ prevalent in their respective contexts, it is not its substance which is special, rather it is the absence and resistance to such ‘knowing’ in the mainstream, rendering the barriers pupils face an organisational failing, not an individual one.

7.2.5 Differing sorts of 'special'

To what extent were pupils at the PRU and the ISS 'special'? In many ways their fixed identities had a commonality, yet differed. They were common because neither set of pupils appeared to 'fit' into the mainstream and many of the pupils were stated by staff to have experienced mainstream placement failure. Did this suggest an inability to 'know' fully these children in the mainstream? The information I was privy to suggested many of the pupils were a poor 'fit' in the mainstream and it was this that precipitated the breakdown of their placement. Yet given the different sorts of 'formal knowing' and expectations found one might argue it is an institutional failing, for as Booth stated (2002) inclusion necessitates institutional and cultural change. I suggest that what the 'special' sector does highlight, rather than individualised failings, is the failings of the mainstream in relation to all the pupils it will not and cannot accommodate. Nevertheless a rigidity of 'knowing' was also detected in the 'special' sector as the following subsection illustrates.

7.2.6 Billy's Story

The following observations taken from my field notes at the PRU illustrates how when emergent 'formal knowing' stakes a challenge to the dominant 'knowing' of a pupil identity as disordered, it is met with resistance. In addition it also reveals that the skill sets in these very differing contexts are highly local and narrow in their remit, bounded by the expectations of pupil type. Thus not 'special' in relation to their breadth of 'knowing', as such it highlights the seismic task mainstream teachers are expected to undertake, when entrusted to respond to all pupil diversity.

"Billy has joined the class mid-term, but he does not fit in well and appears subject to significant bullying, this understandably upsets him and is acting as a further impetus to tantrums and aggression. Although staff show awareness of these difficulties, they also appear unwilling to intervene, holding Billy accountable for his inability to regulate his own emotions".

"Billy has been diagnosed with ASD, but remains at the PRU because of his behavioural issues. Every week he appears worse than the last and staff in conversation admit that the placement is unsuitable and indeed was from the offset, as Billy was known to be in the middle of psychological assessments.

Even senior management are concerned, yet allude that they hold no jurisdictions over future placement of pupils”.

“This is a testing, but interesting time for me as a researcher and as a mother with a son a similar age who is on the spectrum. I cannot help thinking of the boys I had met in the ISS, who even acknowledging the concerns raised, were never subject to the ruthless bullying that is a daily occurrence, not the sanctions applied for any reactions. Following Billy’s diagnosis I assumed staff would recognise many of the behaviours exhibited were not within his control. I also assumed staff would be familiar with presentations of ASD and respond accordingly. But this is beginning to look like an erroneous assumption. Ongoing staff responses do not suggest understanding of ASD or employment of common school strategies for managing pupils on the spectrum. On several occasions I have now observed this pupil taunted to distress during break and lunch, in full view of staff, yet only when his outbursts are obvious do staff intervene”.

“Today, despite the C/T’s apparent apathy she has confessed that” “he shouldn’t be here really, but what can we do, there is nowhere else for him to be, we are not set up to manage ASD pupils”. “I enquired why the parents were not actively seeking alternative placement, or indeed why they accepted this one and was told that the pupil was difficult to manage at home and that ‘mum’ had younger children to manage. Ludicrously the C/T also said if it were her child she would not have accepted such placement! I find such attitude not only sad, but an indicator of how ingrained accountability deflection is in all sectors of the education system” [observation notes PRU].

These records illustrate how ‘formal knowing’ in the PRU is protected, it also emphasises that disability is not an indices commonly ‘known’ to be an impetus to PRU attendance. Yet even when formally evidenced through a medical diagnosis, the premises for Billy’s attendance is not significantly altered. Nor do staff shift their way of ‘formal knowing’ to a disability framework. Interestingly in this case, staff at the PRU do not question the narrowness of theirs or their institutions skill sets. To the contrary, responsibility is levelled toward the local authority to place the pupil appropriately, as well as indirectly onto the parents for an inability or unwillingness to proactively challenge the placement.

Looking at the quality indicators of good PRU practice, this approach is not openly sanctioned, as the DfE guidance below indicates Billy's experiences fall far short of official accepted practice:

“Good PRUs are able to be responsive when a difficult behaviour problem emerges in a school and provide appropriate support. They assess the needs of their pupils and provide personalised programmes for each child, which when possible lead to a return to mainstream school or a progress into further education or employment” (DfE 2012e, pp 19, point 70).

In practice, however, where damaged school careers led by 'behaviour' are a condition of entry as is the case with the PRU, wider causational factors appear to be of lesser consideration. The PRU was minded to rehabilitate in order to reintegrate into the mainstream, or more typically into a dedicated school catering for EBD. Indeed the generic descriptive term EBD appeared to negate diagnostic pursuit, and was conjuring of a tautology, whereupon 'professional knowing' was assumed on account of placement. I raised the issue of medical diagnosis with staff at the PRU on several occasions during my placement. However there appeared to be a complacency towards such endeavour and these conversations rarely evolved in any meaningful way, nor did such consideration appear to detract from the pupils status as children with behavioural difficulties. In conversation with the class teacher it was stated to me that the role of a PRU teacher was to right the negative behavioural patterns that had developed in the mainstream. This was not described in a manner which placed any accountability onto the pupil, rather it was described as a matter of fact.

Pupils at the PRU appeared channelled into a system which held little impetus to delve into the 'why's' of symptomatic behaviour, just as disability was a given in the ISS. In the PRU 'behaviour' was confirmatory of EBD and such 'knowing' acted to make sense of all following behaviours in a manner similar to those noted by Goffman (1968a) and Rosenhan (1973). In all three contexts; mainstream, the ISS and the PRU, dominant expectations serve to colour the sense made of pupil difference and where incongruence was noted, such as the case in the ISS and the PRU, the explanations evoked are externalised, rather than challenging of the dominant systems of 'formal knowing'.

7.2.7 Staff understandings

Staff at the ISS indicated that many pupils had experienced disabling practices within the mainstream, having entered the ISS following statutory assessment review, as the Head of the ISS explains. These difficulties, as was found at the PRU were rarely considered the pupils fault, rather demonstrated the inflexibility of the mainstream.

“Most of these [pupils] have been at mainstream and not managed, quite often when they come to us they have had really negative experiences and we have to address that as much as work with them in relation to their disabilities” [Head Teacher ISS].

Despite the remit of the ISS as a school for children with disabilities, classificatory type rarely appeared to lead or inform classroom or statutory review expectations. Staff were led most typically by their own assessment of pupil dispositions and needs, gradually constructing a nuanced profile of the pupil to assist classroom management. This was contrary to the mainstream where the need to ‘know’ in relation to medical labels operated to disempower teachers, in a manner identified by Gibbs (2010, 2012) and Elliot (2008, 2014). Similarly staff in the ISS rarely stated reliance on external services such as CYPs, although this may reflect the ongoing engagement of agencies working alongside the teaching staff on site.

In both contexts parents emerged as recipients of expertise, not discharging of it, although there were differences in the types of dependencies observed, yet both equally impeded parents position as a source of expertise. Parents in the ISS were dependent by necessity on medical and psychological services and were generally comfortable with their input. In contrast, other writers have found that parents of children attending PRUs exhibit a higher than average reliance on social workers or other advocates and frequently childrens needs are mirrored or exceeded by their parents (Bureau 2011). I was unaware of any visible or effective parental presence within either the ISS or the PRU. Parents rarely attended meetings at the ISS and the C/T stated a lot of cajoling was needed to get parents [more often the mother] into school. During my time at both schools, it was uncommon for parents to be ‘involved’ in the review process, rather staff described such meetings as a forum for professionals to make decisions, guided by the needs of both the child and the parents. At the

PRU this reluctance was stated by the C/T to reflect parents own educational disaffections and was considered to illustrate that there was a cultural dimension to behavioural difficulties that extended between generations. In the ISS parents relied on the expertise of the staff to substantiate their entitlement to placement funding, a practicality that impeded parental proactivity. As identified in Chapter five, parents who cope are vulnerable to having funding and support withdrawn, for parents of children in the ISS this appeared to mitigate against claims to knowledge and on the whole parents deferred to the staffs 'knowing'. For one family at the ISS ability to cope and pay, resulted for a period in their having to fund the placement themselves and indeed to secure placement the parents and teaching staff had to overemphasise the family's needs.

7.2.8 So who was 'special' enough for 'special school'?

There was a paradox to progress in the special sector that appeared to inhibit any expansion of the pedagogical creativity that both institutions displayed. This was a protocol common to both institutions, whereby pupils who demonstrated progress (both learning, behavioural and social) faced potential reintegration back into mainstream schooling, when such progress was fed into the annual review meeting. Indeed the implication of progress, irrespective of disability status appeared to summons question around the pupils support needs, rather than demonstrate the effectiveness of the supports offered. This appeared to me to be directly linked to the allocation of resources and indeed in conversation personally with my child's local authority, the issue of budget restraints was a regular issue when support needs were discussed.

This protocol was also taken as a further indication that the default school provision remains the mainstream, and despite alternative provisions proving their ability to effect progress, this is resisted as it is an (expensive) educational concession, not a right. In practice this protocol was observed twice in the ISS during my time as a volunteer. The first example resulted in a child's unsuccessful readmission to mainstream, reaping further failure onto the child, the second resulted in a part-time mainstream placement with ISS support.

These decisions highlighted above were stated by staff at the ISS to be at core economically based. Thus illustrating the wider connections that determine the shape of 'formal knowing' as well as the decisions such 'knowing' justifies.

Financial issues were highly prominent in the ISS and impacted strongly on pupil placement. Local authorities particularly were known to resist funding unless all other options had been explored, especially those offered by the local authority. These pressures rendered it understandable that the ISS motivation to promote a successful and expert identity, essentially a portfolio of 'formal knowing' unmatched by the local authorities school provision. I was shocked at the high level of fees the ISS demanded and this alone militated against the attendance of more able students who arguably might have benefited.

Staff at the ISS openly discussed insecurities around placement retention, indicating care in pupils reviews to carefully present evidence that least jeopardised placement security. Many times there was visible relief when pupils funding was renewed and not surprisingly the greatest stresses led from the pupils with speech, language and communication difficulties. This too indicated an unstable disability identity, as there was rarely such tension around the pupils with visible medical disabilities as progress appeared less anticipated as well as there being limited medical expertise in the mainstream sector.

Nevertheless equally it was evident that the ISS was managed from a business model and issues of finance and sponsorship was an important part of the foundations rationale. Financial issues were also an issue at the PRU, yet differed in nature as unlike the ISS, PRU funding was determined by government and as such was subject to political and economic uncertainties. The shape of 'formal knowing' in the school context was hence also political and responsive to economic and social concerns. Pupils at the PRU were viewed as in need of control, they were also 'known' by their mainstream schools as a problem. The availability of the PRU and its obligation to admit pupils at risk of permanent exclusion withdrew educative responsibility from the mainstream and indeed the local authority. Similarly the ISS according to teaching staff was accorded a role in the lives of families that exceeded the normal parent/school relationship and I was aware on several occasions where staff stepped into a social work role to support parents in times of crisis, liaising with wider agencies and brokering additional supports. .

7.2.9 Making sense of 'special'

Special education holds a long and controversial history which extends to the current day (Tomlinson 1982, 1985, Sleeter 1987, Connor 2007, Hornby 2013),

and is associated fundamentally with discrimination. Not least in relation to identification bias (Croll 2002, Florian 2006, Dyson 2008, Begeer 2009, Gould 2011, Heilker 2012, Miller 2014), function (Slee 1993), intent (Tomlinson 2005, 2014) and effect (Cremin 2005, McCoy 2012). As Tomlinson (1982) has cautioned 'humanitarianism can itself become an ideology, legitimating principles of social control within a society' (pp7) and it is notable that such sentiment has been equally levelled at 'inclusion' as it has evolved in the mainstream (Dunne 2008, Runswick-Cole 2009). The idea of inclusion in practice operating as an instrument of social control, led by an inflexible ideology, relates most specifically to the mainstreams continued tendency to exclude. This was taken as evidence that inclusion (right to placement) is qualified and that such qualification is presented as the fault of the individual, not the system in practice. Consequently the association of inclusion with mainstream schooling persists, despite exclusion statistics indicating a clear inability to include all. For those outside of the mainstream, their needs or acts are couched as evidence of additional need, falling outside of the parameters of 'normal', rather than difference.

Tomlinson (2015) draws attention to the continuing disproportionate representation of pupils of colour in PRUs and the disadvantaged social indices that are also commonly implicated. As Tomlinson states 'education systems and their special sub-systems are not neutral elements... they are a product of the historical beliefs that still shape the values and understandings of policy-makers, professionals and practitioners' (pp3). Looking at the demographics of the ISS and the PRU, there was an even spread of socio-economic status represented across the ISS and notably few children from wider ethnic backgrounds. Similarly there was no evidence of an ethnic bias at the PRU, however in relation to socio-economic bias, this was heavily weighted to those least advantaged economically. Although these demographics may be reflective of the general surrounding population, in relation to the ISS, pupil intake was not bounded geographically and intake was on an open referral crossing several local authority areas.

It is therefore unsurprising against a culture of political intolerance concerned not only with indiscipline (NASUWT 2008, 2012a, Haydn 2010, DfE 2012d, Neill 2013), but also welfare burden (Garthwaite 2011, Heeney 2015, Hughes 2015,

Roulstone 2015), that 'behaviour' appears disassociated from disability as a mitigating effect and attributed to familial and socio-economic failure for which accountability is metered. It is thus directive of post exclusion destinations, which as Tomlinson (ibid) asserts, is for many individuals already disadvantaged, disproportionately a PRU, rather than a special school aligned to disability. Certainly for the pupils I met in the PRU, their educational pasts were punctuated by their failings, in conversation this was apparent and indeed embellished. In the PRU, pupils appeared to gain social culture (Bourdieu 1986) from engaging in anti-school activity. Observing the pupils interaction it was quickly apparent that this served to negate any feelings of marginalisation school failure may have reasonably wrought.

Nevertheless the problem of how to educate children who present outside of the 'norm' has been historically persistent, conjuring issues that extend beyond issues of pedagogy. Rather they are framed around strong views toward needs, rights, expertise, agenda and stigma (Tomlinson 1982, Frederikson 2004, Ware 2004, Warnock 2005, Cigman 2007, Florian 2008b, McKay 2009, Rogers 2013, Kauffman 2015). Notably these concerns were never discussed in either of the contexts I volunteered in, nor did I have cause to consider them in the daily activity of either context. To date there has been no effective resolution, although toward redress Norwich (2008) calls for a continuum of provision to compact the continuing mainstream/special divide, urging that such a continuum could harvest best practice in both domains. Nevertheless individualised segregation continues, notably both within and without the mainstream, legitimated on the basis of the presenting child's needs and impact (Allan 2006, 2010, Youdell 2006, 2011, Slee 2013). Such segregation has been found to raise issues of discrimination and illegal disadvantage, predicated upon attributions of causal accountability (Parsons 2005, Jull 2008, O'Regan 2009, 2010, OCC 2013)

How to educate and respond to pupil difference is the core issue at the heart of inclusion as an educational vision, as it is integration. Both approaches lean toward the ideal of a one size fits all system of schooling, the difference is how such fit is achieved. The key distinction is coined by Armstrong, Armstrong and Barton (2016), in that integration seeks communal placement on the basis of

pupil adjustment, whereas inclusive schools 'are for all members of the community that they are part of, and serve ... without exception' (pp 72).

The ideals of inclusion and the practical teaching demands of mass education, together generate tensions which are not easily reconciled – usually in regards of how difference is identified and described. Commonly these are conducted upon the ideals of 'typicality' and 'normal ability' (Heir 2002, 2005, Campbell 2008, 2009). Problematically they are also foundational to the logic of which depicts differentiated pedagogical response as 'special'. Indeed as differentiation is a core pedagogical strategy in mixed ability classrooms, it is interesting to consider where the tipping point is between normal differentiation and 'special differentiation'. Notably in relation to 'behaviour' there is suggestion that there is no arbitrary marker or tipping point. Rather what constitutes 'behaviour' is determined subjectively and differs on account of both context and individual teachers expectations (Waterhouse 2004, Grieve 2009). As such supports the contention that a 'behavioural difficulty' is the product of a negotiated subjectivity, rather than a stable organic state which can be compared across contexts (Jones 2003b).

Towards a resolution, Norwich (2008) takes issue with the current differentiation between special and mainstream sectors of education, calling for a continuum of provision. Such provision requires a reconceptualization not of 'formal knowing' in relation to the child's difficulties, but of the identities and relationships between the educational sectors. Norwich visualises a 'flexible interacting continua of provision' (pp 141), one which exceeds the current unidimensional model of educational provision. Such a continuum holds the potential to negate the mainstream/special divide, by reconfiguring the shape of provision to one which hosts an interlinking of expertise across the spectrum of provision. The idea of specialist expertise is the cornerstone of the 'special' sector, and particularly in relation to PRUs, such expertise is impressive as Youdell (2011) and McGregor (2012, 2015) indicate. This is not only in relation to behaviour management, but through their ability to offer excluded pupils a second chance. This is achieved not by replicating the dynamics of the mainstream, but by forging a new pedagogy which is adaptable and restorative. Thus the idea of a continuum of provision is seductive and certainly the pupils I observed in both specialist sectors were unlikely to be easily accommodated in

mainstream, given the current emphasis on behavioural and academic standards (Gillborn and Youdell 2000, DfES 2005b, Ofsted 2012, 2014b) which had given rise to an increasingly inflexible system. Thus to reconfigure schooling as an equal continuum necessitates redress of an 'us and them' mentality, alongside the diminishing of the ability stratifications inherent to summative educational qualifications. For as long as academic qualifications continue to dominate and enjoy a greater status than other forms of learning outcomes, there will be segregation at this very base level.

It is unsurprising therefore that Barnes (2013) considers school reconfiguration to be more idealistic than realistic. Barnes thus cautions against the invocation of any version of 'inclusion' which remains 'supported by uncritical use of the language of special needs', stating that 'as long as there is a form of language that depicts individuals as 'not normal' and 'special', discriminatory and exclusionary forms of provision and practice will continue to exist and be legitimated' (pp, 8). The language depicting difference is described as a powerful positioning tool both contemporarily (Graham 2012) and historically (Corbett 1996, Stiker 1997, Armstrong 2003, Borsay 2005). It is also considered to exceed the boundaries of description to represent what Grant (2010) describes as 'warranted ascription' (pp3).

Positioning processes are defined by Honkasilta (2015) as 'discursively constructed social identities that entail a "cluster of rights and duties to perform certain actions' (pp 676). Positioning can also delineate formal stratifications of difference, when legitimation resides upon professional claims to truth.

Problematically, claims to truth are found to be fluid, and in education are considered to have disadvantaged particular populations (Tomlinson 2014).

This is most evident in the mainstream sector where pupils identified as having certain types of 'special need', (most commonly those known to be associated with 'behaviour') are known to have an increased risk of exclusion (DfE 2014, 2015b, 2016).

One might ask therefore whether special education is an inevitable consequence of a determination to educate the majority as cost effectively as possible in mass institutions that cannot by their nature respond efficiently to the extremes of difference. Kauffman (2015) acknowledges that the reality of pupil differences demands differentiation. Nevertheless there is a denial that this

need should automatically be driven by medical labels. What Kauffman suggests is partial differentiation, in terms of delivery of the curriculum and teaching pace, but advocates for the 'full inclusion' of pupils in the ancillary aspects of school. Such vision, however, would require major change if it is to be implemented in the mainstream and in times of economic sobriety can it even be justified if differentiated provisions are meeting needs?

My own experience and indeed that of the parents who participated in this study countermands the assertion that in combination the mainstream and special sectors are meeting needs efficiently. As does the genuine concerns raised by teachers, not only in this study, but in larger research initiatives (NASUWT 2008, 2012b, NFER 2012). Nevertheless by far the greatest indication of failing is the enduring level of permanent and fixed term exclusions. These are sanctions which are not only legitimated through formal individualised accountabilities, but also are metered less overtly in the form of illegal exclusions (OCC 2013). Personally the most striking aspect of our familial experience was the disposition of the special sector to exclude our son. This raised for me the question as to where pupils like my son could go when excluded from the only sector which is stated to be tailored to the needs of challenging pupils.

Certainly I highlighted concerns as they emerged during my placements as well as those concerns that emerged personally during my son's 'special' college placement. These concerns, however, need to be balanced against the concerns parents shared in relation to their experiences in the mainstream and indeed those encountered personally. Although Norwich (2008) has called for a continuum of provision and the pooling of expertise, Kauffman suggests that the current undue emphasis on placement serves to deflect attention away from individual pupils needs, creating an illusion of inclusion which is unsustainable, and in working practice continues to attract 'special' interventions to accommodate difference. As Kauffman notes 'the place of instruction, rather than the specifics of appropriate instruction has become the central issue' (pp 72). Yet notably challenges to the integrity of inclusion as it pertains to the mainstream celebrate the value of separate provision and the protections these accord, rather than 'special' teaching expertise. Parents in my study similarly indicated an appreciation that there was a greater understanding evident in the

special sector, described as 'getting it', yet this also did not indicate 'special pedagogy', just a different way of 'knowing' the child. These differing conceptualisations of 'special' have added weight to demand that inclusion be reconceptualised as an emotive rather than locational issue. (Warnock 2005, Cigman 2007).

Parents and teachers emphasised that some pupils needs defied a common approach and looking back I would not disagree. However I would dispute the sense made of these pupils and the rigidities of 'formal knowing' which were evident, supporting Youdell's (2011) assertion that education is not neutral, but embedded with value judgements which serve to perpetuate and substantiate inequality. Yet these value judgements may be seen as an inevitable by-product of positioning inclusion in mainstream as the default provision, 'unless there are compelling reasons not to' (UNESCO 1994, pp, ix). In practice this served to position the special sector as second choice and generated associations with defect and disorder.

Similarly the expectation that the mainstream caters for 'typically developing' pupils, contributes to appearances of difference, not only in terms of ability, but social connectedness. Parents were acutely aware of these shortfalls as Freya alludes when speaking about her son's enquiry as to 'what a retard' was after being called one by other children. For parents these were the big issues, whilst for teachers in the mainstream it was practical difficulties which dominated their thoughts. Nevertheless both concerns point to a common difficulty - namely the expectation that children can and should be subject to a common educational curricular, in a common environment, which when found unsuitable signal individual not systemic failings.

Nevertheless, mainstream schooling has a long history of being the default placement for children, historically special schools emerged to cater for those children who fell short of what was anticipated to be within the bounds of 'regular' child ability and although these differences varied in their constitution, their ambition was to remediate where possible the child's ability to the 'regular' (Winsor 2007). Barnes (1991a) notes similarly that from the '1890s onward, government documents present special provision as a necessary adjunct to mainstream education because of its appropriateness for individuals whose needs were/are different from the rest of the community' (pp 29). It is therefore

significant that contemporarily, failure in the mainstream is one of the main means of entry into the special sector as I indicated in Chapter five.

The other means of entry into the special sector is through medical validation and supporting evidence, as was the case for many of the children in the ISS. In contrast where 'behaviour' is the issue, school failure attracts accountability, deflecting search for causational indices. Indeed these two main entry pathways were reflected in the identities the ISS and the PRU enjoyed. Therefore as I have outlined, the PRU was disassociated with disability and conjured in the community mistrust, despite being part of the local authority's portfolio of specialist provision. In contrast there was heady sympathy and community support for the ISS, where its pupils were blameless victims of disability.

These divisions hint of latent expertise embedded within the ISS and a more regulative structure for those with 'behaviour' problems. The former being centred round the needs and rights of the disabled child, the latter catering to controlling the unregulated child. Considering the functions of separation, Barnes (1991a) has suggested that segregation is led predominantly by a desire to 'maximise efficiency' in the mainstream classroom, resulting in the exclusion of pupils seen to disrupt these processes. The pragmatics of this strategy was openly indicated to me by senior management at the PRU and indeed this was considered by them to be driving selective exclusions.

The above concerns highlight the political nature of education as Youdell (2011) emphasised. It also illustrates that previous concerns raised in relation to a rationing of education continue unabated and in fact have exacerbated since the following caution was made. 'The obsession with measurable and elite standards, the publication of school league tables, heightened surveillance of schools and increased competition for resources (all central to the reforms) are part of the problem not the solution (Gillborn and Youdell 2000, pp1).

The idea of selective exclusion and indeed segregation within the mainstream, defies the notion of 'special' as the sole rationale for alternative placement, rather it could be more aptly named convenient. Yet as is shown below, historically, legislation has written in qualifications to educational entitlements, qualifications which exceed the boundaries of school, filtering our legal system and our tolerance.

7.2.10 rationalising qualifications to educational entitlement and attaching blame

The special sector relies upon the inability of the mainstream for its existence and claims to be special. Yet the special sector hosts a variety of provision which is attracting of very differing accordances of blame. Pupils at the ISS, may be seen to hold 'labels of forgiveness' (Slee 1995, Lloyd and Norris 1999, Riddell 2007), conferred through uncontested disability diagnoses, which in turn guides the 'knowing' of others, including staff at the ISS. In contrast pupils at the PRU may be said to hold unforgiving labels, which have indeterminate causes, and are frequently linked to personal, familial and cultural deficit. The roots of such 'unforgiveness' may be seen to reside in the labels applied to this population, or more precisely, extend from the lack of a neurologically accredited label. As Lloyd and Norris (1999) astutely noted 'not all labels are created equally, children with EBD may be choosing to behave badly, but those with ADHD may be seen to have no choice' (pp 507). Broomhead (2013b) draws upon the term 'guilty until proven innocent' in respect of parents of children with behavioural difficulties (pp 15). In Broomhead's opinion, diagnosis is the key to demonstrating innocence, supporting the term 'defensive diagnosis' which I introduced in Chapter one.

In the special sector the division of medical labels appeared arbitrary, whereupon those whose behaviour was not ascribed to neurology filtered into the PRUs. It is telling that such arbitrary filtering which I term as the 'knowing' of pupils, during my volunteering only conflicted once as Billy's story indicates (pp, 494), whereby Billy is found to hold a diagnosis of autism and a profile as a PRU pupil. In mainstream schooling, however, there are no readymade divisions, thus the mainstream becomes a site of debate, what one SENCO described as sorting the "cannot's from the wont's". It is in this context that the conferment of blame is most clearly levelled, manifesting as exclusions and in-house segregation. Nevertheless, these debates do not occur in isolation, rather are linked to wider legal processes and have implication for the protective value of equality legislation.

Qualifications to mainstream entitlement are found embedded in successive education and equality policy, and as such circumvent the rights accorded to both disabled and non-disabled pupils. Nevertheless although it is not clearly stated, these restrictions pertain chiefly to conduct and as such delineate a sub

section of the school population whose rights are vulnerable to compromise, despite the possibility or actual presence of a disability which should confer protection. As O'Connell (2016) has noted, equality rights concede to criminal law where there is an adverse impact of a person on another or the collective, concession which is equally evident in education although it results in exclusion, rather than criminal charges.

Jull (2008) acknowledges these tendencies in education, stating that mainstream responses to behavioural disruption run contrary to other school responses to SEN and disability and is disavowing of circumstance or institutional impact. Thus Jull suggests that 'formal knowing' in respect of behaviour might be more usefully informed by careful observation of the contextual triggers that act as an impetus to 'challenging behaviour'. Furthermore accepting that for some children, the pressures of the mainstream are untenable. These were observations that Baroness Warnock indicated during our interview, suggesting that some children simply do not adjust to the mainstream, yet had indicated no difficulties prior to school. Baroness Warnock thus suggested that for many pupils considered to have EBD, the underlying difficulty is contextual, rather than organic.

Notably Jull (2008) does not take issue with actual separation from the mainstream, his issue revolves around 'the punitive disciplinary context as a pretext to addressing disruptive behaviour and which takes shape as exclusion and suggests an absence of capability within a school' (pp 16). Yet despite Jull's call for a 'best fit' approach, this observation of a punitive element to exclusions for 'behaviour', renders explicable why the PRU as a school provision holds a differing – and more negative - identity than the ISS as a 'special school' in the classic sense for children with medical and cognitive disabilities. Jull further notes that EBD remains enigmatic, 'because unlike other SEN designations, educators remain confounded by how best to respond to students whose particular special educational need seems to justify punitive disciplinary action, including exclusion' (pp 13).

As stated at the beginning of this sub-section, this enigma is mirrored legislatively, resulting in qualifications to educational rights. Hence although successive education acts have legislated on the rights and forms of education available to children with disabilities (Parliament 1944 1970, 1981, 2001, 2010b,

2014), all have retained the qualifications that Barnes (1991a) traces back to the 1890s. These qualifications not only legitimate segregation from the mainstream where a pupil's presence compromises the efficient education of the collective, (either through conduct or additional need), they also individualise accountability for difficulties posed. It is this I suggest which acts to confer individualised failure for pupils whose needs are not defined in medical terms, although in wider society, accountability is metered in different ways. Hence although a move to the special sector may be stated as on the basis of 'additional need', and appropriateness of provision, the subtext for some is blameworthy and regulative.

7.3 Section three: the implications of 'formal knowing' in the special sector?

Chapters four and five illustrated a divide between 'formal' and 'familial knowing', suggesting that the former was responsive to narrower, professionally informed indices, which by their nature are partial, contextually driven and heightening of difference rather than similarities. 'Familial knowledge' on the other hand was considered to exceed the bounds of difference, embracing the child's unique qualities and quirks. In the 'special' sector it is reasonable to suggest that the basic questions surrounding 'formal knowing' are answered by admission, a resolution to the 'can't versus won't' equation. On that basis one might assume that 'formal knowing' in these sectors may be more expansive, reflecting some of the identified characteristics of 'familial knowing'. However over time it became apparent that the criteria for admission not only informed on 'formal knowing', it also acted as the framework to guide and filter emergent 'knowing', which although responsive to wider social variables, remained bounded to the 'type' of pupil each school catered for, a typology that was moulded by the demographic configurations common to each institution.

Typically boys at the PRU strongly outnumbered girls, mirroring the disproportionality observed in contemporary exclusion statistics, whereupon boys remain three times more likely to be subject to fixed term and permanent exclusions (DfE 2015b; 2016c). Statistics also indicate as previously noted that pupils with SEN and disabilities are more prone to exclusion than their more able peers, however the majority of pupils in the PRU held no formal statement or diagnosis, yet were overrepresented in terms of free school meals eligibility,

which at the time of placement was 58%. These demographics shaped the 'formal knowing' of PRU pupils as was reflected in the overwhelming opinion that PRU pupils hailed from backgrounds which was both economically and culturally poor. Interestingly at no point during my volunteering did staff consider these pupils were justified in the latent anger they displayed, nor did they suggest that a poor socio-economic background may be underpinning their anger.

Hodge and Wolstenholme's (2016) recent research supports the notion that PRU attendees filter to this provision as a consequence of their backgrounds, yet suggest their cultural and educational deficits reduce their ability to resist admission, rather than cause admission. Hodge and Wolstenholme found following the (politically) recent change to the school exclusion appeals process (Parliament 2011) that parents who held fewer of the skills Nind (2008) previously identified to be implicated in effective navigation of a child's disability, were doubly impaired from any effective challenge to their child's exclusion, rendering them more vulnerable to PRU admission.

Statistics confirm that particular groups of students are disproportionately vulnerable to exclusion (OCC 2012, DfE 2015), however recent research suggests the challenges a pupil poses prior to exclusion are more complex (Trotman 2015) and extend beyond simple class divisions. Rather they are found to accrue from the interaction of a combination of factors, indigenous to both the individual and the organisation, not least transitional adjustment, school expectations and the onset of puberty. Nevertheless just as Hodge and Wolstenholme found, Gazeley (2012) also notes that 'when things go wrong at school, middle-class parents are better positioned to obtain support and advice because of their greater access to material resources and professional social networks' (pp 300). Looking at the 'formal knowing' of the pupils in both 'special' sectors, I would tend to agree, parents of pupils at the PRU were defined by their deficits, as indeed parents at the ISS were, but in a subtlety different way. PRU parents were seen to be a causal factor in their child's difficulties, whereas parents at the ISS were simply viewed as needing 'specialist' guidance. The differences in coping skills were however most noticeable amongst parents in the mainstream, as it was parents who held relevant skills

who were more able to lobby for the supports needed. Although as illustrated through Sacha's story in Chapter five, competency can also impede support.

Nevertheless in both contexts classroom staff echoed assertions also found expressed in the mainstream, most typically in relation to the role and responsibilities of parents. Across all contexts parents were considered a primary factor predisposing to poor behaviour and lack of academic progress. In particular teachers exhibited irritation where their considered lead or advice was not followed, yet conversely when progress was seen, the parental role was rarely acknowledged.

7.3.1 'Special provision, special 'knowing'?

To what extent can the special sector be considered the embodiment of knowledge and skills not commonly found in the mainstream (Landrum 2003). One might suggest that given the continued questioning of the role of both special schools and special education (Barton 1987, Armstrong 2005, Dyson & Kozleski 2008, Tomlinson 2014) pedagogical expertise would form the crux of this sectors defence. Kauffman (2015) contends the specialness of the sector is its responsiveness and flexibility, enabling it to deliver education to a vast array of pupils whose needs deviate from societally defined norms, particularly those pertaining to behaviour (Youdell 2010).

Special schools are also defended for their ability to offer appropriate education to pupils who are found vulnerable in the mainstream (Warnock 2005, Cigman 2007). However such professional altruism is destabilised by a counter perspective which claims historically that special schools have emerged as the masters of reinvention, remodelling their specialties to compensate for their former pupil base (physically disabled pupils and those with moderate learning difficulties) being included in the mainstream. They are therefore seen to have positioned themselves to accommodate the expansion of new neurodevelopmental disabilities which emerged to offer explanation(s) for communication and behavioural differences (Whittaker 2001). It is thus notable that 15 years after Whittaker's assertion, statistics indicate that 22.5 % of special school attendees are identified as having an ASD (DfE 2014). In addition the latest official statistics (DfE 2016aa) record that 'the percentage of

pupils with a statement or EHC who are placed in special schools has been increasing' (pp. 8).

Does this indicate an increasing confidence in this sector, or intimate an increasing discontent with mainstream settings? Certainly the parents engaging with this study indicated the latter stance and they demonstrated an unwavering faith in the greater opportunities for their children in the special sector. Overall a special school placement was suggested by parents to represent an acknowledgement that their children had difficulties that were medically derived. In detail this faith embraced not only the expectation of teachers greater understanding and ability to relate to their children, but the hope that there would be a more pragmatic attitude and a lesser judgmental relationship between themselves and school. For some parents a move was realised, for others it remained an ambition and it is a limitation of this research that time constraints prevented any further interviews to explore with parents how far their difficulties had been addressed by their child's move to the special sector.

7.3.2 Filtering and negotiating 'Formal Knowing'

It has been suggested that parents of disabled children know their children best and as such are a useful resource (De Geeter 2002, Lamb 2009), yet parental expertise is also challenged (Rogers 2011, Thackeray 2013) and as Ferguson (2002) found, filtered through the dominant attributional lens imposed on the disabled child's family. The idea of differing attributional periods resonates with Foucault's (1973) notion of gaze, and suggests that the filters applied to gaze are fluid and at times partial. The lenses Ferguson identifies are of influence not only toward the 'formal knowing' of an individual child or family, but towards how childhood differences come to be understood professionally.

The first period Ferguson (2002) cites revolves around parental blame as the chief causational indices, followed sharply by a shift of focus towards the impact of childhood disability on the family from the 1920s. Looking across my data sets, both periods of attribution can be identified as contemporarily operational in the school context, shaping not only response, but the stock of 'formal knowing'. Thus the tendency to 'gaze' upon the family as the locus of a child's difficulties was the dominant lens implemented in the PRU, whereas in contrast

mainstream schools appeared to adopt lenses eclectically, directed by wider attributions based on social demographics.

Notably in the ISS, 'formal knowing' was already established and directed through medical understandings. Hence 'gaze' privileged the child's impact on the family and the impact of the disability on the child. Nevertheless in the case of the ISS there were additional lenses of observation operational, most specifically focused on parental competency at managing the child's identified difficulties through the following of professional expertise. In particular the home/school record book was the first port of communication and where parents were honest and upfront in their recording, the difficulties faced would often be discussed openly between the C/T and the support staff. Typically these conversations would digress to hypothetical discussion of where the parents were going wrong and how they were failing to follow staffs examples of how to manage the children.

Similarly there were instances where the pupils were admitted overnight into emergency respite accommodation, here to the circumstances that surrounded admission became subject to deconstruction in the classroom, focused upon parental competencies.

Personally my own expertise grew to be respected in the mainstream school my son attended, due in part to the extensive maternal experience I held alongside my research interests. Making these things count, however, can best be described as positioning and was an exercise I regularly engaged in, as indeed did many of the parents who participated in my study. Nevertheless it was much harder to contribute to my son's 'formal knowing' when he was enrolled at the special college. I encountered many barriers created by the projection and beliefs of expertise of the staff there. In this instance I found that their 'formal knowing' was guided by discrete disability knowledge, which acted as a filter during processes of gathering individualised 'knowing'.

In both the ISS and the PRU parental expertise was resisted, serving to position staff as 'expert' and parents in need of guidance. The following excerpt taken from field notes at the ISS illustrates how such positioning processes were present within informal staff conversations:

"The thing is he gets away with it at home; she doesn't make him responsible, she says it's because he has ADHD (speaking of challenging behaviours, whereby the pupil

seemingly cannot engage effectively). I don't believe it personally, I think he chooses to misbehave, he's out of it now because she's had him put on medication, he just needs a firm hand". (LSA in relation to pupil aged 10 with a diagnosis of Autism and ADHD).

There was also indication of exasperation when staff considered parents were not conceding to their lead, irrespective of the professional status of a particular parent:

"It's pointless us making him [pupil] eat properly and try new things if it is not reinforced at home, he seems to be able to get round her [mum]. For a clever woman, she's got a science PhD... she seems unable to cope. Dad is never there either, I think he's gone back home (Saudi) probably to get away from her". (CT in relation to pupil aged 12, with unspecified speech language and communication problems, developmental delay and serious epilepsy).

Within the ISS particularly there was limited opportunity for pupils to resist or challenge the shape that formal understandings took and the impact these had on their school life. Their statements of educational need served to define their 'knowing' medically although informally teachers also built profiles which channelled how they were managed. This less medically driven knowing was a concern, as it involved informal attributions of wilfulness, which in my opinion the children were not capable of. It was at this point that I witnessed a disconnection from disability as the primary factor leading ISS pupils difficulties.

This observation caused great concern as in my class pupils speech and language skills were significantly impaired, which added to their vulnerability. Where pupils spoke of concerns to parents, these were actively resisted by staff and intimated to be malevolent. The following excerpt illustrates this observation:

"The thing is he just runs home and complains to his mum...then we get XX [Deputy Head] on our case. He makes a lot up and he knows he causes trouble, we need to keep on top of these behaviours and make sure she (mum) knows what he is like". (CT in relation to pupil aged 12, diagnosis of Autism and ADHD)".

Thus despite claims that the 'special sector' was a safer environment for pupils with disabilities, I was rapidly becoming less than convinced.

This was also the clearest indication that there was a disassociation of behaviour from disability. Such 'knowing' informed responses and at times led to staff/student interaction which made me feel uncomfortable. Having children with similar difficulties further compounded these concerns as I too had experienced periods during my children's schooling when staff contested the effects of their disabilities and levelled punitive sanctions accordingly.

Having had to rely on other children and their parents to inform me of ‘incidents’ in school I was alarmed that similar discourses were operating in the ISS as there were no peers in this context able to inform on concerns, leaving the class totally at the mercy of teaching staff. Indeed it was the lack of pupils ability to voice concerns, more than any other factor, which persuaded me that there were under- acknowledged safety benefits to having all pupils assimilated within the mainstream.

7.3.3 ‘Formal knowings’ – medical, social or eclectic?

Although the immediate framework of both institutions was directed to education, the foundation of ‘formal knowing’ to inform that education differed markedly between institutions. The ISS was led (in terms of professional expertise) almost exclusively by aligned medical and psychological agencies. Whilst there were a few pupils subject to social concerns, these were viewed, however, as secondary to the medical labels which defined their needs.

I was acutely aware of external agency presence in the ISS as this differed markedly from the usual situation in the mainstream where wider agencies attend as passing visitors and are generally external to daily routines. In the ISS wider agency input was anticipated and interceded on traditional CT jurisdictions. In my class there was a consistent stream of additional specialists who imputed into classroom routines, or withdrew children for assessment. The most regular input came from the speech and language therapists (SALT), who inexplicably appeared to control and deliver selective parts of the English curriculum. Consequently at times it was difficult to understand who held jurisdictions. In some circumstances tensions between the SALT and the classroom teacher were observed centred on the ‘right way of doing things’. This was most notable in relation to the reading scheme the SALT teacher used. It was called the Teaching Handwriting Reading and Spelling Skills programme (THRASS), yet notably differed from the techniques taught to the teacher during her training. This caused significant tension, particularly when the time allocated to the THRASS program impeded on the more general English lessons scheduled by the C/T.

In contrast there were few visitors to the PRU and those who had regular contact held clearly defined roles, the most frequent of which was the attendance welfare officer, the youth offending team officer and the community

psychologist. Notably, although all had clearly defined roles they were never a presence in the classroom, nor did they hold any jurisdiction over classroom routine. Wider agency input also hinted at the conceptual frame operative in the PRU in relation to the locus of the pupils difficulties, echoing teaching staff assertions that environment was the primary impetus to the challenges pupils posed.

Context was found to be definitional of expectation and response. Pupils at the PRU were 'formally known' to have behavioural issues, estrangement from their schools and a general lack of self and external control. This was in essence a condition of entry. Such 'knowing' was also directive of response and the pedagogical approaches conducted. The following excerpt was expressed by the head in response to my query about the schools opinions on behaviour, it also serves to intimate the dominant conceptual model employed within the school:

"Well we are comfortable with that here, although we are never complacent, but we were comfortable. I think the view here is very much that the problems stem from relationships and are resolved by building relationships. Many kids who come here have been for various reasons very badly damaged with previous experiences, and those experiences are not necessarily school related all the time, or even home related, but they certainly provide experiences and lifestyles that provide barriers to developing good relationships".

In relation to the ISS the medical model dominated, creating the working model for teachers and aligned professionals, indeed here disability was the pre-requisite for admission. Nevertheless during informal conversations there were at times open challenge and of scepticism, not toward the integrity of a disability classification, but in common with concerns identified amongst teachers in mainstream toward its misapplication. It was at this juncture that environmental, particularly parenting issues were invoked and accountability accorded as the following excerpt illustrates:

"I'm not convinced by ADHD...they say some of our pupils have it but I don't think so...it's one of those conditions that can be misinterpreted... I think a lot of those kids just need to have consistent boundaries, its where there is a lack of consistency that their behaviour's get out of control" (CT ISS).

The view of the teacher cited above was not unique as similar opinions were subtly detected amongst other staff at the ISS in regards to behaviour. One parent was accused of promoting her son's bad behaviour to gain admission to a particular school, another teacher stated that parents would instruct their children on how to behave in a medical assessment to gain a diagnosis. In this

instance the motivation imputed was financial, whereas the former example indicated simple manipulation. Nevertheless all acted to undermine confidence in the diagnostic process. Indeed within all contexts (ISS, PRU and mainstream school) this challenging stance opened spaces for the accordance of parental and environmental accountability.

7.3.4 The impact of role on 'formal knowing'

Within both institutions, the professional standing of staff appeared to guide 'formal knowing'. Subtle differences between what classroom staff thought and did and what senior management thought and entrusted the staff to do were observed in both placements. It was notable that the open challenges to parents observed by me originated from classroom teachers and took shape during informal collegial conversations. Senior management in contrast were less expansive and emitted a more moderated stance aligned to the official role of their school.

Interestingly in both contexts there was a tension detected by me between senior management and classroom teachers. This in brief centred on the ability of classroom staff to deliver all the demands senior management made. A regular source of discontent paradoxically was classroom teachers assertion that senior managers did not appreciate the strains of the role, or the extent of demands placed on them. This tension was considered a similar communication breach to that indicated between parents and mainstream teachers. 'Formal knowing' amongst managers appeared to be theory led; in contrast staff (and equally parents) were informed by the practical effects of the difficulties the children displayed.

In the PRU the daily briefing conducted by senior management offered me the opportunity to gain an impression of emergent issues and priorities. There was heavy emphasis on training opportunities and wider agency collaboration, although the main focus remained on re-placing pupils into permanent schools. All staff including myself were invited to these, regardless of status, thus formal knowing in the PRU was highly transparent. It also highlighted a gulf between junior staff and senior management: at ground level staff were much more vocal in their theorising of the locus of the child's difficulties. Senior staff, however, indicated a more open minded approach and demonstrated through the briefing

meetings their efforts to locate causation from an eclectic range of sources, including explanations of a medical/psychological nature. Nevertheless the eclectic tendencies of senior management at the PRU did not dilute teachers' certainties, who were steadfast in their belief that culture and parenting were the main causal factors, giving a clear intimation that these teachers were operating from within a social model of disability.

In contrast the ISS was much less transparent, as were the processes that founded particularly senior management's 'formal knowledge'. I was never invited to briefing sessions at the ISS and my engagement with staff whilst always cordial, was distant. I was always a visitor and this made it harder to see from the inside, although exposure to daily class-based practices over a considerable timeframe did mitigate this. Over time I reflected on this distance and concluded that this distant relationship was not a personal affront, rather it reflected the number of outsiders coming into the school. The ISS attracted significant interest, not only in research terms (Douse 2009), but due to its status as a charity and the networks that maintain its main funding sources. The disability status of pupils in the ISS appeared to me to be unquestioned, unlike the open challenges indicated in the mainstream. Nevertheless familial blame was observed, centred on parents' capacity to manage their children as ISS staff considered appropriate. In contrast pupils in the PRU were 'known' to have behavioural issues and this again was generally uncontested, as a consequence disability as a causal factor driving behavioural challenges was rarely considered.

Looking across both contexts I concluded that 'formal knowing' in the special sector was shaped by the population of students it catered for. Hence the 'formal knowing' of pupils was established through admission, effecting a conceptual platform through which future and emergent 'knowing was filtered'. I also concluded that in the mainstream, 'formal knowing' was still in progress; as such was subject to the ongoing causal debates that were identified in Chapter five, framed around nature versus nurture.

7.3.5 Blame and empathy (simultaneously)

Parents in both contexts, were regularly viewed as a contributing factor to pupil difficulties. In the PRU, however, there was ongoing suggestion that pupils were

placed at risk by familial deficit. As a teacher from the PRU states, “at home there's no consistency, they can act out here (school) it's safe, but at home they can't” [c/t]. This statement illustrates a very precise form of ‘formal knowing’, one demonstrating both ‘knowing’ in a causational manner and empathetic ‘knowing’ in relation to the difficulties the pupils are considered to face. Indeed it was rare that the pupils were personally blamed, even where parental over-indulgence is noted as this teacher states:

“Jason’s mum gives him £5 if he comes to school! Yeah some of them reward them [pupils] with expensive gifts, Sonny in KS 4 gets loads of gear bought, it’s just rewarding their bad behaviour - they don’t stand a chance”.

This comment suggests staff at the PRU were both conscious of and held sympathy toward the effects of their pupils’ familial culture. This also stood in stark contrast to the more ambivalent attitudes of teachers indicated in Chapter five, which alluded to little or no compassion toward the pupil as a victim of circumstance.

Hence although parental accountability was common in all contexts, the ‘formal knowing’ staff at the PRU exhibited at classroom level was complex and empathetic, differing in form from that which I had witnessed at the ISS. ‘Formal knowing’ at the ISS - whilst medically informed - also extended to parental judgement. These were similar in nature to the opinions teachers in the mainstream expressed in terms of judging familial competency. ‘Formal knowing’ in the mainstream was guided by perceived impact in the classroom and was thus contextually specific, in contrast ‘formal knowing’ in the PRU resembled in shape, if not content, the guise of ‘familial knowing’. Such ‘knowing’ was considered to indicate a deeper type of ‘seeing’, one which extended beyond immediate presenting differences, embracing not only contextual triggers and the implications of difference, but the child’s core personality (being). As an observer this extended ‘knowing’ appeared nurturing of the children. Indeed senior staff in conversation suggested to me that their role was to focus not only on the immediate difficulties of the child, and need to reintegrate into a further school placement, but equally to consider the potential life trajectories of the children without school and wider agency interventions. In this sense the PRU was acting in a similar frame of mind to a parent, projecting forward to possible dangers, in order to prevent them.

7.3.6 'Being known' and its relationship with exclusion

Being 'formally known' has been shown to be complex and related to multifarious social factors. In terms of knowing as a precursor to blame and exclusion it is useful to consider Levitas's (2007) distinction between 'social' and 'deep' exclusion, whereby the latter refers to exclusions based across multiple dimensions of disadvantage. Such a distinction is not new, indeed Miliband (2006) stratified further, distinguishing exclusion on three levels; 'wide', 'concentrated' and 'deep'. In both cases, 'deep' exclusion is used to indicate disadvantage and disengagement 'across more than one domain or dimension of disadvantage, resulting in severe negative consequences for quality of life, well-being and future life chances' (Daniels and Cole 2010, pp 116).

Looking again at the socio-economic status of many of the parents of pupils at the PRU, one can suggest that those identified as eligible for free school meals can be one indicator of 'deep' exclusion. These demographics (see point 6.2.1) contrasted sharply with the more evenly distributed parent population at the ISS. Thus despite Thackray's (2013) observation that systemic barriers were primarily implicated in disadvantage, such disadvantage is found to impact differently across class and cultural divisions, supporting previously referenced assertions that class remains a major indicator of an ability to negotiate and resist school exclusion (Gazeley 2012, 2015, Hodge and Wolstenholme 2015).

Looking back to Chapter five and Leanne's struggle to obtain a diagnosis for her son, it appeared to me that it was the limitations of Leanne's socio-economic background (as described in Chapter three), rather than her son's clinical presentation which impeded any 'formal knowing' of her son within a disability context. Thus despite the claim by one participating SENCO that "there is an expectation that every teacher does accept that they will have some of these students (students with disability and SEN) in their classes", additional social factors shape initial impressions and colour how a child comes to be 'formally known'. This 'knowing' is equally determining of outcomes.

The processes of 'formal knowing' might be reasonably assumed to be informed objectively and professionally, yet as the following SENCO cautions in relation to the mainstream "I don't think we can assume that they (teachers) are knowledgeable and skilled in how to cope and deal with them (pupils)". Such opinion challenges Rafalovich's (2001, a; b) claim of an alliance between the

teaching and medial professions and also the ambition of the recently introduced code of SEN conduct in the UK (DfE 2015a).

7.3.7 Blame

At the PRU familial insufficiency was infrequently stated, rather appeared in response to my enquiries to be a given. Something 'known'. PRU pupils had 'difficult' home lives, it was part of being a PRU pupil. This 'knowing' positioned PRU parents as a causational force. However this was incongruent with my own experiences, it was also unsettling, given the struggles and sacrifices we had to make as a family in order to help our son's progress to adulthood. This taken for granted 'knowing' did however resonate with some of the narratives shared by families who spoke openly about the sense of blame they detected as the following comment illustrates:

"I was made to feel like a bad parent, yet the child paediatrician turned round and said some schools don't really understand what the symptoms of some disability conditions are. She was trying to defend them saying that they don't understand, but that doesn't excuse the way they treated me".

Although most of the time the PRU operated a fluid system of rewards and sanctions, situated in the moment, I also witnessed other times when the sanctions levelled against pupils by particular teachers appeared designed to deliberately inconvenience and punish the children's families. On several occasions I overheard the C/T and the assistant affirming the decision to hold a child back because of classroom behaviour, despite the known inconvenience to the child's parents. On one of these occasions the C/T openly expressed indifference to this and stated "well it serves her right, she should see what we have to put up with". This attitude further supported the previous indication noted that staff held parents more than the pupils accountable for the child's difficulties. It also emphasised the unequal relationship between parents and PRU staff and from the outside looking in, I could see no way of circumventing this positioning. It resonated with Holts (2008, 2010a) research amongst families subject to compulsory parenting orders and the sense of powerlessness they detected. I did not have the opportunity to engage with parents from either the PRU or the ISS and it would have been useful to have been able to gauge the extent to which they felt able to resist the negative ascriptions levelled toward them.

The tendency to hold parents accountable was common to all school contexts and during my time as a volunteer in both contexts I observed staff conversations which implicated parents as contributory to their child's difficulties, particularly where parents appeared to be resistant to school 'expertise'. Parental resistance was viewed as unreasonable and there was little evidence of staff valuing or conceding to 'familial knowing' in any of the school sectors.

Whilst writing up this research the head of Ofsted, Sir Michael Wilshaw is recorded as stating "we should be tough on feckless parents who allow their children to break the rules" (BBC 2016). The position of PRU staff personified this sentiment and further supported the impression that behavioural difficulties were considered to be modifiable, responsive in essence to both will and sanction. These beliefs run contrary to the working definition of disability and further convinced me that 'behaviour' did not hold axiomatic association with disability.

Looking at my own experience in mainstream schools and that of some of the families I interviewed, I determined that the medical and social certainties that were apparent in the ISS and the PRU were unmatched in the mainstream. As a result there was a dependency for 'formal knowing' on aligned professionals from the medical field, which as has been suggested in Chapter five, paradoxical conjured tensions and led to a divide between 'medical knowing' and 'pedagogical knowing'.

7.3.8 The economic implications of 'formal knowledge'

Neither provision extended admission solely on the basis of parental or even pupil choice. Typically, admission was negotiated on the basis of formal knowledge and the profile this engendered. Parental input varied in these processes, not only in relation to skill and cultural position, but differed markedly between the two contexts. The most obvious difference I found was that pupils were 'sent' to the PRU, whereas pupils 'sought' ISS placement. A solid evidence base was central to successful placement funding, and a primary precursor to admission. Notably mainstream state education is free in the UK at the point of delivery, in maintained schools and academies, but is not in the

special sector. Therefore placement funding was a precursor to admission and during my time at the ISS, was observed to jeopardise and deny placement.

'The formal knowledge' coalescing around the pupil was found to be an integral part of the process of admission into the special sector, just as it was integral to exclusionary processes in the mainstream. This 'functionality' supported Foucault's (2000) assertion that claims to knowledge are rarely neutral (pp 567). As I discovered during my period of volunteering and as a parent, 'formal knowing' is purposeful and in the education system is shaped by the criteria laid down to secure both needed resources (Florian 2008a) and the legitimacy or discontinuity of placement.

The faith that parents indicated in the special sector appeared genuine, even if, as I found, it to be misplaced. Nor can it be said that the ISS was openly inclusive, as even though on-roll exclusions were rare, it was apparent that ISS exclusions were pre-emptive, executed through admission screening. Notably ISS policy dictated that pupils with 'behavioural' problems were unsuited to the ISS, even though I witnessed pupils with behavioural issues regularly during my time at the ISS, extending from the disabilities the children held (as is implied by the regular use of the calm room, described on page).

Stringent selection processes at the ISS acted to prevent pupils whose difficulties were not warranted being admitted. Notably listening to staff conversations, during the year I spent at the ISS I was not aware of any discussion of exclusion, it was much more common to hear staff talk about pupils unsuitability for the ISS. There was a pre-emptive screening programme, where prospective pupils were offered a trial period as part of the placement process. These children were colloquially known as 'assessment children' and involved a two week placement to enable staff to gauge 'fit'. During my time at the ISS I was aware of several 'difficult' pupils being denied a permanent placement.

In comparison the PRU had a policy of exclusion, which in the context of a PRU seemed a little absurd. Nevertheless it is important to emphasise that some of the pupils at the PRU had extreme tendencies to violence that to retain these pupils compromised both staff and pupil safety. Exclusion from the PRU was rarely absolute, when in-house placement failed there was provision off site,

known as outreach, if this also failed it was at this point that consideration of exclusion was likely.

Whilst funding was also an issue at the PRU, it was notably less so and indeed appeared not to benefit the institution directly, unlike the ISS. Looking for explanation it seemed reasonable to suggest that this in part was due to the PRU being one of the authority's own maintained schools. Hence finance was staying 'in house' and pupil relocation within the authority offered a solution to an out of school child.

Despite their claims to 'special' neither sector posed any real challenge to the dominance of mainstream provision. Nor did either specialist provision give the impression of trying to compete with the mainstream. Both sectors appeared complicit toward their role in supporting the mainstream, essentially 'mopping up' those pupils the mainstream could/would not accommodate. Looking at this role, it appeared to be the antithesis of 'special', as both the ISS and the PRU were positioned as secondary, a last choice, whose need had to be evidenced to secure placement. The primacy of the mainstream as the default educational provision in the UK is evidenced further through the common practice of re-integrating children from the special sector back into mainstream when a child's progress exceeds expectation. I suggest that if the special sector was positioned within the portfolio of educational provision as an equal partner; pupil progress would be substantiating of that sector's pedagogical success, as it is in the mainstream, yet such success serves to legitimate the reduction of SEN funding and at times a return to the mainstream.

7.3. 9 What is 'special' about 'formal knowing' in the special sector?

It is telling that many of the issues raised by parents in this study surrounded what was considered 'known' and indeed there was two aspects of 'knowing' that parents reported were lacking from the mainstream. Firstly Freya suggested that effective 'knowing' really equated to understanding. This was viewed as necessitating an open and honest channel of communication between teachers and parents, one which extended beyond issues of pedagogy and learning:

"It's just about understanding really, understanding about the lifestyle of a child with not just the autism just the whole range, understanding because your life just doesn't tick by like normal peoples do, it doesn't at all does it? It's very disjointed and an understanding, a better understanding really".

I had experienced such a lack of understanding myself and could empathise with these sentiments, most particularly in relation to the effect of school on the child at home. Hence I had always wondered if a special school environment would have offered a greater understanding and more effective response to my child's difficulties.

Secondly Chris (Sacha's partner) suggested that the lack of 'formal knowing' in the mainstream context stemmed from an ideological vision, disavowing of the practicalities of implementation and engendering disadvantages onto those least able to resist:

"It's a bit like care in the community isn't it? You have this grand idea so you close down the mental health in-patient places and don't fully replace support. I think there is a parallel with the way the special schools have been closed and care supposedly integrated into the mainstream".

Both Chris and Sacha indicated irritation at this lack of appropriate provision, suggesting inclusion to be an ideological impracticality, a "grand idea", which for them failed to deliver. Indeed concerns toward the effects of inclusion in the mainstream consistently are used to support a continuance of specialist provision (Warnock 2005, Cigman 2007, Humphrey 2008a; b, Kauffman 2015).

It was notable that parents were rarely visible at either of the special schools. Communication was mainly conducted through 'home books', or in the case of the PRU, phone calls to the family home as parents rarely engaged with staff. Thus the glimpses I had of the parent/school relationship were gleaned from staff conversations. These conversations were often informal in nature and suggested that the unequal relationship between parents and teachers witnessed in the mainstream, persisted in the special sector. Teachers indicated during communal 'chat' that they considered themselves by virtue of context and role to hold a 'specialised formal knowing', which parents by extension were considered not to hold. Honkasilta (2015) found parental desire to input on an equal basis was inhibited by the unequal relations that exist between parents and schools. Finding that just as parents were mistrustful of the adequacy of teachers knowledge so too were teachers resistant to parents knowledge claims.

7.3.10 Different forms of 'formal knowing' in the special sector

Looking back on the conversations with parents, the special schools they depicted most closely resembled that of the ISS, not the PRU. This

differentiation may well reflect their belief that such a move was through informed choice, reflecting the shortcomings of the mainstream, rather than the result of a decision made by the mainstream in the form of a permanent exclusion. Indeed the criteria for entry to the ISS is subtly different from that of the PRU. The former is frequently associated with 'need' and necessitates evidence of the mainstream's inability to meet such need, alongside medical evidence to support disability status, if the local authority is to fund the placement and the school is to accept the application for placement.

In contrast entry to the PRU is rarely associated with choice, rather it holds association with school misconduct. Such association was witnessed amongst the pupils at the PRU as the following field notes indicate:

Talking to pupils they indicated that the PRU was a school that you got sent to for being 'naughty', yet they also told me that Thorps EBD School was a mainstream school for pupils with problems. The five boys I spoke with (in a group) all aligned themselves with this position and stated that was their likely destination. [FN/PRU].

These distinctions were troubling as the PRU was described by its head as a short stay assessment unit for pupils, a link in the chain to placement reallocation. Notably none of the parents, despite the enormity of their challenges, mentioned either the role or indeed experience of a PRU as a short stay assessment unit. They did however indicate awareness of special schools as somewhere they would like their children to go. Indeed the parents who alluded most graphically to their children's behavioural difficulties, expressed satisfaction and welcome at the expertise of their children's special EBD schools.

The parents in my study also indicated that their mainstream schools discriminated between the types of needs that led entitlement to 'special school' provision and those that led to an 'EBD' school:

"I think that it is treat differently when it is behaviour. I mean they say they can manage children who have learning difficulties or who have Asperger's, Autism things like that, but when you have a child who has behaviour difficulties it is just classed as naughtiness".

Such awareness supported my contention that there were differing attributions levelled toward 'behaviour', than those accorded disability.

7.3.11 The fusion of 'familial' and 'formal knowing'

Parents in this study emphasised their attempts to have their children recognised as they themselves recognised their child. Chiefly as blameless through organic or developmental circumstance. To be effective in this task they also needed to position themselves as knowledgeable or professionally supported (Emerald and Carpenter 2010). Nevertheless once parents secured a 'special school' placement, parental knowledgeability was less determining. Indeed for parents at the ISS there was an informal expectation that parents would concede to staff expertise which was only revealed when parents did not exhibit due deference. For parents of children at the PRU knowledgeability was the antithesis of professional expectation, and constituted a deviation from the anticipated scripts that circulated around 'out of control children' and 'behaviour'. Thus although these were unstated professional expectations, in working practice they impacted upon 'formal knowing' and mitigated against equal parent/teacher collaboration.

For parents across all sectors, the processes of 'formal knowing' conferred varying types of accountability. Nevertheless where behaviour was an issue, pupils identities was shaped by the nature of their misdemeanours as was the child's family. Behaviour was imputed to be a wilful act, not a symptom of an underlying disability. Although in the PRU, accountability was transferred to the parents, rather than the child. In this context an empathy for the pupils was detected as the following comment indicates:

"Many of the kids parents were here themselves so they don't stand a chance, it just goes round and round". (PRU C/T).

This served to position many PRU pupils in their teacher's eyes as victims of their circumstance. This empathy was notably absent from the mainstream and did not emerge in any consistent form as relevant as a mitigating factor.

One of the key forums for the stating of truths and needs is during the drawing up of an educational statement; yet here too wider factors, typically those of a financial nature, interceded in what was accepted as 'formal knowing' or more simply pupil need. The statementing process is intricately bound up with the resources allocation and supports Florian's (2008a) assertion that disability

classifications are functional in the education context as a means of assessing entitlement to resources. The formalising of a child's needs in the educational arena may thus be more aptly considered, less of a forum for the consolidation of 'knowing', rather a forum for the metering of resources. Such reconceptualization reinforces Tomlinson's (2015) assertion that there is a lack of neutrality in relation to both the configuration and allocation of educational provision. Indeed parental narrative highlighted the effects of a skills divide between parents, in terms of desired outcomes and identity.

'Formal knowing' may therefore be conceptualised as the outcome of a protracted 'fight', rather than a collaboration, a fight Andy (parent) states is common to all parents of children with disability and SEN:

"What was it someone once said to me?"... "You can't say special needs in a sentence without mentioning the word fight before you get too far into a conversation".

The guise of fight is exemplified in the following narrative in relation to the statement process, and alludes to the political and strategic game-playing that appears endemic to the outcomes of 'formal knowing':

"I mean the one that came back was useless, the usual bog standard one size fits all, and you think no, so you have to stick your ground and re-write it and keep re-writing it and re-writing it. It is a kind of who will blink first, about whether you can back everything up with evidence, there is this veiled threat of legal challenge in the background, so I feel so sorry for people who don't have the resources that we had to navigate the system, you see if you don't know your way around the system you have no chance".

The tone of this comment demonstrates the often unseen negotiations in the pursuit of 'formal knowing' and the inherent relations of power. Thus this may also explain why parents at the ISS were less visible, as for them, they had achieved many of the objectives the parents at the mainstream were still pursuing in relation to access to a statement and access to a special school:

"I thought it's the start of the year and I am going to get my son a statement [laughs]. I mean who has this as a goal? So I went into the school and told them this, they said 'oh no he is doing fine', but I said I was not happy and in the end I had the autism outreach worker, and the parent partnership worker, actually I think it was just the autism worker there, and I said 'if you are not going to help me get this statement, I am going to do it myself', and then there was loads of mucking about and flapping and then they said, oh ok we will help you".

Harre (1999) suggests that positioning is implicit within the dynamics of social communication in that 'positions are relational...for one to be positioned as powerful, others must be positioned as powerless' (pp1). Hence although at a medical level, neurodevelopmental conditions may be considered random, their formal recognition appears to yield from the outcome of contested knowledge

claims, which constitute in themselves positioning acts. The mother quoted above, was persistent and indeed did achieve her goal of a statement. Other parents were not so fortunate and were unable to resist the negative ascriptions levelled at them. I asked one mum how long she had been fighting for recognition for her son and resisting the label of 'naughty', she told me "since year 7 really and he will be in year 10 in September, he has never had a full day in school really.

7.3.12 Parental positioning or resistance?

How parents engaged with schools and presented their children's difficulties can usefully be viewed as positioning activity, although parents did not refer to their actions in those terms. Nevertheless parents were contributory to the nature of 'formal knowing' as their presentation and skills were noted towards the sense teachers and wider professionals made of the child's differences. Ryan (2009) drawing upon Foucauldian notions of the symbiotic relationship between power and resistance, suggests that social activism may also represent a means of resistance, a means of countering the increased visibility parents are known to be subjected to (Kingston 2007). Certainly the parents in my study indicated a determination to have their children and indeed themselves 'seen', not as deficient or feckless, but as ordinary families, managing extraordinary challenges. Notably Holt (2010a) similarly found pockets of resistance amongst parents, who in the context of compulsory parenting orders were least placed to resist. These parents were found to embrace the very limited means at their disposal, to prove, not however to others that they were competent, but to themselves. Such action suggests there to be very complex effects of negative parental ascriptions, which are themselves worthy of a longitudinal study.

It was notable that parents in my study who struggled to adapt and who lacked the resources to be effective demonstrated their frustration in ways that alienated them more, as Rogers (2011) states, 'they (parents) do not always behave in ways that health, education and social work professionals deem to be the most appropriate, and they are sometimes blamed for their child's difficult behaviour' (pp 565). Leanne in particular offers an example of the tautology of blame some parents become embroiled in, as is similarly found by Farah's narrative. Unsurprisingly the parents I engaged with who lacked adaptability and

wider skills were by necessity reliant on the skills of the professionals, reliability which Leslie Henderson found personally to be inconsistent. This led me to consider more deeply how special were the special schools I engaged with; and in particular was their support and knowing superior to that of the mainstream? The following section offers my conclusions based on my time in these two very different special schools.

7.4 Section four – Concluding debates

Having spent one day a week over an entire year at the ISS and one and a half years at the PRU I felt suitably placed to consider what was special about the pedagogy in these special sectors. Up until the point of volunteering my familiarity with the special sector mostly resembled 'formal knowing', centred on the big debates in academia, not least issues of rights, stigma and the enigma of inclusion. Personal considerations interceded in this 'knowing' and challenged my perceptions of the special sector, leading me to re-evaluate its role in the education of disabled children. Ironically because of the many battles I have engaged in the mainstream, I now celebrate the mainstream's potential, when it is managed reflexively and creatively.

Looking back at this personal journey, I found that it was creativity and responsiveness that retained one of my younger sons in the mainstream, despite the excesses of behaviour he demonstrated, which had led to years not months of school absence, in the form of legal and illegal exclusions. It is notable however, that this creativity stemmed not only from my persistence within school, but in the first instance from my insistence of medical evaluations which led to an eventual diagnosis. This diagnosis was not merely descriptive or generative of understanding of the difficulties my son faced. It accorded rights to my son and responsibilities to his school. This was the juncture which opened spaces for discussion and the funding to creatively fit together a bespoke package of support to enable my son's continuation in the school of his choice.

Notably the creativity we have benefitted from as a family is suggestive of the cultural shifts Booth (2001) initially emphasised to be a key factor in the development of inclusive schools. Nevertheless, the continuing backdrop of legislatively legitimated exclusion rates, suggests that such inclusivity is destined to remain an ambition. Particularly as my data indicates that inclusion

is not guaranteed, even in the special sector. Rather it is brokered on the basis of interpretations of entitlement, led chiefly by the presentation and collation of 'formal knowing'. Such 'knowing' appears to resist 'familial knowing' through the positional barriers that punctuate school procedures, which are themselves founded upon an ever present undercurrent of parental accountability.

7.4.1 Specialist pedagogy in the ISS

Upon reflection, was anything special about this sector and how did it impact on understandings of disability both within and without? Firstly all pupils on roll had diagnosed disability conditions, indicating a tendency toward medical understandings of disability. Yet this was not absolute as the previously referenced conversation about ADHD indicated. Parents nevertheless appeared comfortable with a formal medical diagnoses, which may itself reflect practical necessities. Indeed a statement of SEN was obligatory to secure a local authority special school placement, which itself invariably was substantiated on a formal diagnosis of disability. I found that the faith parents expressed toward the special sector indicated a clear challenge to the supremacy of mainstream. It was especially telling that parents and teachers in the special sector expressed belief that exclusionary barriers were inherent to the constitution of the mainstream; and that disabled pupils were especially vulnerable to exclusionary practices. As one teacher in the ISS stated, the structures common to the mainstream cannot accommodate easily pupils who deviate from 'typicality', thus leading for some pupils to serial exclusions. I determined that the awareness of such barriers was compatible with the social model of disability, despite the ISS depending upon medical delineations of difference. Despite being considered segregated provision, emphasis on inclusivity was founded upon a wider definition of inclusion which exceeded a mainstream/special dichotomy. Professional expertise was highly prized and staff indicated confidence in their ability to meet their pupils needs. This was the key feature deemed 'special'. Disability effects were adjusted for, both in terms of staff configurations [medical and educational] and indeed building layout [calm room]. Difficulties were thus pre-empted and managed in the moment, rarely warranting recourse to phone calls home or exclusion. Does this indicate a 'special' understanding of disability? It might be argued not, rather reflecting

an honest appreciation of the messy effects of disability, an embodied appreciation.

In relation to categorisation equity, my observations suggested that despite an embrace of a causal medical model, there was residual discomfort toward behavioural disabilities, as suggested by admission protocols. Similarly, acceptance of a condition appeared no guarantee that complicity in relation to disability presentations would not be levelled at the pupils' parents/carers. A paternalistic culture was evident, whereby school and staff were positioned as experts, conversely positioning parents/carers in an inferior position. Parents were frequently positioned as needing guidance in respect of their children's management, negating effective partnership.

As all pupils were 'disabled', there was at times a suggestion of complacency, rendering them non-special. Nevertheless, disability hierarchies were evident: some pupils appearing disproportionately accountable where corresponding peers were not, led by teachers' expectations of individual pupils. Similarly, despite the input of medical evidence and a statement of special educational need, some routine questioning of diagnostic application and ability to moderate behaviours was observed, typically amongst 'higher functioning' pupils. Ultimately, pupils had to demonstrate 'special' to secure admission and retain 'specialness' to remain. Placement was thus determined not on need or individual benefit, but on demonstration of deficit and incapacity to manage in mainstream settings. In such a frame, special school provision was not an equal alternative, rather an overflow, supporting the mainstream, not offering an alternative to it.

So in the context of the ISS is the term 'special' appropriate? Certainly the medical expertise and willingness to dispense medicines and emergency medical/residential care, did warrant accolade. Yet I would dispute that this is reasonably described as 'specialist pedagogy' as the skills in this respect revolve around pastoral care, rather than the learning relationship inherent to communal education. Looking toward this learning relationship it was more difficult to establish what could be depicted as special. Indeed as stated (on page) there were instances in the ISS which raised concerns. These revolved around the pupil/teacher relationship and the potential for abuses of power without the checks accorded by the usual visibility in a communal classroom.

In the context of the ISS, all children were disabled and thus none were 'special'. This was a major concern and a demographic circumstance that led to a complacency and at times unrealistic expectations. Although the pace of teaching was adjusted to reflect the pupils difficulties and the staff/pupil ratio was generally one teacher and classroom assistant to seven pupils, this did not always mean greater attention. Far from it, I observed on numerous occasions pupils left to self-manage whilst staff conducted private conversations, I also observed staff openly discussing pupils within earshot of those pupils.

These concerns reaffirmed my commitment to a fully inclusive education system. As a parent of a child with significant vulnerabilities I can attest that the mainstream whilst far from perfect, does through its diversity guard against many of the concerns I identified in the ISS. What the mainstream lacks, however, is an unqualified or pragmatic attitude to difference and systems that can respond flexibly to events in the moment. Notably the forms of difference which were less tolerated revolved around behaviour, which was interpreted as a continuing lack of acceptance that behaviour is an indicator of disability.

7.4 2 Specialist Pedagogy at the PRU

The most notable feature of the PRU was the dedication of staff, who showed a tireless commitment and genuine affection for most of the pupils. Two aspects of this observation may be described as worthy of the claim to 'special'. Firstly was the tolerance of PRU staff and their ability to work with the extremes of behaviour I observed. In the PRU the traditional pupil/teacher relationship was altered, defying the system of cumulative sanctions that commonly in the mainstream lead to exclusion. Secondly, these more equitable relationships led to different forms of 'formal knowing' and as suggested resembled in form the deeper emotive 'familial knowing' identified amongst families. These dispositions were evident across the entire staff base and I rarely detected disaffection from staff. Indeed staff indicated great awareness of the challenges pupils had encountered in the mainstream and that these challenges were not always the 'fault' of the pupil per se. To the contrary, they were described as stemmed to a large degree from mainstream inflexibility and an intolerance of behavioural difference in particular. Staff consistently expressed concern that mainstream schools were selectively screening their pupil base and using exclusion to remove 'difficult' pupils.

Despite the PRU's successes with 'excluded' pupils, staff indicated concern towards the lack of communication between themselves and mainstream settings. As the following statement suggests, this has resulted in PRU staff having little means of measuring their pedagogical strategies against successful reintegration of pupils back into the mainstream:

"We never get to hear what happens to them, unless they get kicked out that is... It's really upsetting, we never get to know if we have been successful with them [pupils] or not, it would be good to know, it would inform our practice. I guess it's just how the system is, we are just here to take them [pupils] when no one else will, sort out the messes that have been made in mainstream and send them back, I don't think we are really valued"(CT in-class conversation).

This class teacher also summarises the irritation that was often evident amongst teachers in the PRU, toward what they felt was a dismissal of their expertise. So although the PRU did not identify itself as a 'special school', not in the manner the ISS did, it did consider itself skilled at managing the extremes of behaviour the mainstream rejected. This was a role that was taken very seriously, as indeed one teacher emphasised "if we don't catch them now, it will be too late and then what happens"? Recognising the unique dynamics between staff and pupils at the PRU I felt it important to question why there was not a stronger relationship between the mainstream and the PRU, working to prevent, rather than mop-up exclusions.

Notably many pupils at the PRU were highly vulnerable, a state which is confirmed by the National Children's Bureau Audit (2011) and which suggests that PRU pupils have complex vulnerabilities which are obscured by challenging behaviours. PRU staff indicated recognition of these vulnerabilities and this was a testament to the breadth of their 'formal knowing', brokered in the main through the relationships forged in the PRU. This contrasted sharply with the attitudes teachers in the mainstream displayed and who appeared divided in their opinions toward the causes of pupil 'behaviour'. These insecurities were found to have serious implications for the confidence staff indicated to have in responding to behaviours of indeterminate origin, a barrier that has led to questioning over the usefulness of disability labels as a mechanism to inform pedagogy (Florian 2008).

This contention is supported by the dynamics I observed in the PRU and the simplistic tenets that underpinned it are amenable to any educational context, if there is willingness to reconsider the assumptions that legitimate accountability and the accumulation of sanctions which often lead to eventual exclusion. The dynamics referenced involved staff at the PRU responding in the moment to pupil misdemeanours and applying small sanctions in that moment. These sanctions rarely accumulated and indeed for much of the time pupils moved between challenging and complicity several times in the course of a day. Staff tended not to over acknowledge negative behaviours, preferring instead to emphasise pupils attempts to redeem situations. Can this be called special pedagogy? In my opinion yes, as it offered means to retain in school pupils who had already experienced rejection and as such were suspicious of their placement security.

It is important not to over-romanticise the response of the pupils in the PRU. They were challenging in every way and there was little doubt in my mind that they would have been difficult to manage in the context of a larger mainstream classroom. Nevertheless, it was notable that the protocol of not accumulating sanctions and escalating challenges beyond initial proportion was an effective way of building the pupils self-confidence and their identity as learners. The most effective teaching observed, peppered sensitivity with humour, enabling relationships and progress to be built upon a genuine sense of rapport and trust. It also enabled reasonable leverage for the pupils to make mistakes without undoing previous progress. The effectiveness of this approach was shown in the enduring connections to the PRU some pupils had forged, returning in adulthood to show appreciation and their successes.

What are the implications of the discourses operational within the PRU? In relation to understandings of disability there appeared resistance to defining behavioural challenges along such terms, both amongst staff and indeed parents. Where parents had followed a diagnostic route this was frequently challenged by staff in terms of legitimacy and self-interest motivation. Unlike pupils at the ISS who represented a vast range of socio-economic groups, pupils at the PRU were over represented in relation to low socio-economic status. They were more likely to have erratic backgrounds and parents with support needs themselves. During placement I was unsettled by their

willingness to accept that such demographics offered an explanation and felt different demographics may have triggered an alternative lens. Even where disability was identified, it too was subsumed under the predominant behavioural modification model. Overall, staff excelled at responding to difficult behaviours, within a particularly bounded framework of understanding.

Disability categorisation as an explanatory framework was nevertheless found in informal conversation, depicted as an excusatory ploy. Did this suggest a contesting of categorisations? Seemingly not, conversations that ensued tended toward questioning of diagnostic application, rather than categorisation legitimacy itself, or indeed ability of pupils/parents to stage-manage the diagnostic process. It was difficult to assess what models of disability were employed as disability was an infrequent theme. Notably, where suggestions of disability as an explanation for difficulty was raised, it was greeted in staff room conversation with scepticism.

The PRU ironically did demonstrate specialist pedagogy, although whether this was deliberate or indeed directed by the practicalities of managing such extreme behaviours is unclear. The handling of pupil misdemeanours enabled pupils to manage and rebuild their identities within a controlled environment. The PRU did not employ a traditional cumulative school sanction code, resulting in accruing negative sanctions and thus identity. The PRU appeared as Masters at offering second third and even fourth chances. It was through such persistence and grace that pupils gradually responded, most evidenced amongst older pupils. It was amusing at one point following a request to support a KS3 group, pupils quizzed me about the 'little ones' and joked about how "radge" they were, "they're mad, always throwing stuff around and kicking off".

School surveillance protocols generally operate from a medical model of disability, stratified further through the status of discrete disability types as my data suggested. In the PRU and indeed the mainstream, a medical model appeared to concede to a generic model of behavioural modification founded upon external drivers, this suggested a social orientation as opposed to medical understandings. In the mainstream where this was most commonly employed, a dual and often paradoxical response was witnessed, involving acceptance of medical/psychological categorisations in principle, alongside selective questioning of diagnostic application and motivation to seek diagnosis.

What does this suggest in relation to understandings of disability in the PRU? Placement experience confirmed my own experience of bias toward environmental attributions for the explanation of challenging behaviours and a resistance toward understanding within a disability frame. This is significant as such tendency inhibits motivation to explore medically the causes of behavioural challenges, which have been considered indicative of certain 'hidden' disabilities (Curtis 2002, Hardwood 2006, Cross 2011). There are also further implications for appropriate educational responses, notably that some pupils may be channelled to EBD schools or left long term in the PRU whilst their needs remain inadequately understood (Hardwood 2006, Cross 2011).

7.4.3 'Special education' – was it as 'special' as parents intimated?

Parents in my study emphasised the benefits of a special school place, benefits which highlighted emotive referents such as belonging and acceptance. Catlin sums up what moving into the special sector meant to her daughter, sentiment that can be rationalised from the position of group belonging or rejection:

"I think the schools often try to put a round peg into a square hole, I mean Alice is happy now, at her last school she would pick her hands, over and over again until they were raw, but now she's one of the cool kids, that is what she said to me 'I am one of the cool kids now mam', and she has also got her first best friend".

Looking at Catlin's statement it is evident that feeling part of and being accepted were not positive experiences that were available to her daughter in mainstream school. Yet it is notable that there is no reference to 'specialist pedagogy', rather the 'specialness', appears to derive from group membership. Did I witness such belonging whilst in the ISS and the PRU? I would argue that in some cases yes, at the ISS the boys in my class were insulated against peer relationships that may have led to bullying, but they also missed out on the social learning opportunities which one suggests are vital if there is to be any eventual integration into mainstream society in adulthood. In that sense the ISS offered a false and misleading environment that could not be sustained in later life. Whereas in the mainstream as Allen (1999) previously observed, peers were in essence 'inclusion gatekeepers, which if carefully monitored held the potential to stimulate coping skills which are invaluable in later life.

In the context of the PRU, its claim to 'special' was led by the relational and accountability structures inherent to the institution, nevertheless the communal education of so many disaffected pupils was questionable, in a sense they

appeared to affirm their difficulties and resisted pro-school values, which were essential for any successful assimilation into the mainstream of school or indeed society. Nevertheless it was this which appeared primary to parental faith in the 'special' sector. Leanne similarly tells that her desire to move her son into an EBD school stems from the negative excluded identity he is absorbing in the mainstream, "I'm the first one waiting for him to come in and say 'look, school don't always care and neither do I', then what will they do"?

There are similarities and contrasts between Anna and Leanne's statements, both speak of belonging and the effects of acceptance and exclusion, conveying concerns that have also been drawn upon by opponents of inclusion (Warnock 2005, Cigman 2007). Yet they also operate to challenge the mainstream, in particular the exclusionary structures that lead parents to feel a need to remove their children.

In terms of access, parents experienced a subtle entitlement divide. Anna was able to have her child placed as she wished into a special school, yet parents Leanne and Farah both encountered a resistance on the part of their current schools to supporting a move. In essence the mainstream may be seen to be acting not only as a gatekeeper, but as a pre-emptive jury, as Julie states "they don't want him to go because the teacher thinks he is too bright and will bully the other children". Farah also expressed similar experiences and felt her son was being demonised, both in school and in the community. These experiences illustrate the pervasiveness of blame, where behaviour is an issue. They also support the contention that the attributions that accrue to behaviour deviate from a traditional disability frame. Such deviation opens up spaces for cumulative accountability. I suggest therefore that 'behaviour' (irrespective of disability status) serves to negate entitlement to (compulsory) school education in a manner similar to that identified by O'Connell in the legal system. Toward a deeper appreciation of the systems behind these effects, this thesis considers the data my study generated from a theoretical perspective, toward a deeper understanding of the distinctions evident toward neurodevelopmental disabilities that effect 'challenging' behaviour.

7.4.4 Final note

As a final point it is helpful to return to the areas of foci adopted in Chapter six, and to consider their significance within this sector which are listed presently.

The main question addressed of the mainstream sector was are all disabilities equally validated? Secondly it was an area of foci to consider why some children are more vulnerable to exclusion than others. There was also a focus on the level of confidence teachers expressed in relation to managing diverse classrooms given the rapid expansion of medical labels and finally attention was directed to the discourses circulating around difference, in particular those dividing between a 'nature versus nurture' explanation for difference.

The significance of this return is that it enables a consideration of what is different in the special sector. Is it the level of training, or culture of the school? Equally in what sense are the tensions noted in the mainstream reconciled in schools, who by definition rely on difference, particularly that considered too difficult for the mainstream. These are considerations which as a parent of children who were potential and actually service users, I found to resurface in varying guises at differing crossroads in my children's lives.

I felt then and if truthful probably still feel that in terms of what is best for the child it would be preferable to take the best of both sectors in order to forge a synthesis which could accommodate all children; and as importantly cater to the needs of all children without the spectre of blame and accountability. However that would require an address of the priorities and functions mainstream schools are subject to and perform, which as has been discussed at various junctures in this thesis, are found to exceed matters of education and are implicated in wider economic relations, as they also are in relation to the social and political spheres. Undoubtedly there was a greater level of expertise in the special sector, particularly in regards to the specific population to which they catered. These schools were not insulated from the demands the mainstream sector faces, but there appeared to be a culture of forgiveness in respect of official expectations in regards to summative success, although this was tempered by an observed greater demand to demonstrate success in other ways. In the pupil referral unit, attendance the avoidance of offending and successful reintegration were priorities I was informed by the head that the school was judged upon.

Similarly in the independent special sector, whilst there was stress on the school to produce evidence of pupil progress and the requirement to satisfy Ofsted inspectors, there were wider circulating discourses that mitigated against keeping pace with the mainstream. Notably these discourses did divide

between 'nature versus nurture'. The independent special school was heavily aligned to the medical and psychological professions and they were directive in how educational services were delivered. They hence had a voice in regards to what may be seen as educational success and failings, for they were primary to setting the boundaries of success and failure. In this both the mainstream and the special sector shared a commonality. Both were definitional of what successes could be gained. Equally in the PRU, attention was firmly in the environmental sphere, the pupils were seen (and to be fair were in the main) socially and economically disadvantaged. This dominance directed attention away from medical explanations for behavioural difference and as was discussed earlier in this Chapter, had a deleterious effect on how a pupil was seen and indeed known.

This brings me back again to Arnold (2009) and the argument that were there is a division of educational sectors and a mind-set which permits exclusion, there will always be those who are on the margins of educational services. Blame and accountability are the lynch pins that legitimate exclusion and for some special sectors such as the PRU and dedicated EBD schools define their role and existence. Problematically the experiences parents narrated and indeed those experienced speak to discrimination, yet it is a discrimination that only those implicated appear to be able to see. Toward a wider recognition there is urgent need to expose these practices to be discriminatory, rather than legitimately regulatory and that of itself will necessitate a much closer interrogation of the functions blame and accountability can be seen to serve. The concluding chapter of this thesis addresses these issues and looks to the experience and theory of blame.

Chapter 8 – Observing, experiencing and theorising disability accountability

In this thesis I have explored the origins of disability accountability as experienced by me and my family. As I outlined in Chapter one, these experiences were an impetus for my research interests. Particularly in regards to the reasons for, and legitimation of, unfavourable response to challenging behaviours, even when they are known to be representative of a neurodevelopmental disability. I contend that all disabilities are not equal and that disadvantage is disproportionately levelled toward what is termed 'behaviour'. Furthermore, I demonstrate that acts of disadvantage can manifest as accountability and blame, action which I argue are tantamount to disability discrimination.

Toward a wider appreciation of the nature of disability challenge, I have identified three main frameworks from which to explain the nature of disability and how it can be understood. These were a medical frame; a constructionist frame and a relational framework. Within these three paradigms of explanation, two main avenues of challenge emerged: firstly challenges which emanate from within a medical frame and which are concerned with the integrity of a classification and the fit of the criteria that is delineated for diagnostic purposes. Secondly, challenges that contest the medicalisation of difference per se and the scientific truths upon which they are founded, tending towards a constructivist explanation for stratifications of difference. Thirdly, I point to a relational framework which extended between both the medical and constructionist arenas. It was in this context that the dynamics of relational engagement were found to be directed what I have termed 'knowing' and which refers to the sense made of difference and the inferences founded upon such sense making: directive of not only identities, but also entitlements to support and exoneration, or conversely punishment and exclusion.

To interrogate further the guise of disability challenge (either medical or constructivist or relational) in my research I explored the perspectives of teachers and SENCOs, to investigate whether they considered all classifications of disability to be equally validated, and if not why. I also explored how SENCOs co-ordinated the needs of pupils and teachers and what (if any)

barriers to effective disability response were perceived. Finally I was interested to explore whether the challenges I had faced were unique to me, or if other parents shared similar experiences. In combination the respondent groups (parents, teacher and SENCOs) offered a snapshot of disability understanding and opinion and so revealed both the locus of challenge and the premises upon which it was founded.

Across the data sets consistent patterns emerged, the most persistent being the presence of blame and accountability. This emerged in differing guises, but in all cases intimated the presence of ineffective channels of communication and pre-formed assumptions, which acted to rationalise its accordance.

Nevertheless 'challenging childhoods' were stated by parents to be highly visible and highly regulated, countermanding any notion of ill-discipline or wilfulness. Far from being complicit, the narratives parents shared highlighted the extreme pressures they faced, and the efforts they made to reduce their children's challenging behaviour. Parental narrative also indicated feelings of stigma and helplessness, concern for the future and of the way their children were 'seen' both in school and the local community.

In my research, behaviour was found to be inconsistently linked to disability, indeed its linkage very much depended on the persuasions of individual professionals and the ethos of the schools the children attended. As a result, parents expressed feeling vulnerable and strove to have their children recognised medically. Importantly, unlike teachers and SENCOs, parental concern transcended issues of educational achievement, but focused on longer term priorities and immediate emotional wellbeing. Parents also indicated sadness that their children were defined outside of the family by the difficulties they exhibited, and as such, were only partially known. Parents expressed a desire for their children's unique qualities to be acknowledged, yet felt teachers resisted their input.

Teachers and SENCOs showed an equal reliance on medical labels, to explain pupil difficulties and inform pedagogy, also to excuse where applicable a lack of progress and to support applications for additional support funding.

Interestingly, at times I detected a tension between the truths of medicine and those of pedagogy, particular that aligned to behavioural control. Thus where

medical protocols appeared incompatible with pedagogical protocols, teachers would err to the latter, which at times appeared to stimulate challenge to the medical validation accorded to the pupil. The contextual exigencies of the respondents roles was found to guide how each party came to know the child. I termed this 'familial' and 'formal' knowing. In addition I identified amongst teachers a tendency toward both a 'medical knowing' and a 'pedagogical' knowing, a duality which was at times incongruent and led to disability challenge, which appeared to effect conceptual congruence. The snapshot of disability understandings and concerns was echoed by the two prominent persons I interviewed separately, Baroness Warnock and Leslie Henderson. This affirmed that the respondent groups I had chosen were indeed representative of their wider populations.

In Chapter seven (subsection 7.3) I outline the nature of accountability as it was revealed to me during my research. It further considers the profile of the challenging child as constructed from both personal experience and the narrative of participant parents and is affirming of concerns raised in Chapter three in regards to the subjectivity of what constitutes trouble (Carlile 2013, Ribbens McCarthy 2013). This profile contradicts the notion of out 'of' control youth or parental complicity; rather it exemplifies the vulnerability and helplessness of the families who shared their stories. The relationship between the identified differing types of 'knowing' is presented, proffering explanation for why neurodevelopmental disability is unaccepted as mitigation for its behavioural manifestations. This chapter also highlights the effects of blame and its longevity across the life span.

Finally the chapter endeavours to propose a theoretical explanation, drawing upon the functions that blame and accountability may be seen to serve. This is unapologetically linked to wider understandings of the guise and exercise of power. The chapter concludes with a discussion of how the wrongs identified can be righted, alongside consideration of the extent to which such address is practical amidst the current interpretation of inclusion in the mainstream and its alignment with mainstream mass education.

8.1 Medical labels

The legitimacy of medical labels may be viewed as the consolidation of scientific truths. Their privilege may also be seen to accrue from the wider esteem the medical profession continues to enjoy. As discussed in Chapter two I considered this to be representative of an all-encompassing culture, rendering other explanatory frames unthinkable (Lupton (2012). Undeniably the notion that medicine operates as a culture, is a plausible reason why it has successfully deflected challenges to its own truths (Szasz 1974, 1987; 2012). As a discipline, medicine is aligned to the scientific method and speaks of certainties, probabilities and evidence: yet in respect of neurodevelopmental disability classifications, there are claims to truth, without certainty and without evidence. I found this to be a primary site of challenge in the literature (see for example Conrad and Potter 2000, Conrad 2005; 2007; 2010, Conrad and Bergey 2014, Timimi 2004a and Timimi and McCabe 2010). Notably, however, these arguments were not raised in my data. Equally, although the anti-psychiatry movement vehemently challenged the profession of psychiatry, their arguments were primarily directed against the orthodoxy and regulatory practices common to psychiatric practice in the 1960s and 1970s, whereas more recent challenges have been in regards to particular medical labels, for example ADHD and Autism.

To a certain degree the anti-psychiatry movement successfully raised awareness of coercive and unfair practices and was foundational to change within the profession. It may be said, however, to have had a lesser influence on challenging discrete classifications of mental illness themselves, despite the movement being underpinned by concerns toward a lack of tangible evidence to support the delineation of specific conditions (Szasz 1974, 1987; 207; 2012, Wakefield 1992, Aftab 2014). Deacon (2013) rightly asks 'how can mental disorders be considered biologically-based brain diseases, or valid medical conditions, when researchers have not identified biological variables capable of reliably diagnosing any mental disorder?' (pp 857). These concerns cannot be dismissed, as the management of many conditions includes elements of physical and behavioural controls and may reasonably be described as regulatory. In this sense there appears limited progress from the early

challenges levelled by the antipsychiatry movement and it would appear that we have moved into an era of control in the community, not care.

8.1.1 Medicine – influential and influenced

Foucault's (1972) writing on discourse offers means to further rationalise the influence of science, urging attention to beyond what is said, to a greater focus on who is speaking and notably who is not. This focus alludes to relationships of power and most particularly the power to define, a right which remains through diagnostic licence and professional delineations with medical practitioners.

Nevertheless as I have suggested, aligned professionals have adopted secondary professional positions and thus influence not only whether medical labels are pursued, but which conditions are assessed (Rafalovich 2001a,b; 2004). Such input raises questions around both ability to guide diagnosis, as much as it does the capacity for objectivity in its pursuit. For as my data suggests, teachers oscillated between what I termed 'medical' knowing and 'pedagogical' knowing, division which was found divided between internal attributions and those of an environmental nature. Similarly, teachers did not consider themselves experts, and indeed indicated concern toward their levels of expertise. Teachers also offered inconsistent opinions towards the range of classifications offered in their ranking exercises, which was itself a concern in regards to their objectivity when acting in a secondary medical capacity.

Medical labels were openly stated by teachers to be controversial when invited to comment on the deliberately controversial questions I included in the quick questionnaire I distributed. Medical labels were therefore found to be quietly contested. Equally teachers were critical of environmental factors and suggested that they were contributory to behavioural difficulties. Notably, teachers did not reference the school context as contributory, although it is suggested in the literature that they are (Waterhouse 2004, Graham 2008) although only in relation to the familial and cultural contexts, not in relation to the school environment. Hence the potential for objective pseudo-psychological evaluation was considered limited and may help to explain why some of the parents in my study struggled to navigate the diagnostic system and why they also felt unsupported by schools.

8.1.2 Medical Labels – the contrasting of theory and reality

The history of psychiatry and psychology is punctuated by concerns around control and abuse of power (Stiker 1997, Borsay 2005) yet retrospective personal records indicate that from the patient perspective there were benefits derived from the services offered (Taylor 2014) as well as critique in relation to stigma and the negation of rights (Atkinson 1997). Considered utility from the perspective of former patients suggests that there remains a need for such service provision, but only if stringently regulated. It is nevertheless notable that three of the parents in my study openly stated that their child needed a secure unit (for their own and the family's protection). This need is illustrated by reference to Sacha's story where it was explained to me that at one point of crisis, inpatient treatment was the only hope of moving forward and reclaiming the child lost.

The reality of the stories told by the parents and indeed my own, disinclined me to wholeheartedly embrace arguments that call into question medical labels and interventions. The realities spoke of need, of fear and of danger; these realities were not exclusive to my study, but are also suggested by Carpenter and Emerald (2009). Through ethnographic description, Carpenter and Emerald allude to the very real dangers and stress parents and children are exposed to; they also speak of the dangers of doing nothing. Particularly the danger of detached theorising when it does not put forward practical strategies or means to address the very real problems some children face. Nevertheless as Carpenter and Emerald note, there are both personal and systemic barriers to parents disclosing the more disturbing aspects of their children's difficulties and such barriers serve to marginalise further an already marginalised population.

Having first-hand experience of behavioural difficulties I could empathise with the reasoning of families and the desire to mask the less salubrious aspects of family life. Yet throughout the darkest periods faced, I also became defiant, this led to introspection towards why I and others felt such disposition. In answer I decided it was a similar tendency to that experienced by victims of domestic abuse, a tendency to not only shy from external blame, but also evidence of personal blame. This realisation was an impetus to break the silence and to explore and challenge the tendency to both blame and accountability. I found during the years of my research that whilst parents similarly placed were

comfortable talking to me as a parent in the same position, they actively avoided such disclosures even to family and friends. This realisation led me to conclude that the effects of behavioural disabilities amounted to a modern day taboo, and possibly even the last taboo of embodied disability effect. As such I considered this to be disavowing of any possibility for an open and embodied perspective to expose not only its realities and effects, but also the needs of the child and family.

Some parents spoke of a need for secure accommodation for their children and of the struggle to obtain this; and indeed inpatient psychiatric facilities have been seen to decline since the therapeutic move to care in the community (Saxena 2007, Keown 2008). Controversially the use of private inpatient special units is increasing, stated to be tailored to the needs of specific disability types, particularly autism (Patil 2013). These units have been welcomed (Woodbury-Smith 2014) as they are viewed optimistically as able to address the particular needs of persons with neurodevelopmental disorders.

However, as well as holding a potential to rehabilitate, their functions are also regulatory and at the very least, where admission is involuntary they incur the consequences of being considered lacking in criminal capacity, a status Scholten (2016) terms 'exemptions' (pp 205). Although such exemptions extend from the acceptance of incapacity as mitigation for deeds committed, there remains a sting in the tail to psychological exemptions which is fundamental to 'knowing'. This 'sting' refers to a disavowal of the potential for the individual concerned to change. This acts to both legitimate segregation from the community, as well as being generative of a profile of dangerous. The idea of dangerous is interesting; in essence projecting and pre-empting through segregation what someone 'might' do, not what they have done. As such it may be considered ethically questionable (Saxena 2007, Dimock 2015).

In my own son's case, although medical exemptions were eventually accepted by his school, such acceptance was an impetus to a health and safety assessment which legitimated untenable controls and restrictions (see appendix). This served to illustrate the impossible positions conjured when mitigation for behaviour is sought and granted on the grounds of disability. The narrative of parents also served to highlight the underlying functions served, namely regulation and minimising of damage or risk to wider parties. Hence for

parents such as Leanne, school responses compounded already pressing disadvantage. This was found typically not only in terms of additional supervision made necessary through limited school hours, but as Micha's story illustrated, through the intimation of blame and the questioning of familial competences. These strategies also represented an effective means of maintaining not only the status quo, but of emphasising the boundaries of acceptable and unacceptable difference.

Disability classifications may thus be seen to both explain difference and define the parameters of normal. Medical labels also conjure impression of sameness within a classification, generating expectations which may disavow the heterogeneity of persons across a spectrum. The privileging of a range of 'typicality' consolidated the feelings of ill-ease when faced with 'difference'. It appeared as a prompt to action. Thus when faced with difference, schools as indeed parents appear driven to do something, either to refer for medical/psychological assessment or to hold accountable and sanction where conduct is an issue.

It may be said that the failing of a pupil to exhibit 'typicality' or to respond to interventions drives organisational insecurities, prompts further challenge which generates vulnerability to accordances of dangerousness. Indeed, uncertainties around conduct appears to drive what and who is deemed dangerous. Kelly (2005) cautions 'concerns about danger and risk, provoke a range of practices and relations of regulation that have the potential (always) to impact negatively on young people' (pp 17). Problematically medical labels may themselves legitimate practices of regulation (in the name of rehabilitation), which when framed as the attempt to restore to normal appears the epitome of reason.

Runswick–Cole (2014) finds the call put forward by autistic lobbyists and advocates to re-visualise what has been termed neurodevelopmental disability as neurological difference (Sinclair 2005, Wrongplanet.net 2012), problematic in the current Neoliberal culture. Most particularly it was found by Runswick- Cole that the characteristic trademarks of Neoliberalism (personal responsibility and reduction in State support) were counterproductive to the best interests of many autistic persons. Thus although ideologically and ethically, equity toward human

difference is laudable, in working practice it may jeopardise a much needed right or opportunity to social and financial support.

8.1.3 The nature of disability challenge

Considering these dilemmas in terms of my own children and the families who participated, it is questionable whether the ideal of 'difference as variation' not disability would have been tenable or indeed helpful. Certainly in my own children's cases, at the very least, the potential for independence and gainful employment remains directly impacted on by the difficulties they possess, irrespective of how it is framed. The concessions gained through disability status are therefore largely welcomed and outside of periods of crisis, helpful toward their independence. Therefore it must be acknowledged that there are positives to medical labels in that they can bring both the understanding and support of 'difference'. Indeed the majority of families in my study sought understanding through medical acknowledgment, which was taken as an indicator of pragmatism. It would also appear that the faith they indicated in the special sector was led by such pragmatism, particularly the concerns and experience that the mainstream held barriers which served to disadvantage their children.

Florian (2008) cautions medical labels 'serve given purposes, which over time take on additional meanings' (pp 4-5). Notably across my data sets as well as in the literature this was most marked in relation to behaviour (Perlin 2005, Jull 2008, O'Regan 2009, 2010, O'Connell 2016). Labels serve not only to describe, but also to define; definitions which are generative of expectations and identities. The starkest example of this relates to the condition Schizophrenia, which through the identity of the classification itself stimulates public concern (Ferriman 2000, Angermeyer 2005). The guise of labels therefore may be seen to offer insight into functions served and expectations generated. As one SENCO suggested 'when you hear you're) getting a child with a known condition, you think oh I'm in for a bad year, but you have to force yourself to not think like that, rather to wait and see for yourself'.

In the above instance the expectations generated were offset by the professionalism of the staff member interviewed, yet it may be argued that labels act in a self-confirmatory manner as classically found by Rosenhan

(1974). This effect was found by myself, as at times teachers and medical practitioners would explain my child's behaviour by drawing upon his diagnosis as explanation. Nevertheless my personal experience suggested that where there was incongruence of classificatory expectation and presentation this could prompt school challenge to disability status, thereby legitimating blame because such status is disputed. Sacha spoke of witnessing this potential in school whilst a governor (see Chapter five para 5.2.2) and noted how such 'knowing' was inserted into everyday teachers discourse. The other main avenue of challenge that extended from perceived incongruences was teachers propensity to question both the applicability of a diagnosis, as well as was noted in the PRU, a tendency also to challenge parental motivation for diagnosis.

Interestingly, as discussed, despite the scepticism teachers indicated in the final questionnaire, there was a notable lack of direct challenge (through annotation or experience) to the integrity of discrete classifications of disability type. To the contrary, teachers in the mainstream indicated a reliance on these labels to make sense of difference in their classrooms, in a sense medical labels facilitated conceptual order, and were foundational to the information/communication systems that SENCOs in the mainstream developed. In contrast, observations in the special sector suggested teachers were less reliant on medical labels and in the case of the PRU, they appeared secondary to 'behaviour' and behavioural modification techniques. However as I suggested in Chapter seven, this may simply reflect the fact that pupils in both these contexts were already labelled as a particular type of pupil, rendering further explanation obsolete.

In the literature disability challenge was seen to emanate from three direct sources medical, constructivist and relational, (see for example Barkley 2002, 2011, 2012, Conrad 2007, 2010, 2014, Bursztyn 2011). However the data generated in my study revealed that teachers were largely unaware of these 'big debates', although particularly respondents at the NUT conference were keen to be given the opportunity to broaden their understanding. Challenges that did occur were based on eclectic knowledge and an overall broader 'knowing' of the child and family. This 'knowing' filtered into determinations of the nature versus nature divide, and it was notable that families actively sought

to impress as a means through which to influence how their children were defined (see for example chapter five point 5.2.4).

As a consequence I suggest that medical labels were essentially secondary to the first impressions both child and family gave, equally so the 'positioning' made available to parents through their own cultural and educational resources. As Baroness Warnock alluded to, conditions such as Dyslexia have been colloquially known as a middle class disease, not because of any increased vulnerability to the condition, but because there has been a greater ability of parents to pursue and acquire the diagnosis. These comments resonated as I reflected on some of the parents in my study, particularly Leanne, Farah and Ryan. Their stories told not only of the struggle to acquire any medical recognitions for their children's difficulties, but also the negative impression they themselves had made. As Ryan described:

"They asked me 'so do you think that you can with some support?' and I said 'oh yes we would love some support', thinking let's get some help to keep him occupied, to wear him out to give him some one to one support to manage his behaviour and what they offered was parenting classes. I thought what, we don't need support to make us look after the kids better, we need some support from them to say this child has got problems and when he has got serious problems he needs some sort of counselling and advice, but no - 'you need it'..".

Objectively parents who were able to deploy resources were most effective in gaining medical recognition for their children and irrespective of the rights or wrongs of this situation, it served to indicate that medical labels themselves were responsive to wider relationships of influence. It is therefore equally important to consider the symbiotic relationship between 'formal knowing' and social presentation. This necessitates addressing wider relations of power and inequality in the educational domain, as well as the education systems interconnectedness to wider social institutions.

8.2 Exclusion – a marker of inclusion and accountability

The pattern of contemporary educational exclusions, both formal and informal may be said to be a useful indicator of not only inclusion, but also covert disability accountability. The educational exclusion of certain populations is not a new phenomenon and can be found to have acted as an impetus to the 1944 Education Act, Segal's (1967) assertion that no child should be ineducable and the now infamous Warnock (1978) report. Nevertheless it remains both a historically recent (Hornby (1997) and contemporary problem (OCC 2013), both

in relation to educational rights, and the populations found to be disproportionately at risk from disadvantage and exclusion (DfE 2015b). Interestingly in conversation Baroness Warnock made reference to these concerns and how there was governmental resistance to its address for being racially too contentious:

“At about just the same time there was an enquiry set up which had to be abandoned because it was so discriminatory, about why West Indian boys especially were performing badly in school. The first enquiry that was set up was simply scrapped because they realised that the evidence that was going to come out was appallingly racist, so that report was not written. But another one was set up a little later, chaired by someone I knew called Swan, but even so it was a futile report because it had to be so pussyfooted around” (BW).

Interestingly the report Baroness Warnock references, The Swan Report (1985) also cautioned about educational disadvantage and the need to provide equity of provision across all social sectors. The concerns cited pertain not only to children of differing cultures and nationalities, but the range of difference commonly found in contemporary classrooms:

“The fundamental change that is necessary is the recognition that the problem facing the education system is not how to educate children of ethnic minorities, but how to educate all children” (pp 769).

It is the notion of ‘all’ that continues to perplex educational systems, yet it appears that focus on specific populations such as that of the Warnock (1987) Report and that of Swan (1985), serves to inhibit an overview which could highlight the true function of exclusion in all its guises.

Intersectionality in sociology serves to identify the multiple faces of discrimination, and by doing so highlights the beneficiaries of this partisan system; namely the majority who stake a claim to ‘normal’ or ‘typicality’ (Gabel 2008). However the more finely the stratifications of intersection are defined, the more evident it becomes that the ‘majority normal’ are in fact a ‘minority advantaged’ and that this minority have enjoyed a consistent presence, pre and postdating the now classical sociological studies on educational disadvantage (Armstrong 2003, Tomlinson 1982; 2005; 2014). Thus I contend that disability disadvantage in education is but one small component of a much wider pattern of disadvantage. Nevertheless it is useful to consider it discretely, as its guise also points to a wider systemic function, namely the legitimization of not only advantage, but the illusion of meritocracy and inclusion. Thus accountability that appears equally metered as this SENCO illustrates: “I was just told well they

deal with it they have to like they would in the outside world, so they're all treated, they have the same sanctions" is fundamental to the illusion of fairness.

Young (1998) stated that connectivity was foundational to any theoretical evaluation of the education system and "posed the question of educational purpose" (pp 6). Thus it is important to not only challenge the logic of disability accountability, but also to consider the purposes served and it would appear that accountability serves to rationalise exclusionary responses and as such acts to protect the wider system, which is itself the key to the self-perpetuation of the advantaged minority. For as Brantlinger in Ware (2004) cautions "by virtue of education and employment, scholars and teachers are middle class and have a middle class standpoint" (pp13). Thus the sentiment of fairness of opportunity and of educational rights legitimates the individualisation of both failing and infraction as all have enjoyed (in principle) the same opportunities. As a consequence inclusion emerges to be an illusion, serving only to consolidate the myth of equality (Kauffman and Hallahan 1995). Equally 'behaviour' that challenges the status quo implies a rejection of the opportunities offered and by deed negated.

This sentiment was most clearly stated in the secondary data that I outlined in Chapter one, for example as one teacher states, inclusion offers: "excellent chances given to those who really need it and most importantly – want it, otherwise it's no good" [S/D]. Failing is thus skilfully deflected away from the level or responsibility of institution or organisation, it is also disavowing of any recognition of a bigger picture, one which speaks of an ingrained inequality that may be seen to be indigenous to a global economy.

This I suggest is the true function of personal accountability and it is found most fervently applied to pupils who exhibit 'behaviour', as by its very nature it is obvious and hence could highlight the self-perpetuating selective advantages schools maintain cross generationally through the illusion of meritocracy. As Brantlinger (in Ware 2004) states:

"Technical remedies or compensatory treatments are aimed at changing losers. Not only does this approach gain jobs for professionals but it puts others, including those with disabilities, in positions of dependency" (pp13).

Such dependency or in the case of 'behaviour' positioning as a perpetrator, serves also to silence any recognition of the conditions (whether disability or

social) that have given rise to 'behaviour'. Freire (1996) refers to a 'culture of silence' amongst the dispossessed and one suggests that parents and children with complex behavioural difficulties are systemically dispossessed; subject to wider surveillance, judgement and management, whose silence is effected through accountability, individualised blame and stigma. So too is any recognition of the oppression that serves to legitimate disadvantage. As Freire notes 'rather than being encouraged and equipped to know and respond to the concrete realities of their social world, individuals are kept submerged in a situation in which such critical awareness and response were practically impossible' (Freire in Shaul 1996 pp 12).

Bourdieu and Passeron (1988) map the nature of relationships of power through consideration of its subjective exercise and I suggest that in the first instance processes of 'normalisation' set in motion the conditions whereupon parents and children are receptive to the acceptance of a disability diagnosis. However, diagnosis (or indeed suggestion of the need for diagnosis) may itself also be viewed as an act of subjugation. Parents in my study heavily referenced their children against other children and against the expectations of schools. Thus without minimising the very real difficulties these children exhibited, parents were willing to accept responsibility for their children's actions, even where systems were viewed to effect barriers to support, or indeed to enhance the difficulties exhibited (Waterhouse 2004, Graham 2007). These acceptances I suggest fostered unequal relations, such as Brantlinger (2004) has noted and as Bourdieu emphasises:

'Every power to exert symbolic violence, i.e. every power which manages to impose meanings and to impose them as legitimate by concealing the power relations which are the basis of its force, adds its own specifically symbolic force to those power relations' (Bourdieu 1977pp. 4).

Looking at my data, one of the starkest examples of 'symbolic violence' was the need parents felt to control their children for the benefit of schools, as opposed to any medical benefit of their child or even themselves. Such 'violence' may be seen to be exercised through exclusionary nature of the education system and the manner in which this is metered irrespective of disability status.

Interestingly, although the pressure to medicate was referenced several times by parents, alongside suspicion that this was being abused for school benefit, none of the parents indicated any wider insight into the deeper relations of

inequality that they appeared embroiled in. There seemed to be an unstated acceptance that systems were unfair but that there was nothing that could be done about it, this appeared to me to link to wider expectations that it is parental duty (particularly a mothers) duty to cope (Kingston 2007). Ryan illustrates how parents indicated insight into an unfair situation, yet appeared to accept it any way:

“School were please to give him it (medication), so he is fine until about 2pm, but it's when he is coming home, he is a nightmare, but their attitude is it doesn't matter how bad he is at home you can cope with him, but the school teachers don't”.

The awareness of medication for school convenience was a common theme and also a source of parental concern for its effects (as was indicated by Freya in Chapter 5, pp 447). Nevertheless even where the effects were undesirable, parents did not indicate any challenge to the wider systems beyond the school gates. Trying to forge those wider connections it is useful to return to Bourdieu's contention that the educative domain is a prime site of symbolic violence, 'driven to maintain and reproduce dominant relationships of power through implementation of 'rapports de force' (Power and Scott 2004, pp 84). Applying a contemporary perspective on this sentiment I suggest that the option to exclude may be seen as schools primary 'rapport de force'. In addition because of the schools role as a secondary site of psychological evaluation, it also systemically contributes to the mechanisms through which pupils so identified recognise and legitimate the ideological basis of their own domination.

Thus in school systems the exercise of power is revealed as multifaceted and largely uncontested, at face level the embodiment of what Foucault (1973) termed 'the gaze'. They are also constitutive as Foucault (1977a) states:

'Power produces knowledge... there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations' (pp 27).

Thus the dual effect of discourses of meritocracy and inclusion serve to not only individualise explanation for failing, the explanatory framework invoked to rationalise difference guides 'knowing' and is foundational to an internalisation of the reasons cited for inequality. Thus the children in my study were stated to struggle or fail most typically because of individually attributed characteristics; disability or behaviour, or even difficulties that were unidentified (hidden disabilities). Interestingly, even where schools are held accountable through

governmental inspection (Ofsted) processes, identified failings rarely lead to any direct challenge at the level of systems, but rather are rationalised as the failing of an individual or staff team.

Similarly the debates that surround inclusion and the retention of the special school sector, do not signal challenge to the system of education per se, at best it may lead to a reshuffle within. Thus as Slee (2001) observed, inclusion far from radically changing the relations underpinning school systems, simply resulted in 'inclusive practices predicated upon old 'special education' assumptions of disability' (pp 168) which did not procure greater equality, any more than the promise of standardised curriculum has delivered equality of educational achievement (DfES 2003b).

Individualised accountability emerged in this study as uncontested, although its guise oscillated as teachers indicated, between explanations of nature versus nurture. Such accountability may also be as central to the maintenance of the wider relations of power, not only in school, but in society as a whole, where educational currency is the gatekeeper of both occupation and socio-economic security: reproducing (as Bourdieu cautioned) existing inequalities. Thus just as Lupton (2012) inferred the culture of medicine to be ingrained, part of the populous 'lifeworlds' (pp 103), it would appear that so too, is the dominant system of schooling. Hence although it is responsive to and supported by the aligned framework of explanations for success and difficulties that are contemporarily dominant, these explanations maintain, rather than challenge the relations of power that underpin the school system. It is further illustrative of how power is maintained that where challenge has been levelled (Neil 1970, Illich 1971) it has been swiftly undermined as being either radical or subversive.

School systems may be seen, therefore, to both depend on and reinforce medical explanations for difference and lead to a questioning of the system. Active partners in the search for explanation support the potential of an individual explanation as my data showed, and although this divided crudely between nature versus nurture, it was always directed to the individual. Parents similarly reported these explanations which in contemporary schools are based on both merit and inclusion and are individualised. Consequently the accountability of pupils in relation to conduct and behaviour irrespective of disability, supports the contention that identifications of 'difficult' difference

(irrespective of causation) operate as a regulatory force, rather than a benevolent system central to support.

It is useful at this juncture to question why there is a need for a system that legitimates inequality, or more precisely, what are the circumstances that give rise to an unequal population. Practically it is hard to find an historic example of a totally egalitarian society and one might infer from this that Hobbs (1969) notion of man is most accurate, that human disposition is inherently acquisitive and in the case of social groupings these propensities have given rise to inequality on a wider scale.

8.3 Blame (The experience of blame)

Blame and accountability emerged consistently across my data sets, although its guise was responsive to context, role and social demographics. The concept of blame shaped the nature of accountability and impacted across both social and medical explanations for difference. Interestingly, looking at how blame emerged, irrespective of imputed function, a relational explanation is warranted and by extension, suggests that a relational solution may be possible.

Nevertheless it is also important to ask why blame was so prevalent and looking at the data sets as a whole, this suggests that a common purpose inherent to all groups was the drive to understand the differences the children exhibited.

Blame in this respect served an important function and was primary to the sense all parties made of difference; thus it was the contextual differences, not least of role and the priorities that coalesce around role that served to shape the nature of blame.

Overall parents felt that theirs and their children's difficulties were misunderstood and at times disregarded. This was most evident in the case of Sacha's story which not only heightened the difficulties faced, but orchestrated a series of situations that could have had serious consequences. Although Sacha's story was extreme, the stories other parents told echoed similarly, the most extreme being where parents felt driven to seek secure accommodation for their children just to keep them safe.

The situation faced by parents of older children offered an insight into the life pathways that are probable for younger children presenting similarly. This impressed upon me the need for timely intervention, ideally during the primary

years. Indeed my own child's primary school had pre-warned of my son's eventual difficulties, yet did nothing other than note their potential. Parents of younger children also spoke of inaction, that the difficulties their children presented attracted both sanction and blame, but little effective intervention that might serve to prevent future difficulties. Both parents and teachers, particularly in the PRU, made reference to future difficulties, yet neither party expressed a means of addressing this potential pre-emptively. Overall both parents and teachers were aware of the need for support, but the differences observed in relation to causation of difficulties, (nature versus nurture), served to effect barriers to a common approach and fostered the culture of blame referenced above.

Notably, outside of the finer detail there were underlying commonalities between parents and teachers. Firstly, although parents blamed schools and at times individual teachers for both a lack of support and lack of understanding of their children; parents also blamed a lack of wider agency support, particularly in relation to the difficulties they had faced obtaining a 'statement' and prompt diagnostic assessment. Leanne's case was illustrative, Leanne spoke of the years that had elapsed during which time a diagnosis was sought to explain her son's difficulties, yet no recognised diagnosis was made to entitle her (and her son) to effective support and exoneration for blame. Indeed Leanne during her story indicated suspicion that some disability classifications were of higher esteem and attracting of greater funding than others, particularly where behaviour is an issue (pp 464). The stories that families told had familiar traits, not only in relation to my own experience, but to each other (despite not being known to each other), this suggested a commonality of experience.

Teachers and SENCOs in contrast showed a tendency to blame parents, to hold them accountable for the difficulties their children were exhibiting, when behaviour was the main issue. The details of blame varied, but commonly alluded to parental failures, not least in terms of parenting style and competency. Teachers rarely spoke of cultural differences, nor the ambitions that may derived from such difference, to the contrary, it was assumed that school buy-in was a given, even where familial background may not support such a view. Where teachers acknowledged these differences, it was framed by them as further evidence of insufficiency. Teachers also expressed a feeling of

powerlessness at times to change the negative challenges the children were posing. This appeared to be the juncture where attributions of blame were stimulated and operated to deflect any internalising of blame to self and hence it was notable that teachers and SENCOs also expressed condemnation toward a perceived lack of wider agency support, such as financial restrictions led by government policy.

These latter concerns were an area of commonality shared between parents and teachers, yet such commonality remained unrecognised by the respondent groups, each adopting its own position of defence. Overall, the channels of communication between school and parents appeared to privilege what divided parents, not what they had in common. This was thus considered inhibitive of any common purpose being embraced in the best interests of the child. Looking at the differences between the understandings which emerged and particularly the guise of blame, I noted that firstly there was a disconnection between 'behaviour' and disability. There was no obvious connection forged, thus any such connection relied heavily upon a deep 'knowing' of the child, in order to prevent behavioural challenges being seen as definitional of the child per se.

In relation to perceived disability expertise there was a notable difference between parents, teachers and SENCOs. Teachers indicated concerns in relation to their own expertise, particularly in relation to the initial training received. Propensity to blame was considered linked to the level of expertise perceived and it was notable that this was greatly enhanced by personal experience. SENCOs in contrast by virtue of their role emitted an air of knowledgeable and indicated that part of their role was to disseminate this knowledge to both teachers and parents.

The expertise indicated by parents and teachers varied and although parents held differing levels of medical knowledge, parents indicated a deep and broad awareness of the difficulties their children exhibited, they also expressed concern toward the effects of these difficulties on their child. Notably parents did not blame their children for these difficulties, rather indicated a determination to uncover wider explanations that did not implicate the child as accountable. These were typically medical and social; alongside desire to seek diagnosis, parents also pointed to school practices which heightened the difficulties their children were experiencing.

In contrast although the gaps in teachers knowledge also fostered a tendency to proffer an alternative explanation, the guise of these explanations were radically different as were the parameters of concern. Teachers indicated a greater tendency to hold accountable both the child and the family for presenting difficulties, they also indicated a narrower appreciation of the impact of these difficulties, most typically those pertaining to the classroom and school organisation generally. Such insularity of concern is echoed in wider research (NASUWT 2008 a,b; 2012, NFER 2012) and thus supports that the focus identified in my research is fairly typical. Where a child held a diagnosis, this diagnosis conjured expectations of presentation, and that where congruence of expectation was not achieved it was the application of diagnosis which was challenged, not the classification itself. I concluded that the gap between the expectations a medical label conjured and the actual presentation of the child, so who held the label was generative of an incongruence which fostered spaces of accountability and ultimately blame. This blame was directed to the child and to the family, as the lack of congruence faced was typically seen as an erroneous diagnosis, rather than a lack of fit between the expectations of a medical label and the embodied reality of that label in the classroom.

The insecurities that were evident toward explanations for difference were most heightened in regards of behavioural difference and led exclusively to accordances of blame. 'Behaviour', therefore, appeared as a symptom that was less accepted as a legitimate criteria for diagnosis than were physical and organic indicators. This was considered the crux of tendencies to both blame and accountability. Furthermore, looking at the protections accorded in respect of educational and equity rights; behaviour and the impact of behaviour was the key factor negating legal rights. Even where disability was accepted as mitigation for behavioural challenges, the implications of such acknowledgement was found to lead to further disadvantages in terms of entitlements.

Overall blame emerged within my research as instrumental to explanations of difference, this was as evident in the narrative of parents as it was amongst teachers. There were subtle differences however, parents showed a tendency to blame out of frustration and at times a righteous sense of injustice. Teachers on the other hand, were consistent in their inconsistency, for behaviour conjured

mixed and at times conflicting discourses that were distorted by uncertainties as to the locus of the problem. Behaviour is both associated with disability (medically) and environmental issues, hence the resolution of this uncertainty tended to effect the extent to which disability was considered or accepted. Equally in the special sector, parents were still being evaluated, not in respect of causing the difficulties the child presents with, but certainly its management. Also as discussed in chapter six, there was still ripples of challenge to behavioural disabilities found in the independent special sector. Notably, in the PRU there was a stark disassociation of behaviour with disability and it was in this sector that the resolution of the debate regarding causation was most openly reconciled. As a result in reconciliation, determinations appeared to act as a blindfold to what was seen and importantly known.

Nevertheless, across all the sectors, it was clear that there were important differences in the status of neurodevelopmental disabilities as opposed to physical and organic disabilities. It was apparent also that parents were aware of this, yet appeared limited in what change they could effect. This division of status was considered fundamental to the disadvantages parents emphasised, it was also considered primary to tendencies to blame and accountability. This led me to develop a Culpability Model of Disability (as contained in Chapter one) to highlight the disproportionate disadvantages and acts of discrimination that my research discovered.

Overall, although the childhoods depicted spoke of disadvantage and despair, they also alluded to systems of control that were denying of any rehabilitative function. For example, the use of exclusion emerged within my data as schools means of managing a pupil who was causing management problems, similarly so the in-school exclusions that Leanne discussed, including twilight sessions and a radically reduced time table. These practices spoke of controlling the impact of the child and of controlling the integration of the child within the school. Paradoxically, the appearance of lack of control, contrasted markedly with the overt controls and visibility that parents depicted to me and which I observed personally. I therefore contend that the nature of disadvantage holds potential to reveal the relationships of power underpinning their guise and, as, such their function.

8.3.1 Challenging childhoods, visible and highly regulated

The childhoods described by teachers and parents held in common a tendency to visibility and regulation: and although explanations for the differences the children presented varied, their function appeared to be consistent and served regulator purposes. This was found to be the case irrespective of whether disability or wilful intent was cited as a cause. This appeared to render superfluous the expansion of medical explanations for difference as disability status did not err against regulatory responses, nor as parents of older children stated, adequate support or accommodations into adulthood. To the contrary, the wider literature suggests that disability identification can cause greater not less disadvantage (Becrow 2008, Bishop 2008, Talbot 2011, Hughes 2012), which was taken as a further indication that disability discourses in respect of behaviour were first and foremost regulatory.

Regulation is most evident as the basis for school organisation and SENCOs indicated how they attempted to navigate school systems where pupils struggled with the rule structure. I detected a common approach which involved the dissemination of truths. Such disability facts appeared functional to an alternative 'knowing' of children who otherwise may be seen as noncompliant. It might be reasonably assumed that medical truths were therefore directive of 'knowing', yet as I found in my data, the weight of these truths varied and could be seen to be directed by the wider priorities of the schools senior management.

'Difficult difference' (Rogers 2013, pp 132) in school has attracted regulatory interventions irrespective of causal attribution and led to both exclusory response and heightened surveillance. The most extreme examples which emerged in my data involved pedagogical strategies that appeared designed to shame and to effect a high visibility amongst peers and other teachers of being different. The incident described in Chapter five involving a child being forced to sit separately from peers on a designated carpet square is illustrative, and it is hard to consider any educative value (other than containment) that could justify this action. Parents similarly indicated awareness of such visibility; this was for some simply a consequence of their child's difficulties, but at times it also appeared engineered. Julie, for example, told of school practices which highlighted her child's appearance of difference, small nuances such as

different start and finish times, having to supervise her child at lunch and the inconvenience of having a restricted day due to the expectation that she was available during the school day.

The actions described, although varied in nature, may be seen to hold the same function, namely the demonstration of control and in the case of difference extending from disability, control over the biological effects of difference.

Research which claims to be able to remediate differences extending from neurodevelopmental differences have been most obvious in relation to the autistic spectrum (Miyajima 2016, Nikopoulos 2015). These cases demonstrate a determination to reduce the effects generated, rather than accept or channel productively the inherent differences. Notably although there have been challenges to rehabilitative practices from within the autistic community (Sinclair 2005, Wrongplanet.net 2012), most typically they emerge founded upon the basis of claims to scientific status as Newsom and Hovanitz (in Foxx 2015) found, rather than the right to be different. They present consequently as both evaluative and regulative.

Tremain (2005) reflecting on the work of Foucault, suggests that preoccupation with the exercise of power within the judiciary, has obscured the more subtle exercises of power effected through what is termed 'bio power' (pp4). From this stance the object of domination is the conditions of life itself (Rose 1999). I suggest that the school system as it has evolved in a surveillance capacity is the embodiment of both bio-power and social-power, and it is this which leads to a division of attribution by teachers between causes linked to nature (biological) and those linked with nurture (social).

Central to surveillance in the school sphere are delineations of typicality and SENCOs described the varied means schools employed to gauge this. The screening processes described to me included a cognitive aptitude test, a reading and comprehension test and for those families considered at greater risk the Common Assessment Framework (CAF). The CAF (DfES 2004b) was introduced by the then Labour Government as part of the Every Child Matters programme (DfES 2004a) and typically is commenced because of school and/or wider child service concerns. The CAF manifests as the embodiment of multiple agency surveillance, offering prescriptions for living itself. Similar surveillance charges can be levelled against the troubled families project (Casey 2012a,

Bunting 2015), particularly as the social criteria for inclusion in this programme points to the types of social circumstances attached to a profile as 'troubled'. From these examples one can see how a profile pre-dates assessment and therefore that assessment is rarely socially neutral. Sacha's story in particular illustrates how parental competency can inhibit objective appreciation of a child's difficulty, just as a profile of social incompetency was suggested by Leanne in particular to deflect from medical explanations.

Hughes (2005) suggests that 'throughout modernity disabled peoples lives have been blighted and demeaned by a degree of supervision that is probably without historic parallel' (pp83). However looking at the school system and the concerns school staff expressed, it is equally plausible that it is not the disabled per se that are being regulated, rather it is all pupils. Medical explanations for difference are but one branch of a surveillance system which holds licence to classify upcoming populations in need of greater (than average) control. The regulative functions served hold historic precedence as can be exemplified by the concerns levelled by the antipsychiatry movement, concerns which exceeded challenge toward psychiatric classifications, but rather extended to the regulatory potential of the profession as a whole (Foucault 1967, Szasz 1974, 2007; 2012, Laing 1985, Rissmiller 2006). Hence although disability activists and disabled lobbyists have argued for acceptance, in relation to disabilities of a neurodevelopmental nature an intolerance to difference persists and indeed it is such intolerance which may found the rational for surveillance.

8.3.2 The relationship between blame and 'formal' and 'familial' knowing.

Blame emerged from the evaluations of others, both families and professionals and whilst diagnosis served to explain behavioural presentations attracting of blame, it was unsuccessful in deflecting it in its entirety as qualifications to medical mitigation were found to be embedded in both educational and criminal legislation. As O'Connell (2016) has highlighted there are tensions generated through neurological explanations for 'behaviour' and these are embedded in both education and common law. Blame in the school context was directly implicated in the identities students developed, in part itself determined by the impression families made on the school. In addition, the nature of school/staff communication transmitted these identities across school years, producing a longevity of identity that was resistant to change.

Families, in contrast, demonstrated their knowing to extend beyond symptomatic referents (irrespective of a medical label); drawing upon positives and projected future gains. There was notably reference to the real child and to the child 'known' at school, as such alluded to a familial impression of unrecognizability. Parents were resistant to deficit identities and produced alternative rationalisations to counter negative discourses. It was at these junctures that parents showed greatest disposition to blame, not only schools, but the system generally. Finance was a major factor cited and held to be central to a limiting of resources, most typically the statement of educational need (now the Education Health and Care Plan) but also a diagnosis and supports in school. Teachers displayed similar concerns and it is fair to say that these sentiments acted as a deflection, both to familial and school accountabilities.

Blame thus served as an alternative explanation for the difficulties being faced, both in school and in the family. This was found to be an unproductive pursuit as it was generative of barriers to common 'knowing' that could expand teachers understanding of the pupils facing challenges. As a parent I also find such deflection unhelpful retrospectively, for by deflecting the locus of difficulty onto an external source, it detracts from an understanding of how the needs presented will develop in later childhood. Parents of older children recognised their ill-preparedness for adolescence and early childhood and although their regrets surrounding education are valid, there is equally a need to empower parents to project forward to future challenges to limit the strains faced. The nature of blame, however, in this research was highly located in the moment and although parents alluded to concerns in relation to their child's future support when/if they could no longer support, there was notably less discussion around how to navigate the turbulent life stages that all children face.

Blame tended to be positioned 'in the moment' and was responsive to immediate events. This was most evident in the stances of teachers towards pupils, which is itself understandable given the governmental accountability of contemporary schools. Nevertheless in the mainstream, reaction to events 'in the moment', rarely stayed 'in the moment', nor was a diagnosis an automatic buffer as medical labels themselves were generative of challenge which impacted on the formation of the child's identity (see for example subsection

6.1, point 6.1.4). It was more usual for the identities forged to be ported forward to other subject teachers, where they had an impact on wider staff attributions and expectations (hence transcending the moment). As such blame transcended the moment and was constitutive of negative identities. Families, in contrast not only projected blame outwards away from their child, their concerns whilst both immediate and futuristic were not productive of a negative identity. To the contrary, 'familial knowing' was orientated to positives, as such was positively functional to the child/young persons overall wellbeing.

8.3.3 The impact of blame in childhood and across the life trajectory.

Blame exists in the moment, yet can linger forging identities which are cumulative and lasting. Blame and accountability emerged within this study, however the effects differed between parties and it was these that were most responsive to wider social variables. Parents used the resources they had to hand to deflect accountability and blame both in the first instance and pre-emptively in the longer term.

8.4 Theorising blame and the functions blame may be seen to serve.

This section is guided by Francis's (2013) micro political framework as described in Chapter three, it is also influenced in its orientations by Willig's (2008) key questions as outlined in chapter three. Through such engagement one can begin to appreciate how 'formal knowing' irrespective of context functions in synchronicity with wider indices of disadvantage or indeed advantage:

'Truth isn't outside power or lacking in power... Truth is a thing of this world: it is produced only by virtue of multiple forms of constraint. And it induces regular effects of power'... Each society has its regime of truth, its "general politics" of truth –that is, the types of discourse it accepts and makes function as true' (Foucault 2000, pp 131).

Foucault's caution encourages us to consider where blame emerges from and suggests that to be the output of collective truths; truths which legitimate accountability and thus blame. Foucault's sentiment also destabilises the certainties that characterise both 'medical' and 'pedagogical knowing'. This in turn impresses upon us that, consequent upon being mediated, the 'knowing' that accrues from truth aligns to wider truths, and that these reflect dominant interests, rather than objective knowledge. Foucault's (2000) claim that 'truth' 'is produced and transmitted under the control, dominant, if not exclusive, of a few great political and economic apparatuses' (pp131), forces us to consider the

position of the education system within this apparatus. These observations also hint at what Foucault meant by the diffuse nature of power, it is also important to remember that Foucault (1977b) considered the 'relationship between desire power and interest to be... complex' and that 'it is not necessarily those who exercise power who have a vested interest in its execution' (pp 215). Hence even though parents and teachers accorded blame to each other and indeed to the lack of efficient input from aligned services, the crux of their concerns may indeed link to the vested interests of a lesser visible source. In which case although the data generated in this study highlights propensities to blame, and indeed the illogicality of blame, where it is directed to the consequences of action considered derived from a disability, the interests that channel accountability may be albeit linked to the education system, but distant from it. Bearing in mind such caution it is useful to look at contemporary influences in the school system toward an understanding of how power is executed and blame delineated.

Caslin (2014) suggests that increased government involvement in education, particularly in regards to raising standards, has led to the mass education school system in the UK, being led by utilitarian principles. These principles although commonly attributed to Bentham and Mill (2004) extend from the work of Joseph Priestley:

'All people live in society for their mutual advantage; so that the good and happiness of the members, that is the majority of the members of any State is the great standard by which everything relating to that State must be finally determined' (in Priestley, Miller and Miller 1993, pp 13).

As is implicit in the sentiment expressed, equally the development of utilitarianism as extended by Bentham and Mill (2004), the idea of the primacy of the majority leaves little room for accommodations of the minority, who may be seen to impede 'the good and happiness of the members' (Priestley and Miller 1993, pp 13)). Thus as Caslin (2014) suggests that 'despite rhetoric and moves to more inclusive practices, little room exists for those deemed challenging' (pp 162). Nevertheless I argue that intolerance has flourished not despite such moves to inclusivity, but because of such inclusivity.

Schools are bound by two at times irreconcilable demands. The first to sustain and improve output (through summative examination results), aligned to this is the dual discourse of 'behaviour' and its seemingly negative impact on output,

thus schools are also bound to evidence discipline and the maintenance of complicity, by being tough on 'behaviour'. The pursuit of output and standards is, however, practically compromised by the need to comply with the demands of inclusion (Carlile 2012), particularly the placement of 'challenging' pupils, who are increasingly 'known' from within a disability frame. I suggest that it is the reconciliation of these tensions that lead and legitimate exclusionary reaction, not only in education, but in the wider community.

The manifestations of neurodevelopmental disabilities emerge in all contexts as less tolerated and qualified in terms of mitigation and accountability. They are thus unequal to disabilities of a physical or organic nature, whose symptomatic presentations are deemed less accountable. Looking more closely at accountability in this sphere, one can see that accountability in spite of disability identification is the means of reconciling two competing obligations, the need to be inclusive and the need to achieve educational objectives as laid down by government. From this perspective exclusion and accountability are functional responses which maintain, rather than jeopardise the contemporary educational system. It is notable that these reconciliations are mirrored in wider society manifesting most particularly in the criminal justice system.

The pervasiveness of unfavourable response to 'behaviour' as a medical/psychological symptom defies the logic of the medical model within which it is embedded and suggests that this distinction serves a wider purpose, satisfying the needs of a less evident source. It is necessary therefore to consider the wider functions, inclusion, the standards agenda and an expanding disability classificatory system fulfil, most particularly in relation to the populations that are demarcated and catered to, not only in education but in society as a whole. This necessitates a deeper interrogation of the relationships of power that underpin the contexts of injustices identified and address of why such injustice maintains the guise of reason, not discrimination.

Scholten (2016) interrogates the nature of accountability expanding upon Strawson's (2005) paper 'freedom and resentment'. Strawson's paper, initially a lecture given at the British Academy in 1962, debates the nature of culpability and the conditions of human being which deny this. One of the most interesting observations Strawson makes is the view of human-kind that is conjured where

accountability is denied, this can be summed in its extreme as a disavowal of individual agency. Scholten, expanding on this work applies its implications to the schizophrenia spectrum of disorders, although it has equal implication for individuals identified with neurodevelopmental disorders. Scholten argues for exoneration from culpability based upon the Kantian notion of ability or inability to engage fully with an exchange of reason. However as Strawson identified decades earlier, this has important implications for human agency. Both authors draw upon the notion of excuses and exemptions; and these are important distinctions, both in respect of human agency and the nature of exoneration sought.

Excuses may offer an account of why an action should not be deemed accountable, yet retain an individual's agentic rights. The latter however suggests that at the moment of the incident, the individual committing the act may act outside of reason and incapable of contemplating reason. Looking at the issue of disability accountability it is a judgement call as to whether one suggests disability to be a mitigation/excuse, or indeed an exoneration from accountability per se. Scholten describes how exemptions can be accepted and disavow human agency only during the period of transgression, thus retaining future agency. Such a view could exonerate many children with ADHD, who according to Barkley (2012) struggle with impulsivity in the moment, yet can reflect retrospectively, without denying overall agentic rights. Yet in the case of autism, which is deemed pervasive it is entirely plausible that exonerations may deny agency overall as the ability to reflect is considered impaired and definitional of the condition itself.

Viewed contemporarily, one can identify Kant's notions of exemption enacted within the capacity test in the criminal justice system and the criteria for commitment under the mental health act (2007). There are I have noted in this thesis ongoing concerns toward the accountability of and response to persons with neurodevelopmental conditions in terms of human rights and agency (Loucks 2007, Hughes 2012), and it would appear that disability mitigation extends a licence to deny agency based upon a rigid interpretation of a person's capacity to enter into exchanges of reason and their capacity to learn (O'Connell 2016).

The expansion of neurodevelopmental conditions, primarily of impact on behaviour and learning, open up these debates beyond the criminal justice system and demand a differing approach to accountability. One which I suggest mirrors Kant's notion of the temporality of exemption. Using this notion it would be possible to excuse behaviours which are normally accountable and enable therapeutic interventions to be initiated. However as school exclusions and criminal justice statistics allude to, this model of reduced accountability is resisted. I contend that blame and accountability serve important regulatory functions in society, preserving existing relationships of power at a structural level and acting as a deterrent to inhibit wider acts of transgression.

Looking at my data, classifications of neurodevelopmental disability and indeed mental disorder may be seen to fulfil an important function within processes of regulatory surveillance. Hence, contrary to the logic of disability symptoms being unwarranted and devoid of accountability because of the randomness of their choice of host; they serve to identify those members of the population who deviate from socially acceptable difference and 'difficult difference (Rogers 2013, pp 132). Persons who as a consequence may be considered to pose risk to the stability of the social whole (school institution and equally society). These identification processes both resonate and exceed Perlin's (2000, 2008, 2016) delineation of 'sanism'; as the prejudice identified exceeds prejudice toward persons of unsound mind, rather it extends equally to persons who display cognitive differences that deviate from those esteemed as 'normal'. Such surveillance may be seen to operate, covertly not only within school systems, but equally so wider society; manifesting as a taken for granted assumption of superiority. Equally, such identification can be used to further equity as has been seen in Norway. Most specifically, disadvantages that accrue from cognitive difference are highlighted by Mordre's (2012) Norwegian study, which acted to discredit the assumption that 'high functioning' equates to social competency, a presumption that is illustrative of the pretextuality that Perlin (2000, 2008, 2016) details. Mordre's findings signal that disadvantage extends commonly irrespective of intellectual functioning, which has led to a parity of social benefits and support across the disabled community. Such generosity may be viewed as evidence of a strong commitment to social equity (Veit-Wilson 1998), unlike the situation commonly witnessed in the UK, whereby

benefit applications engender suspicion (Garthwaite 2011 Heeney 2015, Hughes 2015, Roulstone 2015).

I therefore suggest that a study similar to Mordre's is needed in the UK to assess the level of disadvantage endured by persons who are high functioning intellectually, but low functioning socially. In doing so, perhaps the extent of covert prejudice extending to persons who display cognitive difference will be exposed. Indeed it is the arena of difference and response to difference which reveals the extent of the regulatory apparatus operative in the UK, serving not only to control but also to reinforce the majority's 'normalness'. As I have suggested, exclusionary entitlements are enshrined in legislation and as such imply that a desire to protect the boundaries of normality and regulate 'difference' are ingrained systemically in society, whilst the assumptions that underpin such action resemble in form and outcome the pretextuality, Perlin (2000; 2008; 2016) highlighted within the legal profession.

Thus one can reconceptualise clinical books such as DSM 5 (APA 2013a) and ICD -10 (WHO 1992) as hegemonic publications, consolidating the boundaries of normal and classifying those members who deviate from these bounds, particularly the population that require surveillance. Looking back at the childhoods the parents in my study depicted, what was apparent was that monitoring and accountability were constants, whilst rehabilitation and a common wider agency working toward a better future for the child and the family were not. So although individual persons (both professional and familial) expressed a focus on the latter, the system they were operating within held a very different agenda, rendering accountability explicable, particularly within a disability frame.

8.5 Detailing the Culpability Model of Disability

On the basis of my data, the literature I have engaged with and my own experience, I have identified the need for a Culpability Model of Disability which could address not only the existence of blame and accountability, but also its foundations and functions in the school context. Blame and accountability are found within this research to substantiate exclusionary practices both in and out of school, irrespective of medical labels; on this basis, schools can segregate pupils who pose significant problems to school order and still maintaining to be

an inclusive school. I found that exclusion took two guises, the first on the basis of medical labels and the premise that specialist teaching/support was needed. The second on the basis that the child is so poorly behaved, his/her conduct compromises the school community as a whole.

'Behaviour' problematically holds dual identity and is linked to environmental triggers and medical labels, there are therefore junctures where tension is generated in relation to which explanation is appropriate. At this point the identities of the medical labels themselves were seen to impact; and as I have discussed, not all medical labels confer forgiveness. Thus forth, although parents may seek a diagnosis to reduce blame, such exoneration is not axiomatic, because as my data reveals, schools are subject to irreconcilable demands; the demand to be inclusive and the demand to demonstrate pupil progress through the comparison of cross school exam scores. These demands are also constitutive of the positions available for pupils to occupy, straddled between the profile of asset or liability.

The Culpability Model of Disability represents diagrammatically and conceptually the pathways that lead to disability accountability and discrimination (as is shown diagrammatically in Chapter one, at point 1.6.1). It also details the pressures that predispose to accountability and discrimination. The Culpability Model illustrates two differing pathways of attribution toward the symptoms and effects of disability, charting how there is a division between disabilities of a physical nature and those of a psychological (and behavioural) nature. The model also recognises there to be an incongruence between the ambition of inclusion and that of the standards agenda, situated within a competitive national school system. The resolution of these tensions is stated to be the rationalisation of accountability for disability effects which are not congruent with these dual objectives, which manifests as (reasonable) school exclusion. The model illustrates how the protections accorded to disabled persons are invalidated where disability presents as behaviour. On that basis such exclusion is reframed as discriminatory. The Culpability Model of Disability thus aims to expose the illogical and discriminatory guise of disability accountability.

8.6 Righting wrongs – conclusions and recommendations.

Looking back at the wider theoretical explanations that can be proffered to explain both blame and accountability it would be easy to attribute its existence to a faceless power source operating in vested interest. However, that would deny the agency of the respondents who engaged with this study and indeed my own experience. How then can the dynamics of these relational engagement be best described or summarised? Drawing upon Positioning Theory I depict the terrain as an interconnecting and fluid field of complex interrelations, shaped by wider priorities, expectations and identities. This involves an inevitable jostling for position, although the currency to procure an advantage varies. The situations myself and the families in my study faced can be reduced to their raw state in these terms; and I found that the currency positioning (and resource entitlement) was based around was typically linked to medical labels, consolidated through the formal statement of educational need (now the Education, Health and Care Plan).

Medical identifications were also fundamental to how the families understood their children and their own position in the wider field of parenthood. It was conspicuous how many of the families I engaged with, post-diagnosis, began to heavily identify with the support networks and social opportunities that coalesced around specific medical labels. Thus although many of the families reported that they felt helpless at times, they did not indicate feeling completely subordinated, notably, many attributed their parenting challenges as extending from support failings not domination and not their child's innate disposition.

There are, however, calls for a structural address of the education system and the wider functions it serves. I do not deny this need, certainly the sentiments expressed within the literature by, for example Robinson (2012, 2015) are persuasive and highlight the wider networks of influence that have, and continue, to impact on the school system in the UK. Similarly the work of Tomlinson (2005, 2008) identifies how the education system links to wider commercial and economic interests and how this association is itself directive of winners and losers in the school system.

Medical labels and the notion of SEN have been accused of being harnessed as the dominant framework to rationalise school failings (Ofsted 2010).

However, I am less confident of this argument, I am more persuaded by Glazzard's (2013) observations of the tensions generated between the standards agenda and the policy of Inclusion, which are stated to have led to a highlighting of, not levelling of difference:

'Within the current policy, there is no hope of a radical transformation of the curriculum or the assessment processes that underpin education. In the absence of a transformation, the most vulnerable learners will continue to be singled out for specialised attention. They will continue to be 'pathologised' and treated as an othered group, even if labels and categories of SEN are not applied (pp 186).

Armstrong (2005) has cautioned similarly; suggesting in interpretation the primacy of the standards agenda has resulted in inclusion being enacted as a regulative force. In example, Armstrong suggests there to be a general tendency to classify pupils who may interrupt the pursuit of examination success (the traditional marker of standards) with pseudo medical terms such as emotional and behavioural difficulties (EBD). Terms which are then invoked to substantiate the marginalisation of identified pupils into special segregated within mainstream units. This was a strategy what was familiar, as one of my sons had spent at least a year and a half in such a unit, prior to his outsourcing into what may be loosely described as 'alternative provision'. Paradoxically the tendency in this particular school was to term this unit as 'the inclusion room'. For my older son, this move had life-changing ramifications that at the point of decision were unthinkable, for alternative provision was in a mainstream Further Education college where my son's vulnerabilities were unrecognised, leaving him vulnerable to the associations he proceeded to forge.

Looking at the pathway paved as a result of school decisions for my son and wider family, emphasises to me how important it is to appreciate the longevity of school decisions. They also serve to highlight how the notion of inclusion can be harnessed and operate in a manner contrary to its philosophical foundation. Not least as decisions taken in the pursuit of inclusion in this instance, have served to lead to a social isolation which remains difficult to overturn. The setting up of separate provision in the mainstream in the name of inclusion is widespread, yet personal experience of 'the inclusion room' is poor, both in terms of teaching (which was led by a teaching assistant), but more so in terms of aspirations. Nevertheless, it would be unjust to suggest that staff were deliberately misleading, for they too had embraced the ideal that segregationally led responses to difficult pupils was inclusive. My data suggested that an inclusive

discourse was also host to an accountability subtext; for it was at the juncture where 'inclusive' responses failed to produce rehabilitation that the onus was put onto parents and pupils to redress effects of psychological differences, school strategies could not. In my experience, this was the juncture where discourses around entitlement were opened, as failings to respond were levelled onto both family and child.

Such observation directs me to question not only why, but also what can be done to reduce the discriminatory effects I have identified in my study. There are two main issues apparent at this juncture, the first a seemingly pervasive need to control 'difficult difference' (Rogers 2013, pp 132) and secondly how to do so in an inclusive way. These two incompatible tensions were revealed through a combination of the data my study has generated, personal experience and academic literature and are stated to be a need to include and maintain complicity in schools to achieve and evidence standards and ongoing progress (Armstrong 2005, Tomlinson 2005, Glazzard 2013). These tensions are found to be mirrored in the wider domain and reflected similarly through practices of accountability which are most clearly evident in the criminal justice system (Karpin and O'Connell 2015, 2016). Thus the basis for blame and accountability, whilst at first glance appears stimulated by behaviour, upon closer inspection appears to be founded on wider utilitarian functions and directed to other political objectives and responsibilities.

The seemingly impractical notion of full inclusion is less fanciful when referenced against the Italian system of inclusion I detailed at point 3.2.1 which demonstrated a capacity to manage whole school populations without resorting to exclusion. Indeed rule 517 through its ratification has promoted a mind-set where exclusion is professionally unthinkable. This system stands in stark contrast to that enacted in the UK and indeed across much of the developed world. As such these recognitions direct attention beyond the school context to the social political and legal arenas. They also demonstrate that inclusion is possible in the stronger sense of the word (Viet-Wilson 1998), which serves to destabilise many of the arguments which claim it impractical on social or pedagogical grounds (Warnock 2005, Cigman 2007). What suggestions therefore can be drawn from the data generated by this study?

Overall I conclude that exclusion is not a social fact of life. Rather it is a deliberate and calculated response, shaped legislatively on the basis of wider tensions and priorities extending from the wider network to which it connects (Armstrong 2005, Glazzard 2013). These networks are themselves attuned to the prevailing political and economic climate and embedded within a global market, resulting as Graham and Slee (2008) argue in the harnessing of inclusion for contrary objectives than which it was initially established, most particularly to facilitate the retention of an education system which offers the false illusion of a meritocracy.

The prevailing Neoliberal culture has mitigated against the ideal of collective responsibility and moved responsibility towards an individualistic frame (Hardy and Woodcock 2015, Runswick-Cole and Goodley 2016). This has clear implications for the entitlement of all disabled persons both in and out of education, particularly for persons whose disability status is in historic terms relatively new and insecure in its legal status (Parsons 2005, Jull 2008, Garthwaite 2011, Heeney 2015, Roulstone 2015, Karpin and O'Connell 2015 and O'Connell 2016).

As a result, there needs to be a heightened awareness of the implications of wider relations of power that underpin all social relations. Particularly in respect of what has been defined as 'difficult difference' (Rogers 2013, pp 132). There is, nevertheless, an equal recognition that the respondent groupings in my study were acting in good faith and displayed agency. On this basis I suggest that although power may be accepted to be faceless and responsive globally to interconnecting networks, at ground level there was agency, and this alone enables there to be hope for change. The acts of injustice parents described are considered to be discriminatory, yet in their enactment it is questionable whether they were intentionally so. This too gives hope for change. One of the most striking features of this study was the emergence of different types of 'knowing', led by context, expectation and role. Teachers knowing most clearly reflected this and in so doing demonstrated its partiality when contrasted against 'familial knowing'. The latter was identified as holding the greatest potential to deflect blame in individual instances, whilst it was determined that there was a wider and equally urgent necessity to address systemically the illogical nature of accountability when metered within a disability frame.

I have described behavioural disability as one of the last taboos of disability and it was notable that parents were reluctant to expose the scale of their difficulties outside of a peer group that was similarly placed. Blame, and equally shame, was stated by the parents in my study to be central to this reluctance. As a result home/school communication was founded upon defence and was the general means employed to resist; engagement that one parent described to me as 'the fight', part of the lot of being a parent to a child with special needs (pp 528).

Looking back at my own experience, I can attest to the benefits of working together, particularly where 'behaviour' is of issue, by contrasting the barriers faced when engaging with school from a position of defence, with the productive resolutions achieved together when there was mutual recognition of the position of both parties. To contextualise; my younger son displayed extreme behaviours in school and for an extended period (year seven to ten) yo-yoed in and out of school. However significant parental experience was generative of a confidence which commanded respect and led to a convivial working relationship which achieved its objectives, namely the return of my son to a mainstream school which was his ambition. Although unconvinced I advocated for this and at the time of writing this conclusion, my son has recently finished year eleven and is successfully at the age of 16 engaged in sixth form.

Looking objectively at this progress and contrasting it with the disastrous management of my older sons, it is clear that where school and family are able to work together without discord, progress in the interests of the child are possible. My role in this process was to communicate my son's wishes, even when at times I did not agree and was unconfident of progress. Nevertheless persistence, consistent advocacy and mutual respect led the search for solutions, to facilitate my son's ambition to return to school and it is to the credit of all parties that my son's ambition was realised successfully.

This outcome is far from the rule as school exclusion statistics demonstrate (DfE 2015b; 2016c). Nevertheless, I suggest that my experience shows that many behavioural issues are surmountable where there is a joint motivation. My data also supported wider research findings which indicate it to be parents with the greatest educational and cultural resources who are able to navigate the education system effectively; and in so doing retain the central focus on the

interests of their child, not the problems perceived to emanate from that child or indeed the family (Nind 2008, Russell, Steer and Goulding 2011, Honkasilta, Vehkakoski and Vehmas 2015).

The diversity of the families who participated with my research highlighted that it was those with fewer resources who faced the greatest communication barriers. These parents actively constructed narratives that defended their contention that their child's problems were of medical origin, not the result of poor parenting. One of the main means of defence was reference to other siblings who were successful, both in and out of school, strategy which echoing similar strategies observed by Holt (2008; 2010).

For some parents in my study, their reaction to blame triggered positions of defence, at which point the centrality of the child's interests slipped, enabling wider considerations of risk and impact on the school institution to dominate. The tendency to appear defensive and to have that defence interpreted as confrontational is discussed by Rogers (2011) who illustrates the tendency of official services to place the onus for defining needed supports onto families, who (in times of stress and crises) are least able to articulate their needs. In these instances, communication distortion renders families vulnerable to being accused of confrontation, whereupon the child's voice is limited. This action, I suggest, sets in motion a self-confirmatory tautology, whereby the particulars of need, where acknowledged are undermining, rather than empowering. Equally I reassert previously stated findings that suggest the practical realities of being supported can become all-consuming, adding to strain. For example, multiple professional input is shown to tend toward serial medical and service provision appointments which are inhibitive of activity outside of the formal professional context, thus impede any economic or socially supportive engagement (Kingston 2007, McLaughlin 2008b).

Blame was found in my study to extend in a multi directional manner (from parents to teachers, from teachers to parents and from both parties to wider agencies and government policies). Such activity was not found to be productive of change or support, rather it amounted to a mere soundboard which too often deflected attention from the child's difficulties. Of the families who had older children, the situations faced were extreme and I considered such deflection to be unacceptable given the seriousness of the situations

faced. This research thus impresses the need of schools and aligned agencies to foster a system where collective responsibility for pupil wellbeing is standard practice and outside of exclusionary discourses. I therefore suggest that withdrawing the right of schools to exclude (apart from in the most extreme of circumstances) would foster more equitable relations between school and the family.

These observations however, are found to run contrary to current sentiment as Richardson's (2016) recent BBC news report indicates; highlighting a policy introduced by a secondary school headmaster which demands pupils found to be disruptive to make mandatory public apologies during school assemblies. In defence the policy is stated to be an attempt to reduce the need for school exclusions. Nevertheless parental accountability can be seen to be a notable subtext, revealed through the additional demand that following fixed term exclusions, a parent will be required, (not requested), to accompany their child to school in lessons, break and lunch upon return (Richardson 2016).

Furthermore, this policy does not indicate any adjustment when the behaviours referenced extend from a disability as the head teachers comment demonstrates:

"Any student whose behaviour disrupts the learning of others will be expected to stand up at the front in their faculty assembly, face their peers, and apologise to the whole faculty for letting them down".

It is hard as a parent to consider how such attitudes can be countered, particularly as they are legitimated on the basis of negative impact on the school community. Such legitimation serves to reinforce the prevalence of utilitarianism as a dominant principle directing school policies, but which can also be seen to be incongruent with the principles of inclusion and equality of human worth rather than ability. The actions described in the head teacher's comment defence put forward suggests that the interests of the collective usurp the needs and vulnerabilities of the individual. They suggest also a culture of blame, which leaves little room for the rights of pupils with a behavioural disability. They are thus accountable; irrespective of the challenges faced by the family, or the efforts they may have to make to protect their child, which as Chapter five demonstrated exceeded the bounds of 'normal parenting'. Parents in these instances are judged covertly, through actions rather than words, held to account in the same manner as their children, as was intimated by the

demand that parents take time out of work, or from wider commitments to be 'responsibly' supervising their children, during the school day.

I therefore call for an urgent address of dispositions to accord both accountability and blame when difficult behaviours are known (or suspected) to accrue from a disability. Most particularly because pupil and parental blame is found in my research and experience, to echo the types of disadvantages which were an impetus to the development of the Social Model of Disability; but which failed nevertheless to protect the rights of this disabled population.

Consequently, despite the impact of the Social Model and despite the introduction of the Equality Act (Parliament 2010), there has been little real change to the social or legal position of persons identified with neurodevelopmental disabilities. This observation was a main impetus to my research and to challenge these tendencies I have developed and presented a Culpability Model of Disability.

8.6.1 Study recommendations

1. The overriding recommendation of this study is that there is an urgent need to acknowledge the incongruence of holding children and young people accountable for behaviour which acts as core diagnostic criteria to support the diagnosis of a legitimated medical condition: but which in the school context and indeed the legal context, diminishes in status and is held accountable nevertheless.
2. There is an equally urgent need to lobby to have blame and accountability reframed as acts of discrimination; in doing I suggest this would enable 'challenging childhoods' to be viewed as symptomatic of disabled childhood, warranting of support, not accountability.
3. Toward recommendation two, there needs to be a broader appreciation of the dimensions of discrimination. Most particularly in relation to current exclusionary responses to behavioural and challenging disability effects. I therefore recommended that the exclusionary clauses noted in both educational and legal statutes be challenged as contrary to the principles of equality and anti-discrimination, rendering actions as highlighted above prohibited.

4. Perceptions of 'normal childhood' and of 'normal child development' link to the types of pupils schools covert and employers need. Such selectivity acts to both marginalise and legitimate exclusionary practices. I therefore assert that there is a need to challenge the basis of normative assumptions, alongside wider scrutiny of the spectrum of disability presentations and the inequalities that exist within it.

5. Training was an issue that all respondents considered to be a concern, parents felt that teachers just 'didn't get it' and teachers equally indicated that they needed more detailed training to respond more effectively. However, there was also a pragmatic appreciation that medical expertise was outside of a pedagogical remit. I therefore recommend that there is a pooling of 'knowing', which can draw upon all parties resources. Toward this the following strategies are proposed:

- In the educational context a central recommendation is that schools commit to develop and maintain effective communication between schools and families (including young people). Drawing upon each party's expertise toward an in-depth 'seeing' of the child as a child, not as a management problem or disability/SEN category. In this capacity the role of intermediators (where communication is terse) is viewed as an essential means of combating a cycle of negativity.
- I recommend the widening of school professional development programmes to encourage teachers to connect with their personal experiences as a professional resource. Respondents at the NUT conference in particular spoke of the impact of personal experience on former negative attitudes. I therefore suggest the endorsement of the employment of such experience in the professional context could encourage a greater appreciation of the impact on disability on the child and on the family. This could facilitate the 'knowing' of the child from a more personal perspective, which in the case of 'difficult disability' may inhibit the cycles of defence my study found.
- I concluded that the pedagogical strategies depicted in the PRU toward behaviour and the fostering of positive identities was special; not

because of its guise, but because it was untypical of the more common sanction led approach employed in mainstream schooling. What I also found special in this sector was the determination to retain and to offer contingency solutions to problems that were common place (namely behavioural and emotional difficulties). This was led by an acceptance of responsibility, that although these problems may be exhibited, it was the duty of school to manage and remediate their effects. I therefore identify there to be an urgent need for all schools to adopt similar responsibility as a primary means of reducing the number of pupils who are disengaged from school, or marginalised in alternative provisions.

- I also identify a need to address the extremes of emotions parents expressed, both shame and fight, in order to reduce the discomforts felt at disclosing the extent of difficulties faced. For without a full appreciation of the challenges faced, there is little prospect of an educational provision that is tailored holistically to the practical realities faced by parents and the embodied realities faced by the child.
- As a consequence I recommend that schools and parents are offered access to intermediators, whose role it is to collate and confer both parties point of view in a non-confrontational manner, keeping at the core the child's holistic needs.
- I finally recommend that schools draw upon the experiential accounts of both former pupils and families, teasing out both positives and negatives to further both creative pedagogical strategies and to highlight the real life-effects of pedagogy on the child and the family. This serves to personalise disability, moving from textbook understandings, to embodied life story narrative.

8.6.2 Contribution to Knowledge

This study explored disability understanding across multiple stake holding groups, of specific interest was whether all disability types were equally validated and what the impact of such opinions were toward the experience of families and the management of pupils exhibiting challenging behaviours.

Research findings indicated disparate yet strategic validations toward disability types. Furthermore I identified significant impact on the experience of families and the responses generated toward pupils and their families: impacts that extend beyond the educative domain.

Specifically this research identified an unchallenged propensity in the compulsory school context to confer blame and culpability toward particular manifestations of disability. Manifestations that may be considered 'difficult', encompassing presentations commonly described as 'challenging' behaviour. Accountability for behaviours that paradoxically are both symptomatic of disability and consolidated as formal diagnostic criteria. As such this implies an incongruent understanding of the definition of disability contained within the 2010 Equality Act (Parliament 2010b). Namely of disability as a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on its host.

Accountability implies an assumption of choice in regards to disability impact and the contribution of this thesis is explication of how these propensities were rationalised within and in parallel with a disability discourse. Toward this I developed a Culpability Model of Disability. This model identifies culpability as the reconciliation of two competing school demands, namely that of the need to comply with disability legislation and adhere to Inclusion as the dominant school paradigm, juxtaposed against parallel demand that schools foster and maintain behavioural complicity.

This thesis identifies that none of the dominant models of disability adequately explains the tendencies to apportion culpability for predominantly behavioural manifestations of disability. This results in certain disabled populations being placed at a heightened risk of discrimination. A further contribution is the capacity of my research to expose that these acts are not recognised as discriminative and that behaviour is rarely referenced within the school or legal contexts from within a disability frame of reference. Two pathways of disability attribution were identified, founded upon division between physical and psychological disability. Central to the legitimization of accountability were qualifications to placement entitlement, predicated upon negative impact on the collective. These qualifications served to legitimate exclusionary responses and

were found to be embedded within contemporary and historic legislation, both in respect of disability equity and inclusive entitlements.

I concluded that a further model of disability was necessary to both explain and caution against the application of culpability in the compulsory education context. An ambition heightened through data that links societal disadvantage to school disengagement. Exclusionary sanction for symptomatic indicators of disability were further deemed unjust and counter to the demand of the new SEN code of conduct (2015). I identified a need to act in an 'anticipatory' manner to remediate disadvantages accrued from a disability or SEN.

An invitation is extended, calling for educators to err from a dependence on medical/psychological categorisations, thus circumventing undue reliance on diagnosis from third party professionals. I urge development of communicative strategies that facilitate both a 'seeing' and a 'knowing' of students as unique individuals. These can draw upon strategies identified in the PRU and emergent from research and practice in higher education; merging school pedagogy from its current position as a discrete domain with wider research-led best practice in education.

8.6.3 Policy Implications

Reframing the accordance of culpability as an act of discrimination holds major implications for the ways in which schools are organised and the manner that compliance is procured. This demands an address of the relations fostered between families and schools and also the accepted ways of 'knowing' a young person. Such changes demands address at the level of education policy and school management, similarly so disability discrimination legislation. Most specifically to tackle the qualifications to entitlement which offers greatest potential to develop social and educational institutions built upon socially just and inclusive principles.

Such change needs acceptance on multifarious levels and that this will necessitate a period of adjustment to encourage the fostering of a 'creative pedagogy'. Within such a climate, the concept of 'training' requires extension, moving from a narrow focus on behavioural modification, curriculum and bounded disability type, to an expansive 'knowing' and 'seeing' of the young person, in a manner reminiscent of a parent. Such focus, I assert, holds the

potential to reduce a narrow focus on symptom and effect, rather it invites the observation of the totality of a child's needs and being. Similarly, this process further offers the potential to encourage educators to engage with their students outside of a traditional didactic role, employing lessons learnt from within the higher education sector.

8.6.4 Future Research

Future research needs to extend the detail of the Culpability Model, engaging directly with educators and families to elucidate further the assumptions and acceptances founding culpability in education. Further research is also needed to gauge the extent of discrimination accruing from culpability, toward an extension of the parameters of discriminatory recognition. Reframing exclusionary sanction as an act of discrimination demands a response that remediates disability effect, not sanction. As such this fosters a move from the current qualifications I identified to be embedded in Equality and Education legislation in Chapter three. A central challenge is how to reframe 'challenging childhoods' as 'disabled childhoods, reintegrating the symptomatic effects of behavioural disability within the remit of disability discourses and as a consequence external to attributions of accountability and blame.

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Appendix

Themes

A1: Autoethnography Documented Historic Material Illustrations

Emergent medical model of causation

1990s Emphasis is very much on self-control:

Communication examples

'If he were my child this would not occur, what he needs is to be made aware of what is expected' (Teacher/parent report communication 1992)

'You are here to collect A, good if you weren't I don't think I could have faced him this afternoon, he has had us all demented this morning... please don't feel obliged to return him this afternoon' (Teacher/parent verbal communication 1991)

'A claims he cannot do his homework because he is all tied up, he would be if he were my child' (Teacher/parent verbal communication 1991)

2000s There seems to be a shift toward medial understandings of some behavioural presentations

Atypical Autism is a formal and internationally recognised disease category, it is a pervasive developmental disorder, and these disorders are intrinsic, i.e. inbuilt, elements of dysfunction of mental processes' (Clinical communication to school 2008).

'Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism) 'This category should be used where there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interests and activities' (DSM -1V).

ADHD: 'a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with development, has symptoms presenting in two or more settings (e.g. at home, school, or work), and negatively impacts directly on social, academic or occupational functioning". The symptoms must be present before age12 (DSM 5).

Communication examples

'C has problems in the area of reading of body language and facial expressions, leading to a mismatch of expectations...Due to strengths these can appear deliberate where it is not' (school assessment 2009)

'C has a restricted repertoire of interests and play...He has poor skills in understanding of play and rules' (school assessment 2009)

'C has a persistent difficulty with receptive language... receptive language refers to the comprehension of language, listening and understanding what is communicated – the receiving aspects of language' (Clinical communication 2008).

Culpability model of impact despite medical understandings

'C will get into a lot of trouble at high school if he can't keep his mouth closed both with staff and pupils' (Secondary transfer assessment 2007)

'C behaviour will not be accepted/tolerated at secondary school and he will get into a lot of trouble' (Secondary transfer assessment 2007).

'C was very disruptive today as usual. He shouted out and interrupted others and talked over the top of people' (ibid).

'C was cheeky and snappy with me... he will seriously struggle at secondary school (Secondary transfer assessment 2007)

'Initially C was better behaved today but gradually he became his usual self, he spoilt the session again by the way he behaved, he wanted his own way and didn't like it when he didn't get it' (Secondary transfer assessment 2007).

'D can be unkind and unfeeling toward other children...and can harbour a grudge for years' (Statement of Educational Need 2013).

'D can frequently be observed zoning in and out of lessons' (ibid).

<p>Rigidity of diagnostic expectation</p>	<p>'Due to C difficulties in social interaction, C does not have a wide net of peers. He tries to be around people and talk to them but quickly upsets or offends them' (School risk assessment 2010).</p> <p>'C has an emotional and social presentation typical of a boy with autistic spectrum disorder' (School review document 2009).</p> <p>'D has difficulties associated with children with ASD especially in the area of understanding social situations and communication' (Statement of Educational Need 2013).</p> <p>'It is inevitable that D's diagnosis of ASD will have a significant impact on his developing social skills. He will have problems in initiating and maintaining conversations as well as repairing them' (Observational assessment special school 2013).</p> <p>'I apologise that I was unaware of D's autism, I am now in a position to understand more fully, I have a list of typical behaviours and tendencies so there should be no more misunderstandings' (Parent evening communication).</p> <p>The conferring of one diagnosis appeared to inhibit further testing for other potentially co-morbid conditions as underscored below in red</p> <p>'The findings of the Connors' score were that in school and at home C presents with oppositional behaviour. X has hyperactivity in both settings and the ADHD score suggests C would benefit from Methylphenidate medication (Clinical communication 2008)'. * <u>No identification of Oppositional Defiance Disorder sought despite identification as tests were for ADHD</u></p> <p>'Dr X shared information from school provided a completed Conner's scale that D has difficulties with cognitive skills and inattention in the school setting' (Statement proposal 2013). * <u>Yet no formal diagnosis of ADHD as ASD was considered to lead presentations.</u></p> <p>'D has been diagnosed with ASD. Currently his condition is inconsistent and a lot of his difficulties can present like learned behaviour' (Statement of Educational Need 2013).</p> <p>'D has a tendency to make very literal interpretations' (Statement of Educational Need 2013)</p>
<p>Disability impact referenced only to school – not to impact on self or wider being in the world</p>	<p>'C can be highly disruptive within the classroom and as such has benefited from placement in the 'inclusion facility' (Review document 2009).</p> <p>'C needs careful monitoring at unstructured times, C's ill-defined risk awareness skills makes his management problematic, most particularly for other pupils'.</p> <p>'If C cannot moderate his behaviours it is unlikely that school will be able to retain him, unless C is willing to access the curriculum via an online programme, individually supervised' (Health and Safety Report 2010).</p> <p>'C's attitude to school is very negative at the moment and staffs consider him very hard to handle, he finds it difficult to accept responsibility for his behaviour' (Termly report (2009).</p> <p>'C's challenging behaviour has included physical aggression and threats to children and staff, inappropriate language, refusal to work, defiance and disruption of lessons (Statement of Educational Needs Review 2010)</p>
<p>Diagnostic challenge</p>	<p>ADHD & Atypical Autism: 'C Doesn't conform to normal profile. C has a great deal of trouble managing anger. Doesn't see other person's side – can't reason when angry. Danger to others & to self when angry can't follow classroom rules' (School Transition Referral Rationale 2007)</p> <p>'We respectfully request consideration of a reassessment of C psychological status, acknowledging that a diagnosis of Atypical Autism has been made it is an ongoing concern that some of C's presentations do not appear to support this diagnosis' (School communication to NHS Psychology Department 2008).</p> <p>'Teacher: 'Autistic people are very literal aren't they?'</p> <p>Parent: 'Yes at times, why?'</p> <p>Teacher: 'It's just that I understand that D has autism and when I tell him to shut up he doesn't, so that's not very literal is it?' (Parent evening communication 2013)</p>

A2: SENCO'S Topic Guide

Points of focus

*Prevalence of formal diagnosis in schools and of children who are considered possibly to require an assessment

*Who leads Identifications: Teacher; SENCO; External Agency; GP; School Medics/Health Visitor; CAMS or other paediatric Department?

*How familiar do SENCOs feel teachers are generally in regards to medical labels?

*Are there any concerns regarding teacher's general awareness of cognitive disabilities?

*Do SENCOs express specific (anonymous) concerns?

*What do SENCOs feel influences teacher's attitudes and opinions?

*Have SENCOs found any conditions to be contested?

*If so what are the reasons for these?

*Do SENCOs feel teacher training equips NQT's fully?

*What do SENCOs feel could be improved and how?

*Any wider concerns/comments?

A3: NUT Conference - Instructions for Respondents

This exercise is designed to encourage participants to personally consider the listed disability/SEN categories in relation to their validity as discrete conditions. It is recognised that the categories listed are legitimated through a medical understanding of disability/SEN and this research is neither endorsing nor challenging such view. It is however acknowledging that these categorisations are in use in education, medicine and psychology and are used to inform practice and response to those so identified.

There are no right or wrong answers, and it is anticipated that some selections may be more difficult than others. To expand understanding it would be really appreciated if you would be willing to annotate briefly the reasons for your choices, or reasons for difficulties in making choices.

The conditions chosen represent common types of disability/SEN frequently associated with within 'normal range' intellectual functioning. The selection also reflects what SENCO's stated to be the most common categories of SEN represented in a selection of schools in the North East of England; this selection was further supported through an internet search of disability advice agencies and legal representatives.

Participants are welcome to choose other categories of SEN if desired, and I would welcome such input.

Ranking sequences

Top = most valid **Bottom** = least valid

Second Row = equally valid but considered possibly less so than the first choice signified

Middle = represent neutrality – no strong opinion held

Fourth Row= choices signify equal negative position

Bottom = signifies least valid, most contested

A4: NUT conference - list of medical labels for ranking

Autistic spectrum disorders

Dyspraxia

ME (chronic fatigue syndrome)

Oppositional defiance disorder

Dyslexia, Dyscalculia

ADHD

Pervasive developmental disorder

Atypical autism

Social, emotional and behavioural difficulties

Physical Disability [incorporating sight and hearing impairment]

Mental Health Problems

A5: NUT Ranking Exercise

Please rank the list of SEN according to your own opinions about their validity.

[Note: There are no right or wrong orders; the exercise is concerned with opinions toward types of SEN solely and aims to develop a snapshot of opinions surrounding categories that already are subject to debate in a number of domains - all data is confidential and is stored anonymously.]

Diamond Ranking

The form is a diamond shape with 10 empty boxes for ranking. The boxes are arranged in four rows: the top row has one box; the second row has two boxes; the third row has three boxes; and the bottom row has one box. The boxes are intended for the user to write the names of SEN categories and their corresponding rank.

Global Education Website
<http://www.globaleducation.edna.edu.au>

Please give brief reasons for ranking choices alongside the boxes

A6: NUT Consent form

Participation in this research is entirely voluntary and respondents can choose to withdraw at any time. The data collected is for academic purposes and is contributory toward a doctoral thesis at Newcastle University, all data collected is completely anonymous and will be stored securely.

Final analysis of the overall project can be obtained from me tania.watson@ncl.ac.uk and I would welcome your continued interest.

Your participation in this research is highly valued and crucial to inform the study area, however participants are free to omit any questions without reasons being divulged.

Participants are also welcome to review the projects progress at any stage of the research project and will be consulted with prior to final submission.

Thank you for your involvement

Tania Watson

School of Education, Communication and Language Sciences

Newcastle University

KGVI Building

St Thomas Street

Newcastle

NE1 7RU

tania.watson@ncl.ac.uk

I ----- have agreed voluntarily to take part in this study, and am aware that I can withdraw at any time.

Date-----

A7: Teachers [in] School Questionnaire



Tania Watson

I PhD Education and Communication [2nd year]

Newcastle University

School of Education, Communication and Language Sciences

King George VI Building

Queen Victoria Road

Newcastle upon Tyne

NE1 7RU

**School of Education,
Communication and
Language Sciences**

King George VI Building
Queen Victoria Road
Newcastle upon Tyne
NE1 7RU
United Kingdom

I am currently conducting a research project contributory toward my doctorate at Newcastle University, and politely seek your participation. The study is centred on teacher's opinions and beliefs toward discrete types of childhood disability/SEN. There are a vast array of discrete conditions currently identified, toward which there are many fierce debates on-going within medicine and psychology, surrounding criterion for diagnosis, validity and treatment/intervention. As teachers the expression of these conditions, and recommended response and support is a daily reality, which impacts greatly on pedagogy and general classroom practicalities, however often teachers are outside of the main debates surrounding types of childhood disability/SEN. It is therefore a research to address this silence and to generate a comprehensive overview of the range of opinions held. I am aiming to collect the opinions of as many teachers as is practical and hope you will participate in this study.

This study was given university approval on the 20th January 2012, under the supervision of Professor Liz Todd, Chair of Inclusion at Newcastle University, and direction of the Programme Leader Dr Sue Pattison.

I would welcome any enquiries and can be contacted at tania.watson@ncl.ac.uk

Kind Regards

Tania Watson



*School of Education,
Communication &
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Sue Robson

Head of School

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The University of Newcastle upon Tyne trading as Newcastle University



**THE QUEEN'S
ANNIVERSARY PRIZES**
FOR HIGHER AND FURTHER EDUCATION

2009

A8: Teachers Consent form

Thank you for agreeing to participate in this research, your participation is greatly appreciated

Informed Consent

Participation in this research is entirely voluntary and respondents can choose to withdraw at any time. The data collected is for academic purposes and is contributory toward a doctoral thesis at Newcastle University, all data collected is completely anonymous and will be stored securely.

Final analysis of the overall project can be obtained either during analysis or upon completion from myself tania.watson@ncl.ac.uk and I welcome your continued interest.

Your interest in this research is highly valued

Tania Watson

I PhD Candidate Education and Communication

Newcastle University

School of Education, Communication and Language sciences

King George IV Building

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Newcastle University

Newcastle upon Tyne

NE1 7RU

A9: Teachers Explanatory notes

Currently within the Diagnostic and Statistical Manual of Mental Disorders [DSM-4 TR] there are a substantial number of discrete categories of childhood disability and disorder. Each of these categories generates significant debate; not only within medicine and psychology but in the wider community, the educational arena, popular media and at a political level. Such debate particularly within medicine and psychology has impact upon the criterion for identification and diagnosis, also in a wider sense popular perception of what such categorisations mean for the individual. As teachers you are positioned on the front line, yet frequently outside of the debates surrounding categorisation of childhood disabilities and disorders, yet pivotal toward the determination of special educational need [SEN].

This research is interested in what teachers opinions are toward a range of discrete disability categorisations in relation to issues of validity [Is the evidence supporting a discrete condition credible? Do you hold doubts, or are you aware of doubts? For example debates surrounding ADHD and indeed some variations on the Autistic Spectrum suggest that these conditions as defined in the DSM are socially not organically constructed. There are also debates that argue that many illustrations of childhood disability/disorder signal difference, normal human variation not deficit or disability, and as such should be considered part of a wider continuum of human diversity only.

I would like you to firstly consider the research question fully, paying attention to the range of disability types listed, you are then invited to rank these according to your own opinions, using the format provided. Respondents are however under no obligation to adhere to this format, further respondents are invited to annotate their ranking fully to further inform the research.

The five areas of consideration concern personal belief surrounding the status of a range of discrete types of disability, either as clear medical/psychological entities or as social constructions. Secondly I ask that thought is given to causation of the range of conditions previously ranked and indicated on the template provided. Questions three and four ask about the difference between childhood disability/disorder and SEN. I am interested in gauging how teachers and parents visualise identified children and young people in relation to their diagnoses. Hence I ask if you would consider in what ways you consider childhood disabilities/disorders to differ from SEN, and in what ways you feel they are similar. Finally I would like to gain an understanding of how your opinions toward childhood disability/SEN were formed, and request that you rank areas from the provided list in order of influence [highest to lowest].

I appreciate that diamond ranking is typically a group activity; however it is a method that is being adopted solely for its utility as a tool to prompt evaluation and reflective sorting. I would welcome any annotations that you feel pertinent and hope that the exercise is both enjoyable and personally informative.

Tania Watson [tania.watson@ncl.ac.uk]

A10: Teachers in school ranking activities

Q1. Please rank the aforementioned list of SEN according to your own opinions about their validity.

[Note: There are no right or wrong orders; the exercise is concerned with opinions toward types of SEN solely and aims to develop a snapshot of opinions surrounding categories that already are subject to debate in a number of domains – all data is confidential and is stored anonymously].

[Most valid at top, least valid bottom]

Autistic Spectrum Disorder
Dyspraxia
ME (chronic fatigue syndrome)
Oppositional Defiance
Disorder
Dyslexia, Dyscalculia
ADHD
Pervasive Developmental
Disorder [non specified]
Atypical Autism
Social, Emotional Behavioural
Difficulties
Physical Difficulties
(incorporating sight and
hearing impairment)
Mental Health Problems

Diamond Ranking

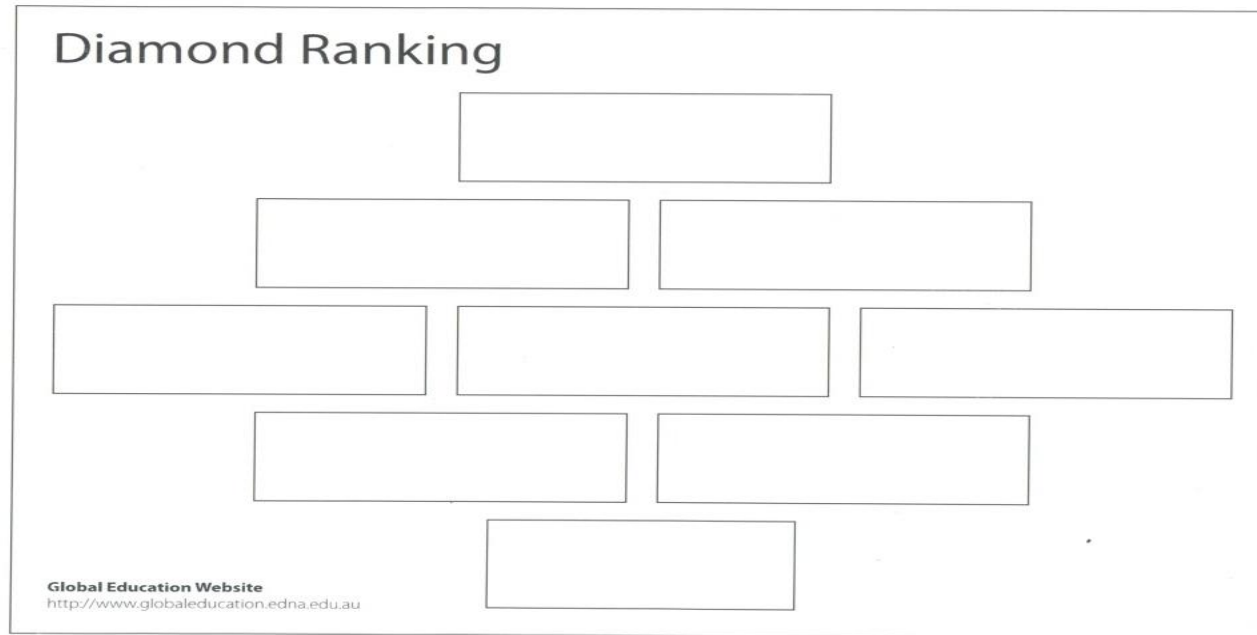
Global Education Website
<http://www.globaleducation.edna.edu.au>

The diagram shows a diamond-shaped grid of 10 empty rectangular boxes. The top row has 1 box, the second row has 2 boxes, the third row has 3 boxes, the fourth row has 2 boxes, and the bottom row has 1 box. The boxes are arranged in a symmetrical diamond pattern. At the bottom left of the grid, there is a small text box containing the website information.

Please give brief reasons for ranking choices alongside the boxes.....

Q2. Thinking about the list of types of childhood disability/SEN, would you indicate what you believe to be their primary causes?

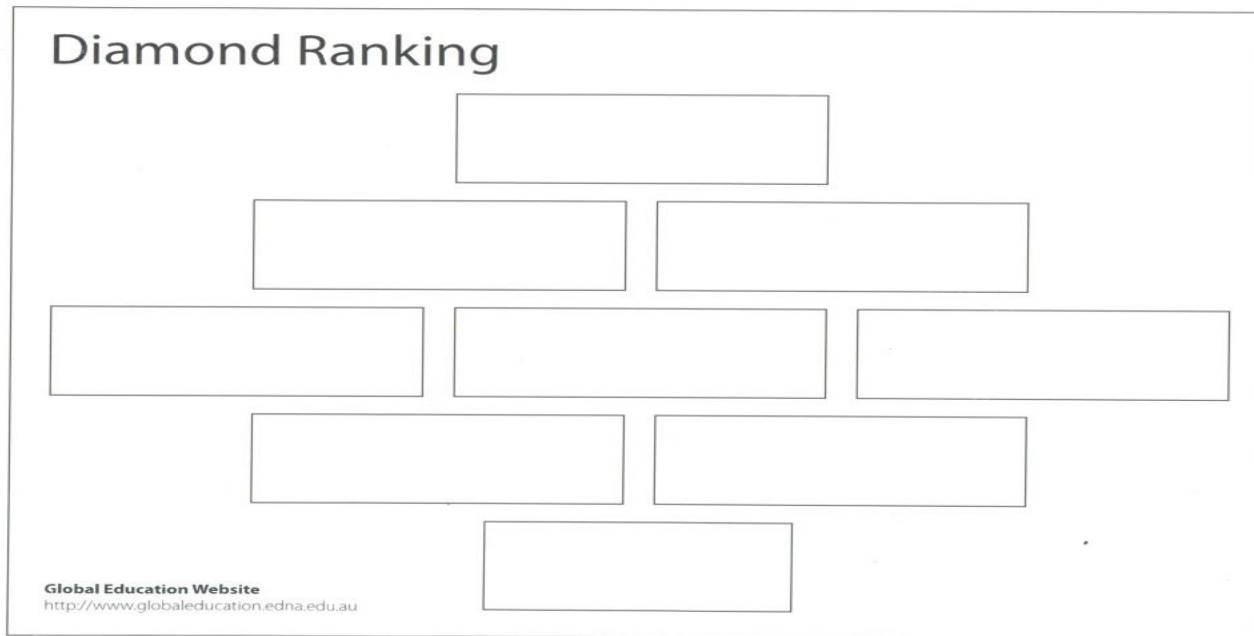
[Strongest evidence of causation top, least bottom]



Please annotate freely.....

Q3. Thinking about discrete types of childhood disability and SEN, what do you consider to be the main differences?

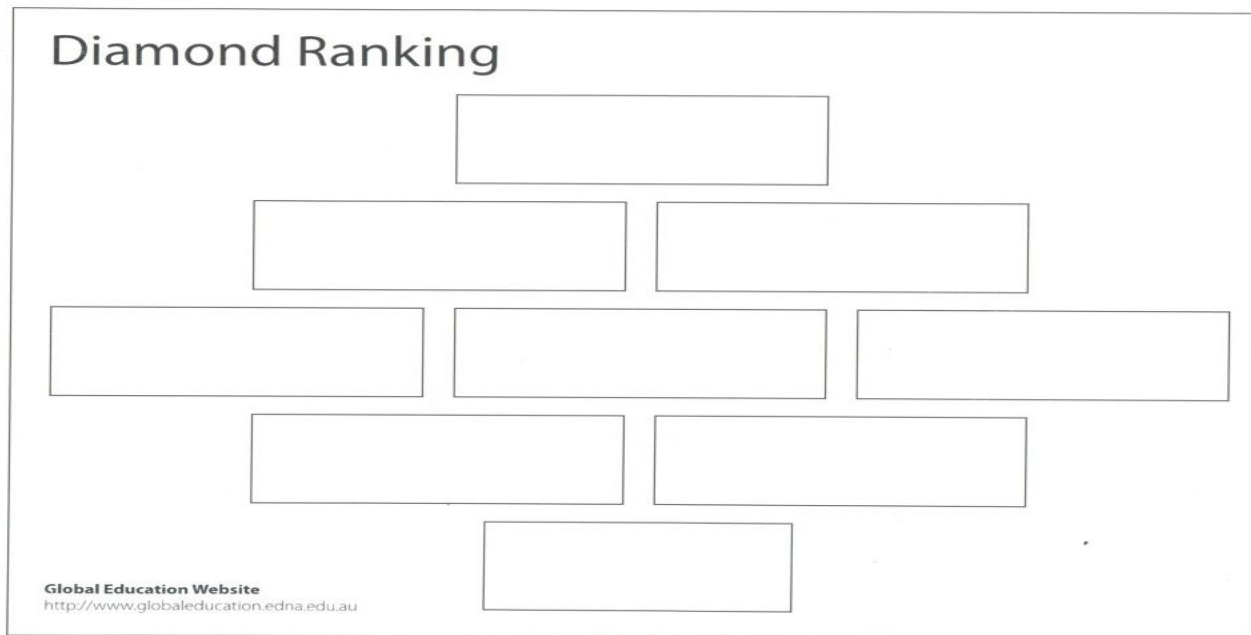
Please rank in order of importance of difference [greatest first - least last]



Please annotate freely.....

Q4. Thinking about discrete types of childhood disability and SEN, what do you consider to be the main similarities?

Please rank in order of importance of similarity [greatest first - least last]



Please annotate freely.....

Q5. Looking at the listed sources below could you rank how they have influenced your opinions towards types of SEN?'

[Most influence top, least bottom]

- Personal experience
- Professional experience
- Training [PGCE]
- In service [CPD]
- Popular media [news coverage, magazine, newspaper]
- Research
- Academic sources
- Literature/film
- Other -please specify

Diamond Ranking

The diagram is a diamond-shaped grid of 10 empty rectangular boxes. The boxes are arranged in five rows: the top row has one box, the second row has two boxes, the third row has three boxes, the fourth row has two boxes, and the bottom row has one box. This layout is intended for ranking the sources listed on the left, with the most influential source at the top and the least influential at the bottom.

Global Education Website
<http://www.globaleducation.edna.edu.au>

Please give brief reasons for choice.....

Biographical data [optional]

.....

Age
.....

Length of Service
.....

Subject
.....

Qualifications
.....

Gender
.....

Experience of disability
.....

Instructions for respondents

Card sorting: - listed are a series of cards each containing a common category of SEN as determined and legitimated through the medical model. In response to the following prompt quotations I would like you to indicate which conditions you personally consider most or least applicable to the quotations by filling in the diamond raking templates directly below each question.

There are no right or wrong answers, and it is anticipated that especially within the middle sequences choice may be more difficult. It would be appreciated if you would be willing to indicate the reasons for your choices, or reasons for difficulties in making choices. Also I invite general comments toward the quotation as a whole, and have dedicated space to do so directly beneath the ranking templates.

The conditions chosen reflect the most common categories of SEN represented in a selection of schools in the North East of England as determined from interviews conducted with SENCO's and is further supported through an internet search, and subsequent review of relevant sites

Participants are welcome to choose other categories of SEN if desired, and I would welcome such input.

Ranking sequences

Top = most applicable/appropriate

Next two = equal but considered less applicable than the first choice signified

Middle band = represents a more neutral position

Lower two = signify equal moderate lack of applicability

Last card = signify least applicable/appropriate

A11: Teachers Quick Questionnaire

This survey asks about your individual professional experience and opinions toward a variety of disability types commonly present in school and forms part of a wider doctoral project which is undertaken solely for academic purposes. All data is held confidentially by the researcher and will not be disclosed to any third party.

Q1. Using a 5 point scale where **1 = very familiar** and **5 = totally unfamiliar**, would you rate your own familiarity toward the following types of disabilities

<u>ADHD</u>	1	2	3	4	5
<u>Atypical Autism</u>	1	2	3	4	5
<u>Autistic Spectrum Disorders</u>	1	2	3	4	5
<u>Dyspraxia</u>	1	2	3	4	5
<u>Dyslexia, Dyscalculia</u>	1	2	3	4	5
<u>Genetic Disorders</u>	1	2	3	4	5
<u>ME [chronic fatigue syndrome]</u>	1	2	3	4	5
<u>Mental Health Problems</u>	1	2	3	4	5
<u>Oppositional Defiance Disorder</u>	1	2	3	4	5
<u>Pervasive Developmental Disorder</u>	1	2	3	4	5
<u>Physical Disability</u>	1	2	3	4	5
<u>Social, Emotional and Behavioural difficulties</u>	1	2	3	4	5

Please share any additional comments-----

----- **Q2.** Please indicate your agreement/disagreement with the following statements [circle as appropriate]

- | | | |
|--|-------|----------|
| a) I am confident that when a child has a diagnosis that it is accurate | Agree | Disagree |
| b) The expansion of types of disabilities reflects greater understanding within psychology | Agree | Disagree |
| c) Some types of disability are used as an excuse to explain bad behaviour | Agree | Disagree |
| d) Some types of disabilities are less credible than others | Agree | Disagree |
| e) All children with disabilities are entitled to be educated within mainstream | Agree | Disagree |
| f) Too many children are being given questionable diagnosis | Agree | Disagree |
| g) Teachers and schools need to accommodate the pupil's needs, rather | | |

than the pupil accommodating the school	Agree	Disagree
H) I am not convinced by some less familiar disabilities that are identified through behavioural symptoms	Agree	Disagree
i) Some children who are diagnosed with a disability are just naughty	Agree	Disagree
j) Teachers need to rely on the expertise of the SENCO and external agencies to best meet the needs of some pupils with challenging needs	Agree	Disagree
k) All types of childhood disabilities are based on sound clinical evidence	Agree	Disagree
l) I sometimes want to challenge the legitimacy of some types of disabilities	Agree	Disagree
m) Much more is understood today about the causation of challenging behaviours	Agree	Disagree

Please share any additional comments-----

Q3. Please complete the following statements in your own words

I feel confident when developing strategies to support successful placement of a pupil with -----

I feel less confident in developing strategies to support successful placement of a pupil with -----

Thank you for your participation

Any queries please to
tania.watson@ncl.ac.uk

Biographical data
[optional]

Age

Length of Service

Subject

Qualifications

Gender

Experience of disability

A12: Contact a Family email

Please share your experiences

Hi my name is Tania Watson and I am parent to two boys with diagnosis of Autism and ADHD; in addition they both are immunologically compromised, and my elder son is pain insensitive and suffers from joint hypermobility. I have dedicated the last 15 years to acting not only as mum, but as advocate, nurse, critical friend and life coach. I have had many ups and downs, none more so than in their school careers, which have to say the least been challenging. I have experienced a range of responses to my son's conditions, and did at one point undergo a disability tribunal complaint. These personal experiences have led me to my current career in post graduate research and I would like to invite parents to share their individual school experiences and those of their children surrounding responses to and opinions detected from teachers towards their child's particular type of SEN/diagnosis. I am interested in all areas of experience and hope to develop a grounded understanding of if/how type of condition/SEN affects your child's and your own relationship with their school generally and specifically your child's daily classroom experience.

This research is part of a doctoral thesis that I am compiling at Newcastle University within the school of Education Communication and Language Sciences; focused on teacher's opinions toward specific types of SEN, and any impact these have on the implementation of inclusion and the relationship shared by the teacher and pupil/parents. It is a priority that as well as looking at teachers opinions an understanding is developed toward how parents and pupils experience such opinions.

As parents we know the miniature of our children's lives, have experienced our own and shared our friends triumphs and battles – please be willing to share these with me, I feel as a parent and a researcher that it is only through more open dialogue that greater understanding and awareness will be forged, making life fairer and more inclusive for all our children.

All information will be held in strictest confidence and anonymity is assured, for further details please contact me tania.watson@ncl.ac.uk

A13: Parents Topic guide

RA1: Could you start by telling me what problem or diagnosis your child has?

RA2: When you first realised there was a problem?

RA3: What role have the school played in identification and understanding of your child's problem?

RA4: How have school received and responded to your child's condition?.

RA5: Do you have any concerns about the schools response?

RA6: Are there any concerns about how willing the school was to accept your child's condition?

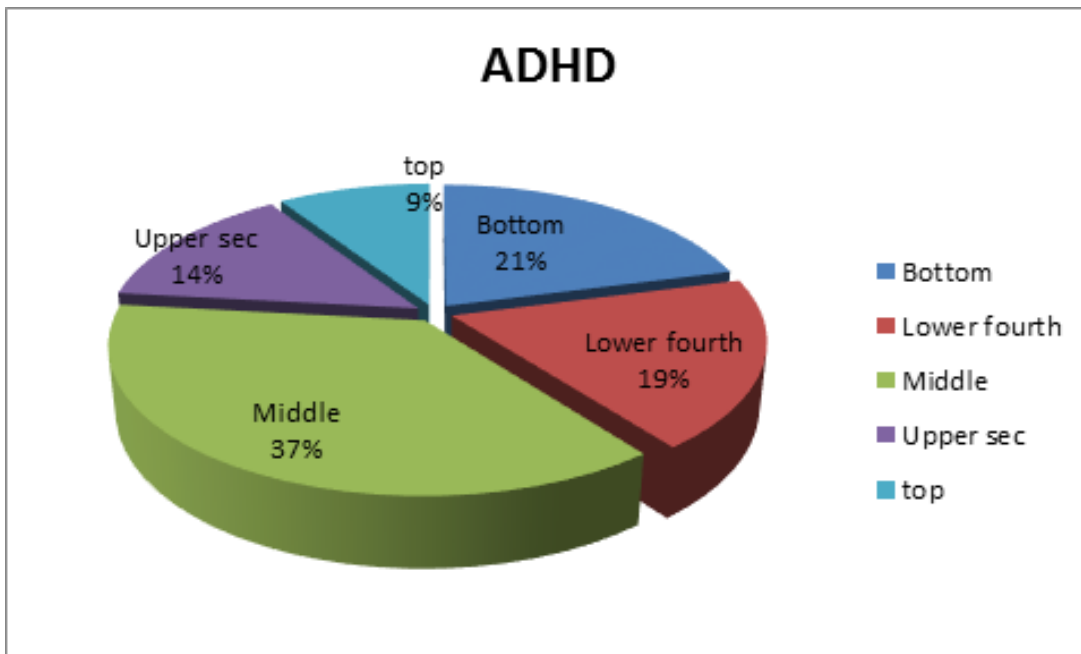
RA7: Who caused most concern [SENCO, head teacher, class teacher, GP]?

RA8: What were your reasons for pursuing or not an explanation for your child's difficulties?

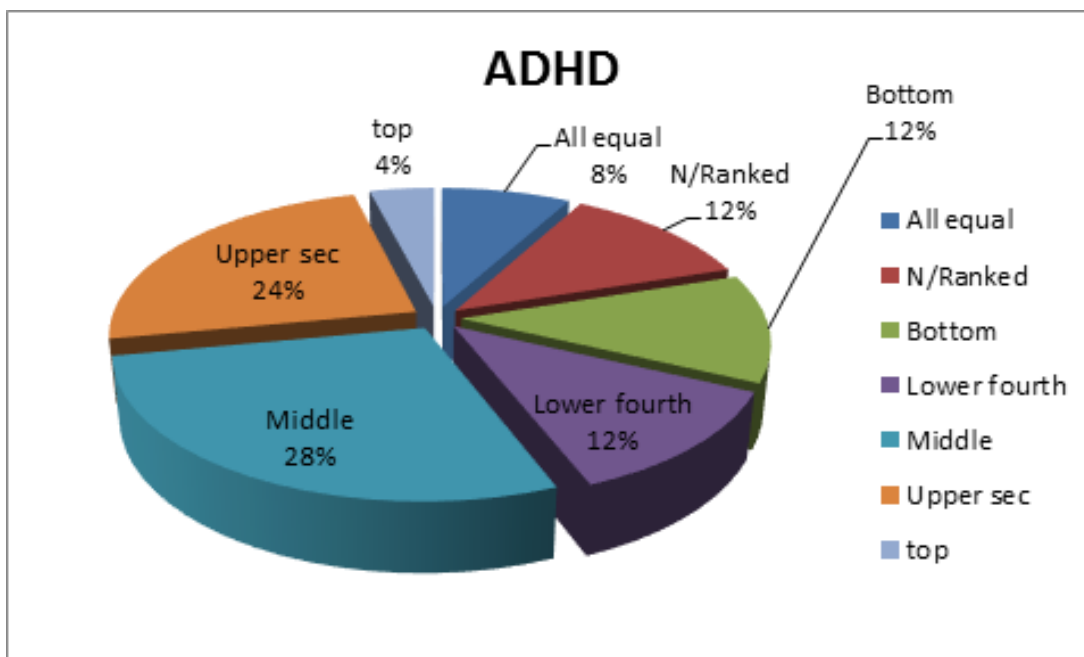
RA9: What are the benefits and disadvantages of having a formal diagnosis to explain your child's problem?

RA10: What would you advise other parents facing your difficulties?

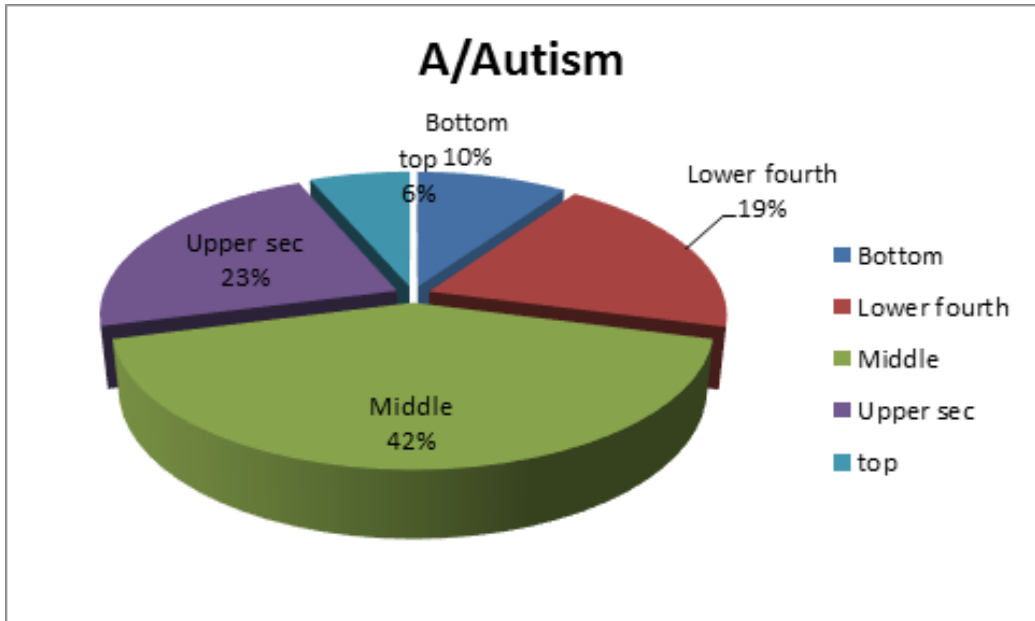
A14: Comparison of ranking positions, NUT conference and in-school questionnaire



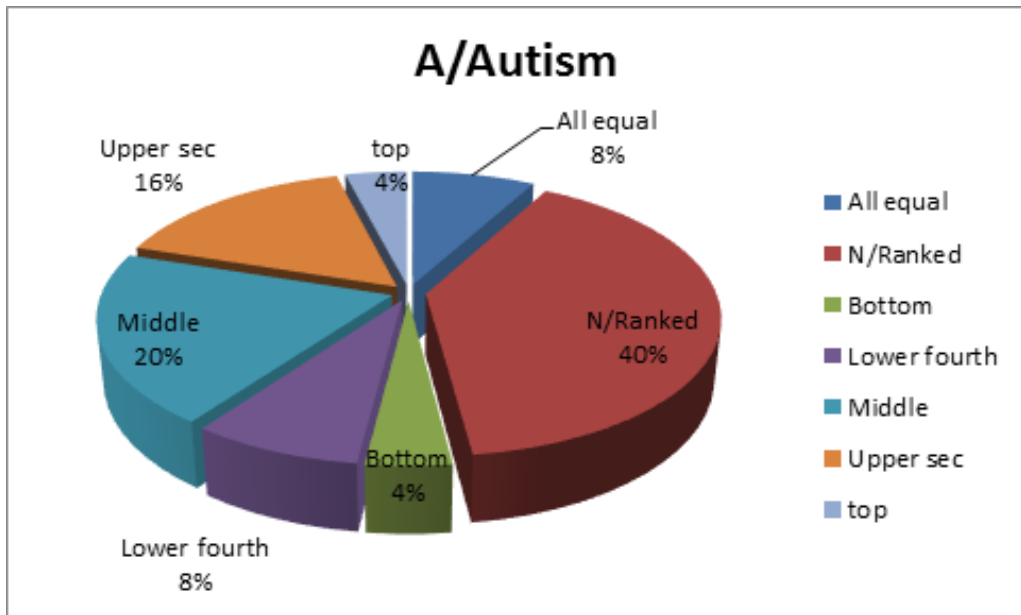
NUT



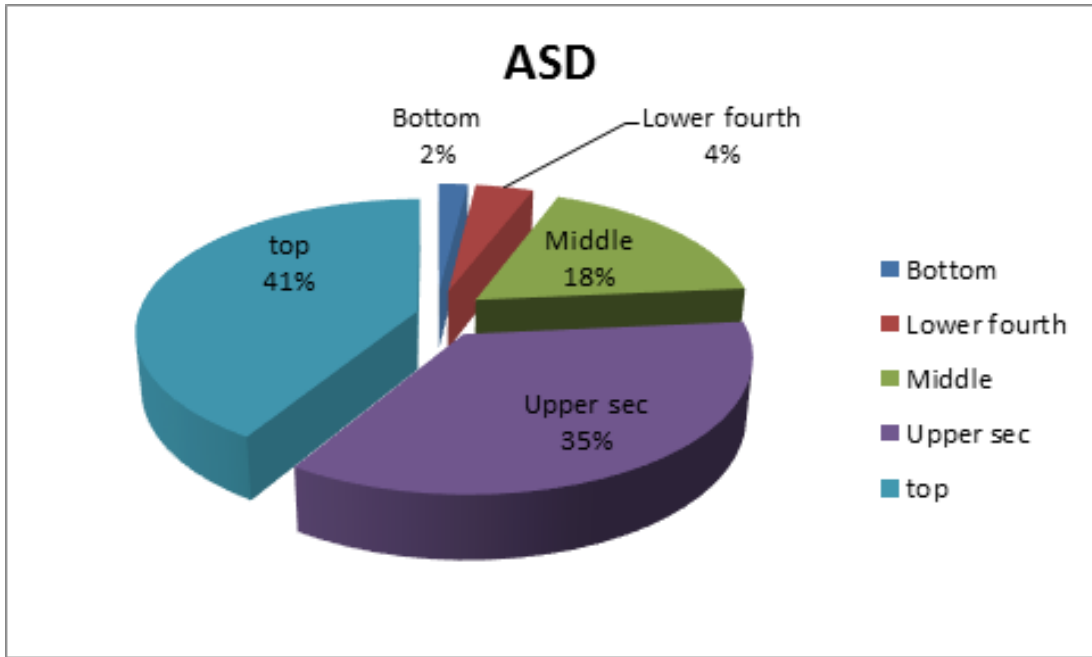
In-school



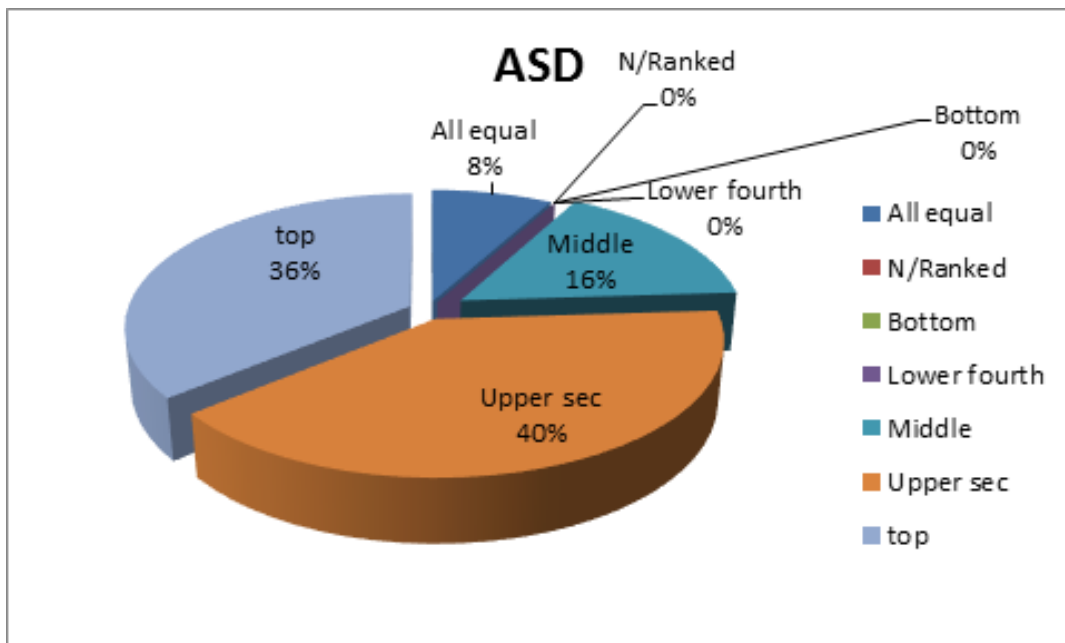
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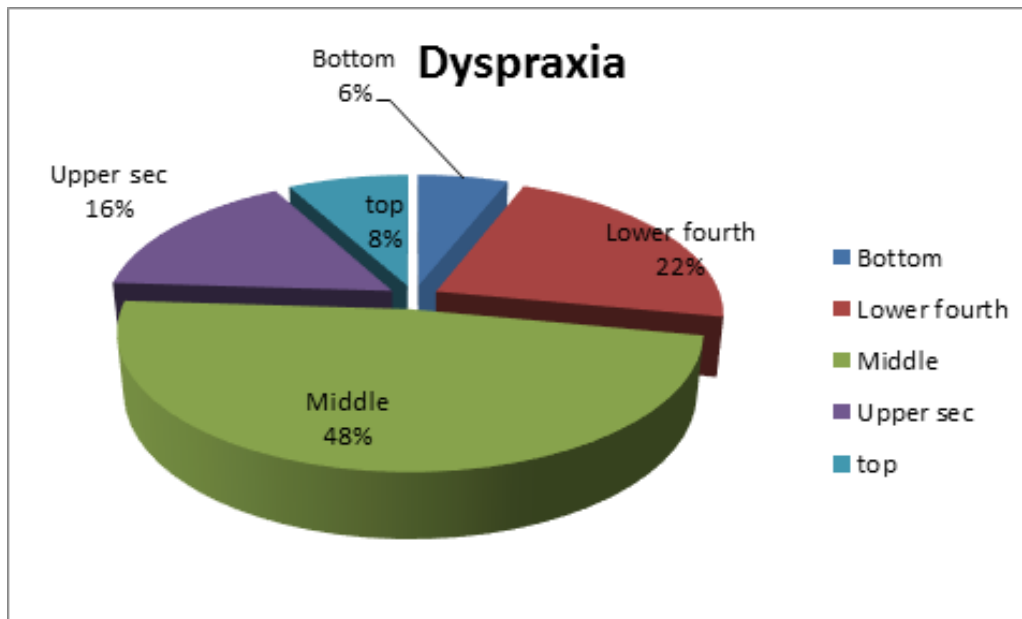
In -school



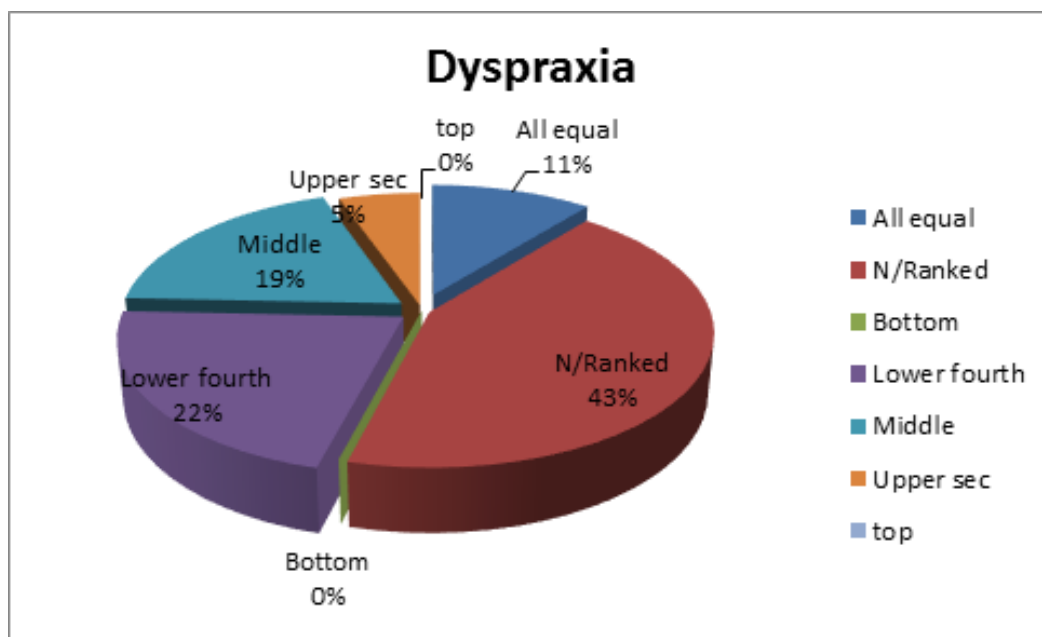
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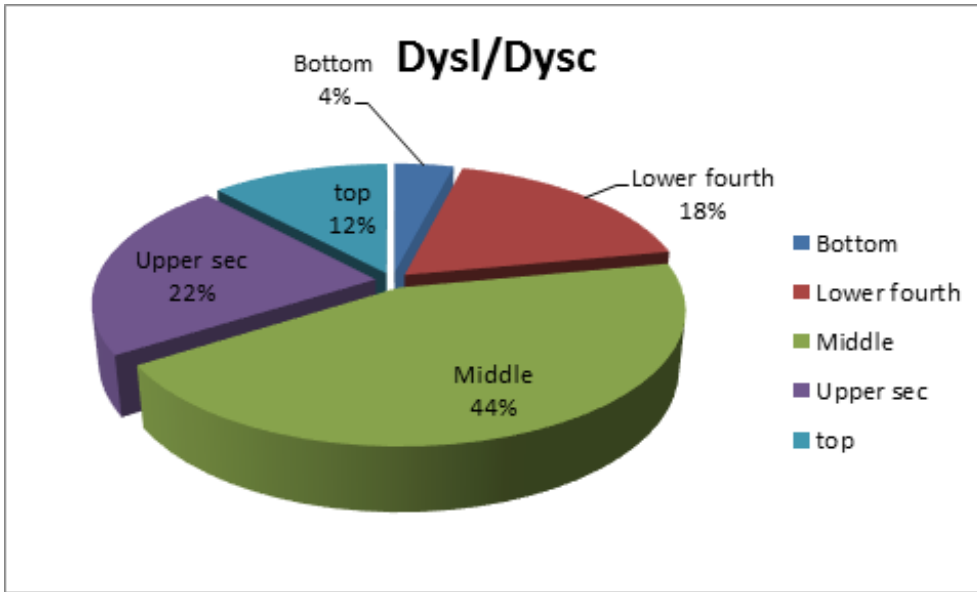
In-school



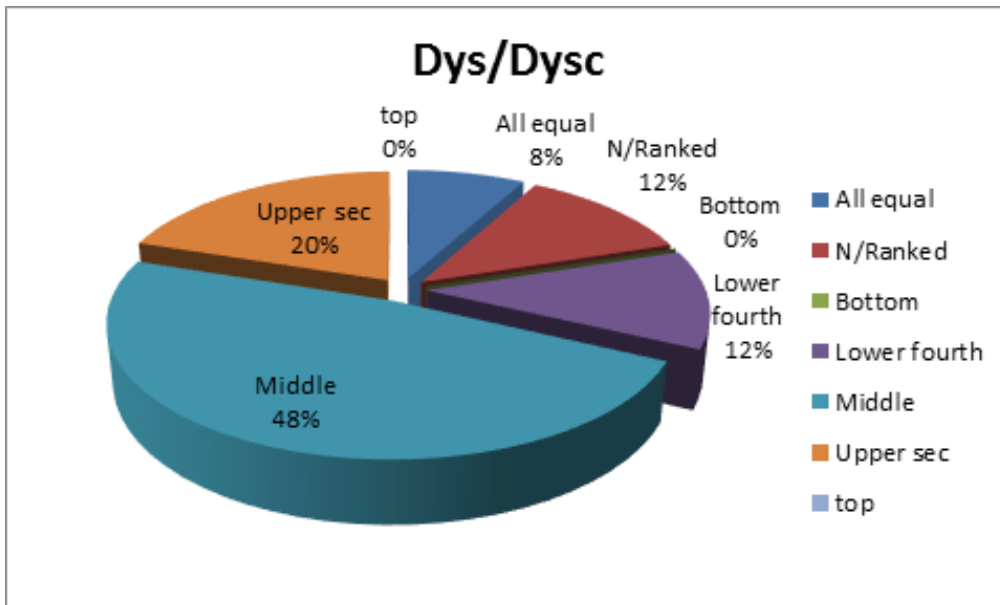
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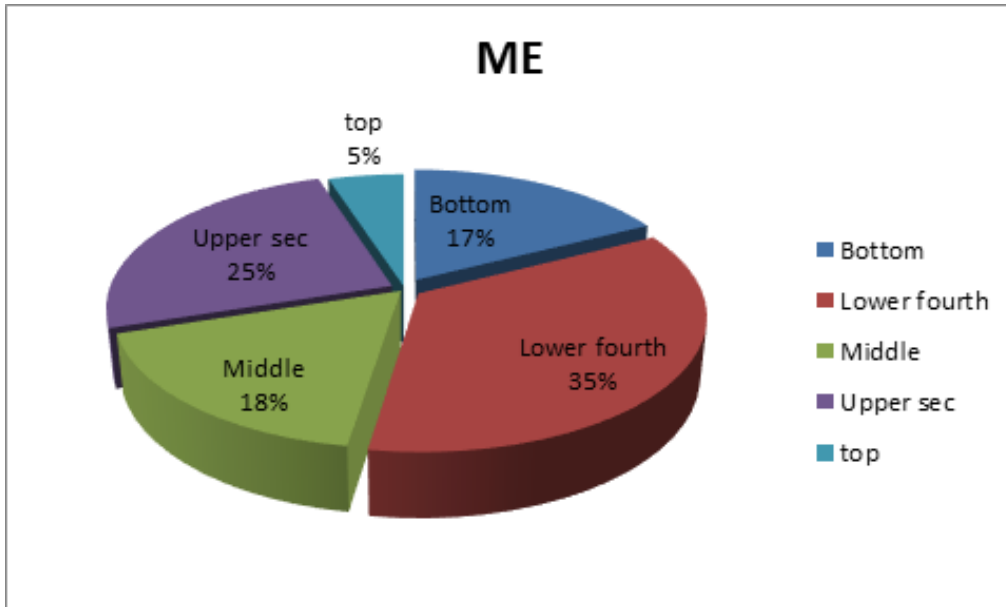
In-school



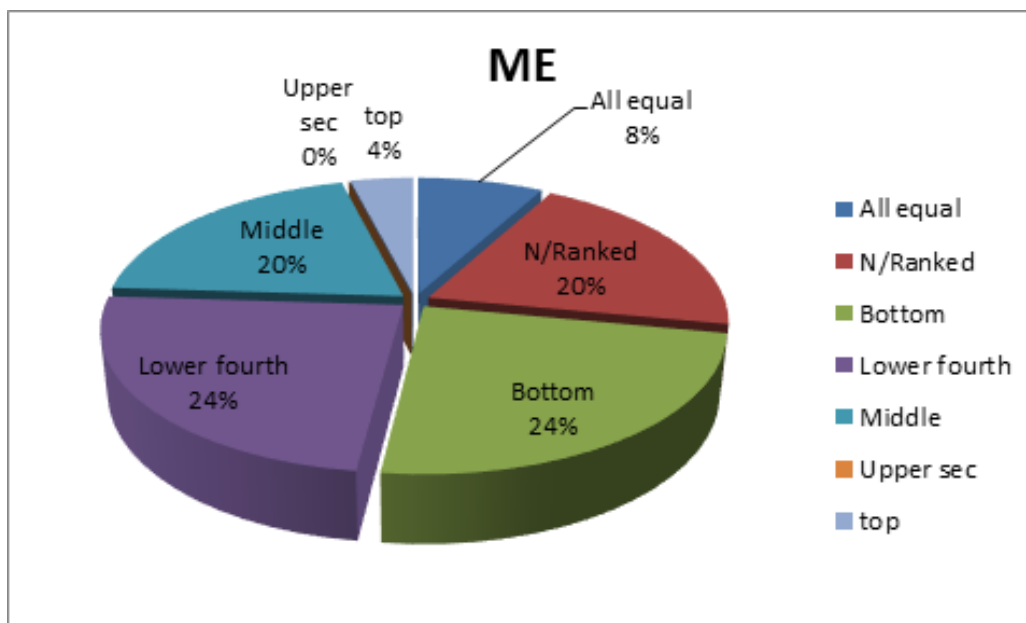
NUT



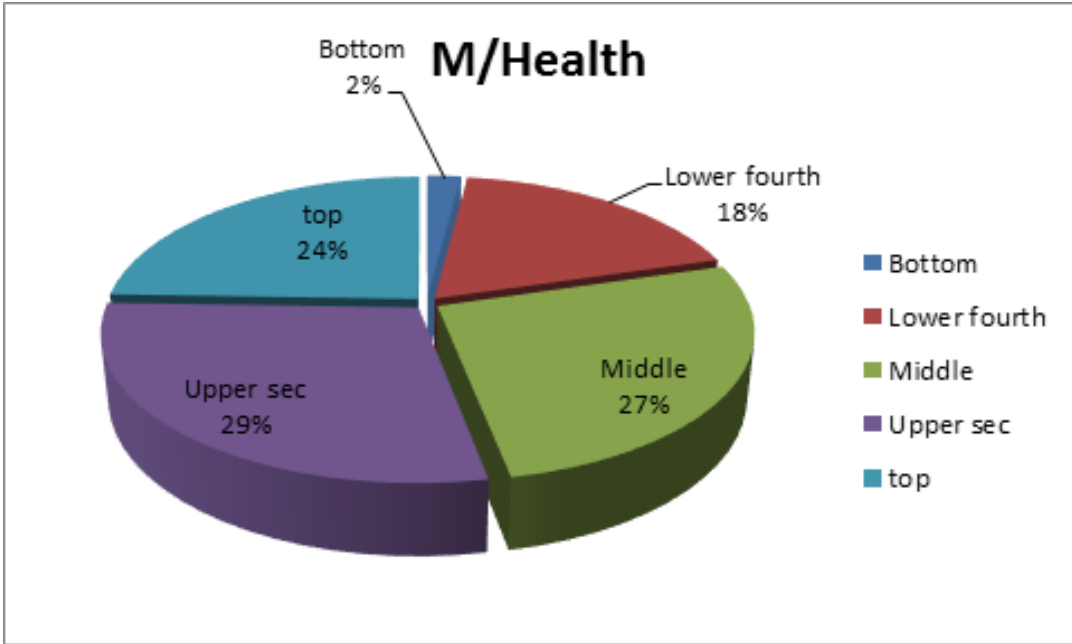
In-school



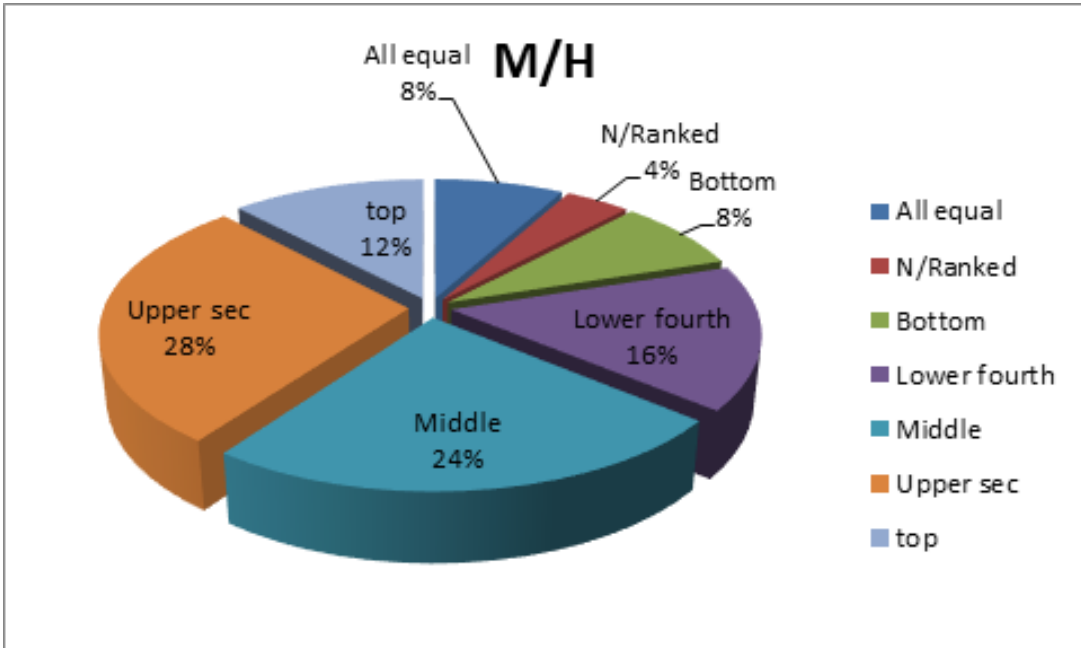
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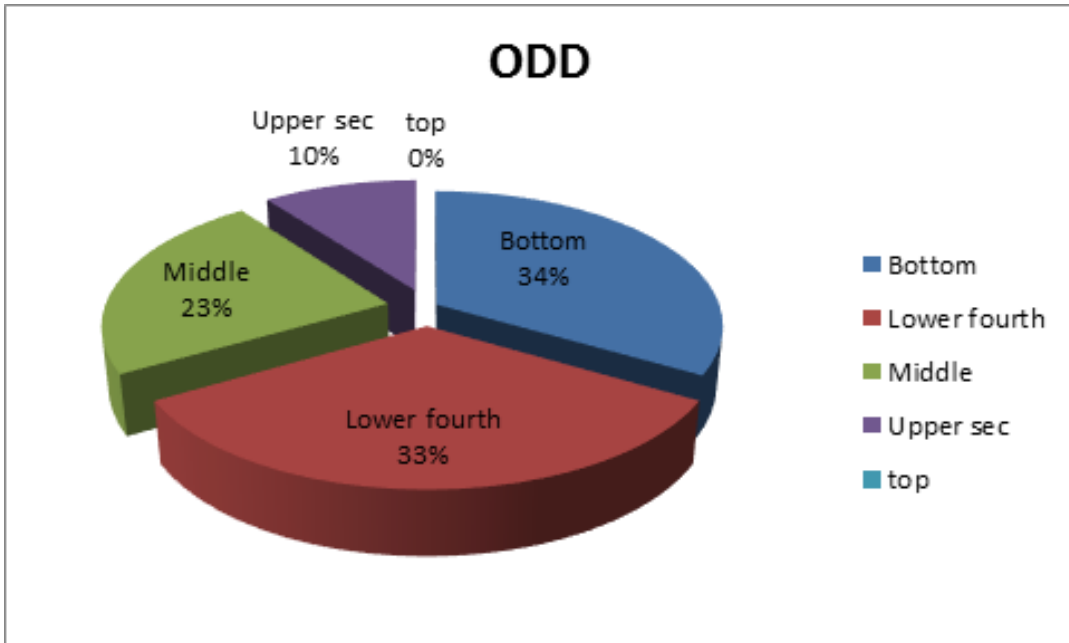
In-school



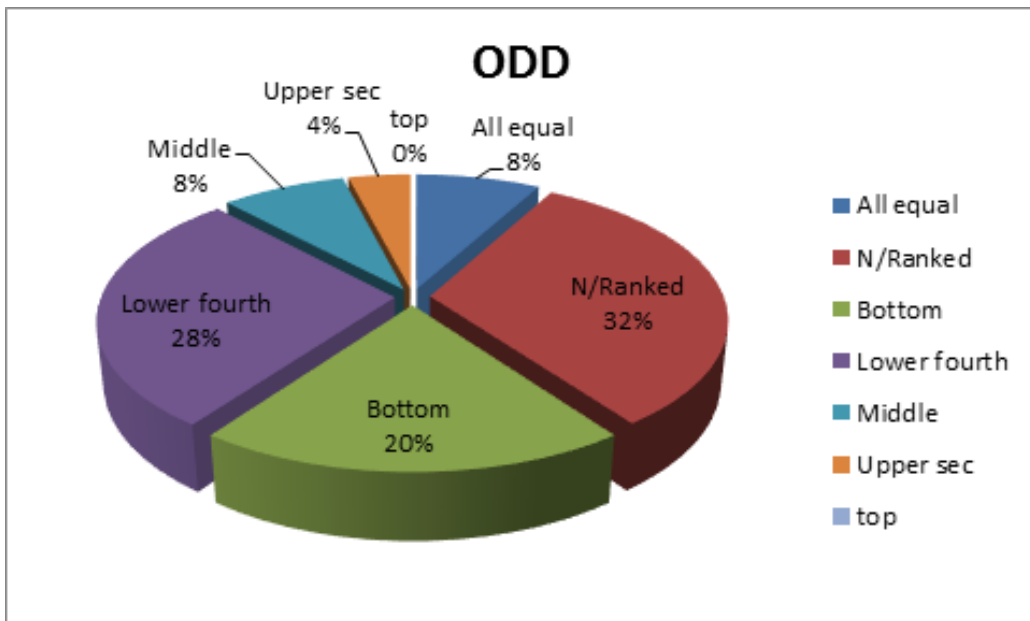
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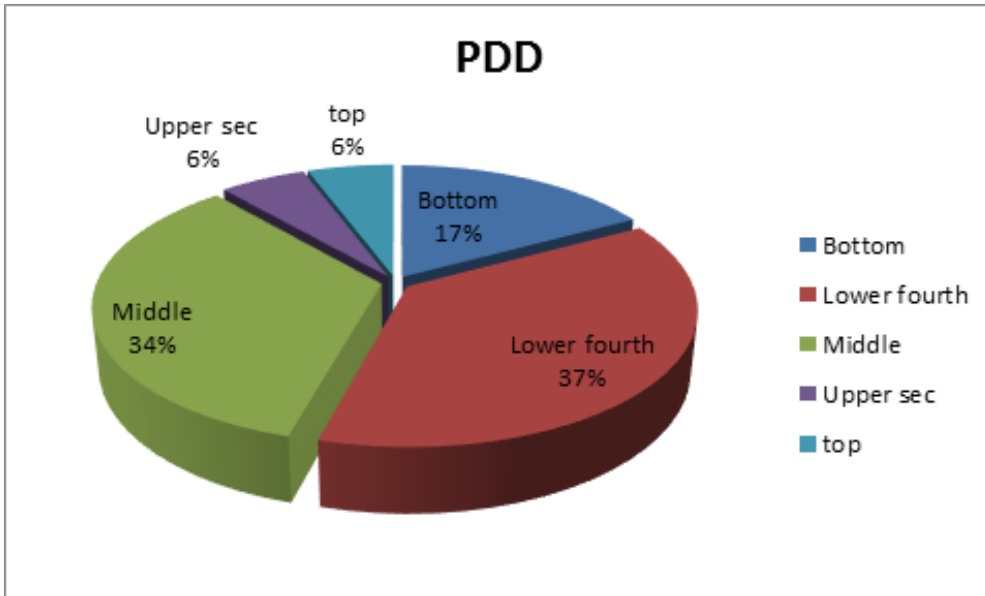
In-school



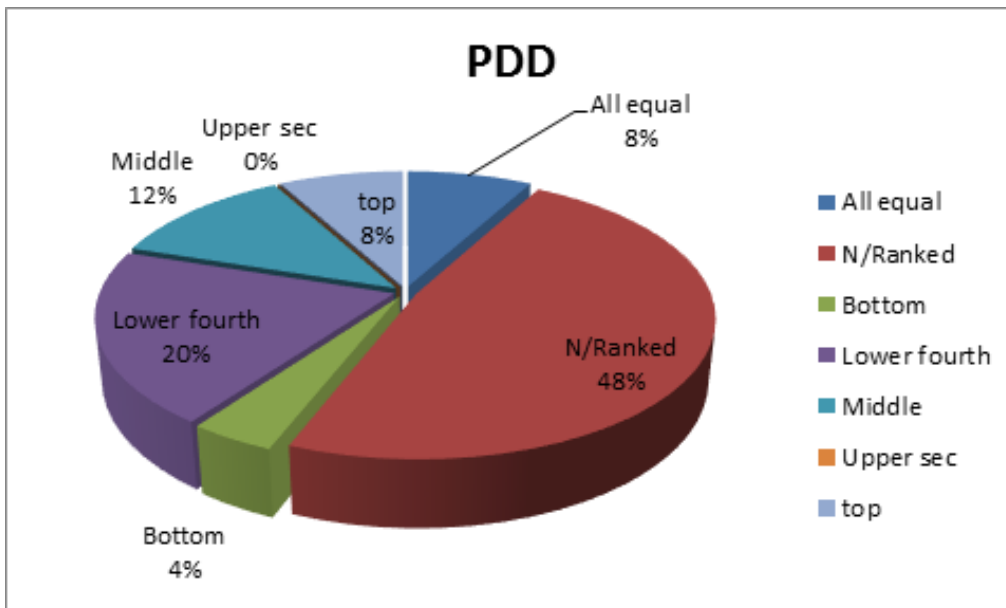
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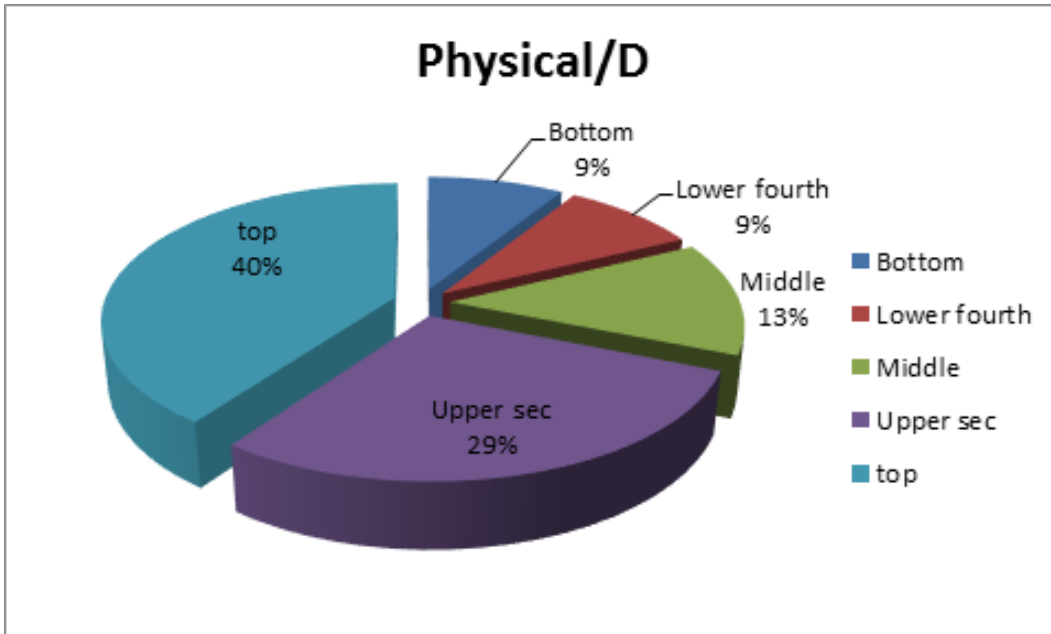
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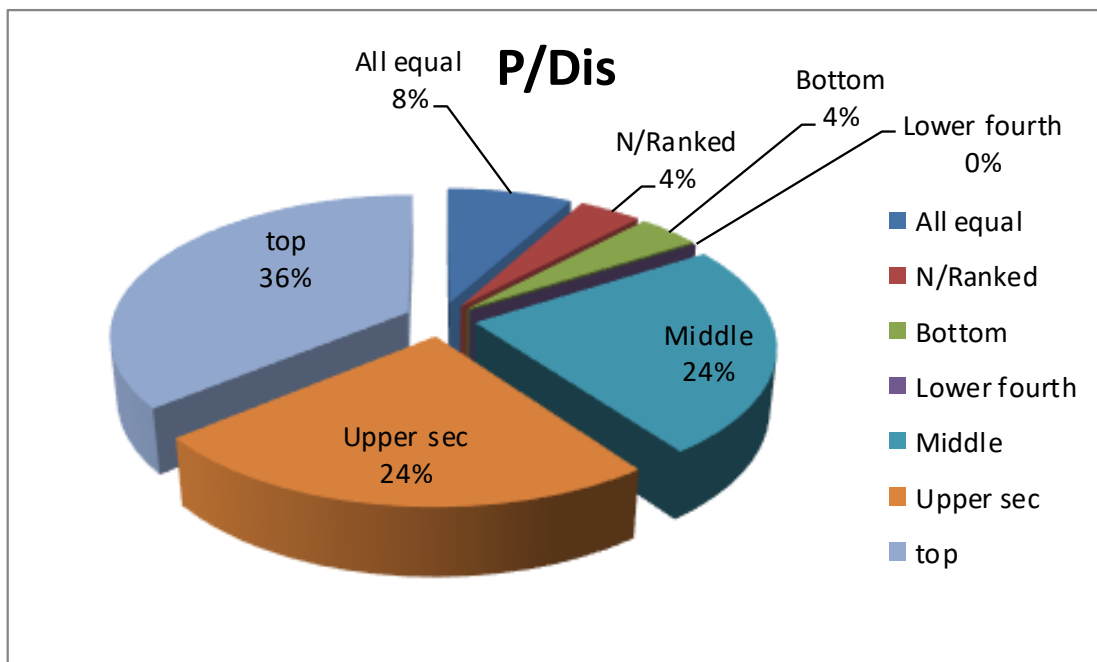
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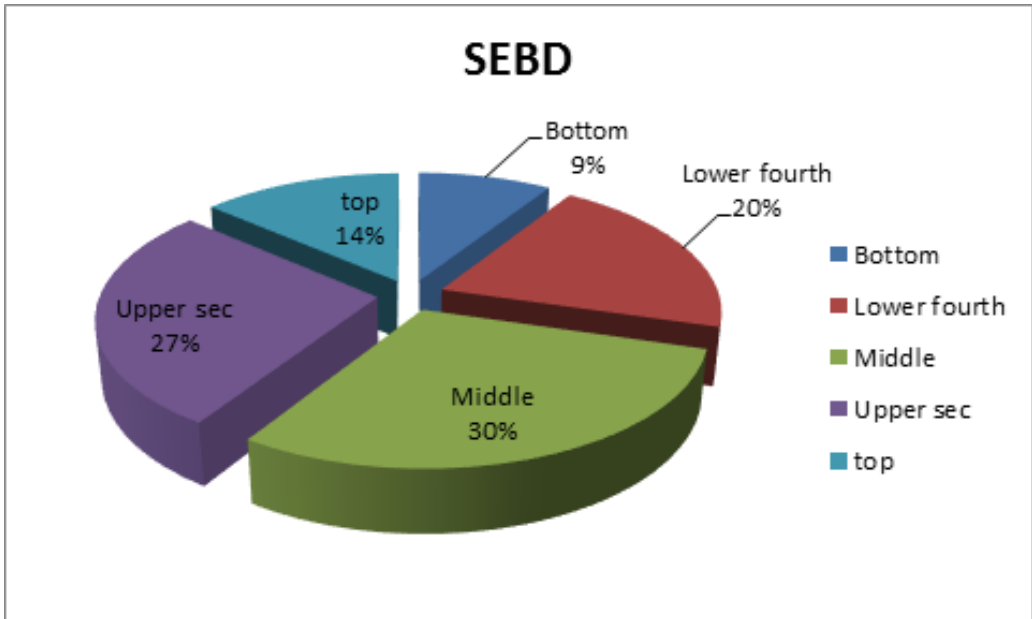
In-school



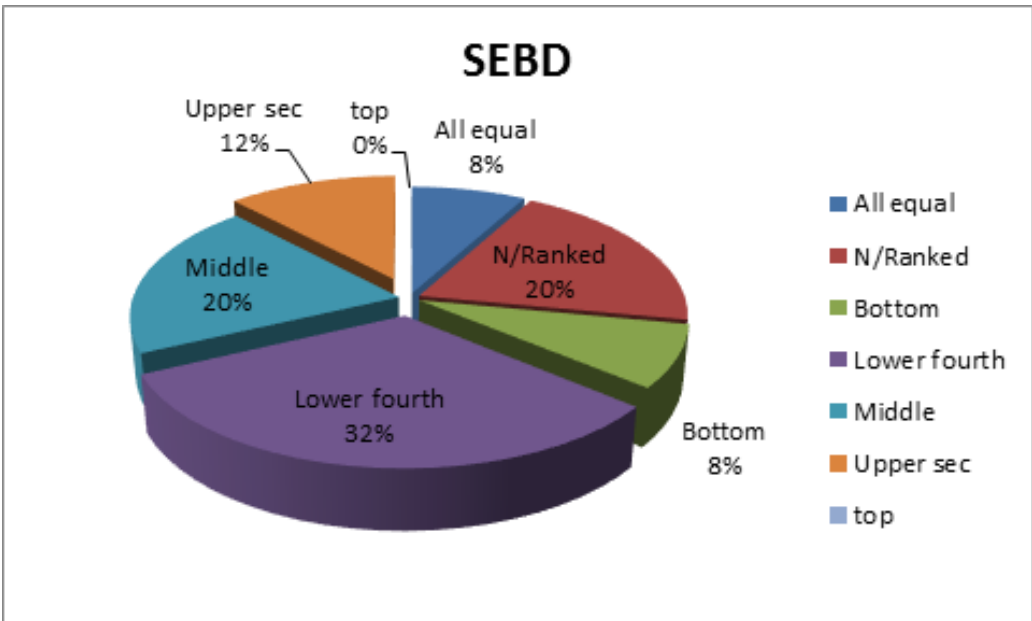
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In-school

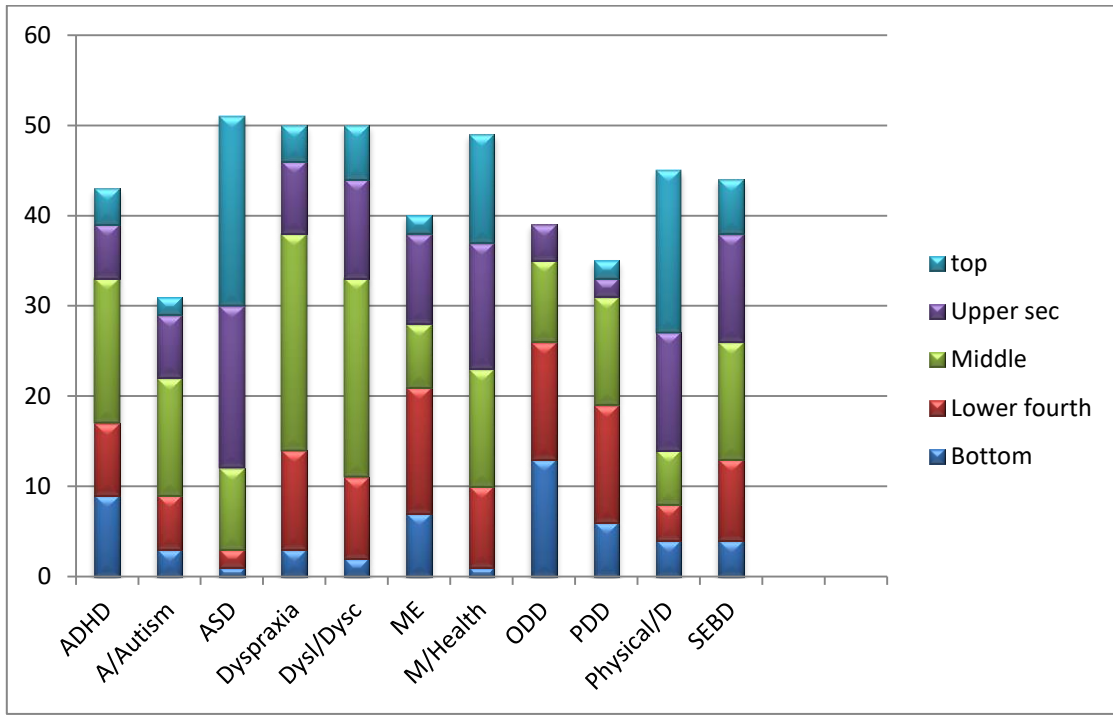


NUT



In-school

A15: Stacking Bar chart of all ranking responses



A16: Abandoned Leads NASUWT [Electronic Survey]

Opinions on types of SEN needed

I am a PhD candidate at Newcastle University collecting data for my PhD thesis which focuses on opinions and experiences around types of SEN, with strong emphasis on type.

This research is part of a wider data collection initiative that aims to explore legitimacies and any considered controversies that are relevant to types of SEN, in particular surrounding the practical implementation of inclusion in the classroom.

Research focused on opinions toward specific types of SEN has not been fully developed and the study aims to address this.

All information is held in the strictest confidence and demographic data is compiled to be personally anonymous, all findings are accessible to respondents prior to final determinations and available upon request, in addition a copy of the final study will be provided to the NASUWT for further comment prior to submission.

I would really appreciate your input, it is really important to generate as broad a range as possible of opinions to make this study representative of a broad spectrum of the teaching profession.

****This survey employs a diamond ranking method; this requires participants to sort from a given list of types of SEN responses to a series of quotations taken from a previous study, which are then organised in a diamond pattern according to relevance in the provided templates.**

Instructions for respondents

Card sorting: - listed are a series of cards each containing a common category of SEN as determined and legitimated through the medical model. In response to the following prompt quotations I would like you to indicate which conditions you personally consider most or least applicable to the quotations by filling in the diamond raking templates directly below each question.

There are no right or wrong answers, and it is anticipated that especially within the middle sequences choice may be more difficult. It would be appreciated if you would be willing to indicate the reasons for your choices, or reasons for difficulties in making choices. Also I invite general comments toward the quotation as a whole, and have dedicated space to do so directly beneath the ranking templates.

The conditions chosen reflect the most common categories of SEN represented in a selection of schools in the North East of England as determined from interviews conducted with SENCO's and is further supported through an internet search, and subsequent review of relevant sites

Participants are welcome to choose other categories of SEN if desired, and I would welcome such input.

Ranking sequences

Top = most applicable/appropriate

Next two = equal but considered less applicable than the first choice signified

Middle band = represents a more neutral position

Lower two = signify equal moderate lack of applicability

Last card = signify least applicable/appropriate

Ranking cards

1. Autistic Spectrum Disorders
2. Dyspraxia
3. ME (chronic fatigue syndrome)
4. Oppositional Defiance Disorder
5. Dyslexia, Dyscalculia
6. ADHD
7. Pervasive Developmental Disorder
8. Atypical Autism
9. Social, Emotional and Behavioural Difficulties
10. Physical Disability [incorporating sight and hearing impairment]
11. Mental Health Problems

Online ranking exercises

*All quotations are genuine and taken from data originating from previous research concentrated upon opinions of inclusion amongst secondary school teachers. Please consider each type of disability in regards to the statement and try to indicate where you would place it on the ranking template. (For example if you feel this statement is most appropriate to pupils with mental health difficulties you would place it at the top).

1. "I think it is a good and positive step to try and include all students into mainstream activities whatever their circumstances as long as it is beneficial to the people you are trying to include".

A ranking template consisting of 10 empty rectangular boxes arranged in a pyramid shape. The top row has 1 box, the second row has 2 boxes, the third row has 3 boxes, the fourth row has 2 boxes, and the fifth row has 1 box.

Please indicate your personal views on this statement and their application to your choices.....

2. "Giving students opportunities to stay in school even if it does not match their needs or fit in with the schools ability to handle them or give them what they need".

Please indicate your personal views on this statement and their application to your choices.....

3. "Taking students out of mainstream lessons, so this avoids external exclusion and consequent government penalties".

Please indicate your personal views on this statement and their application to your choices.....

4. "Current state of inclusion results in staff having to spend too much time on a small number of pupils to the detriment of the main class".

Please indicate your personal views on this statement and their application to your choices.....

5. “In practice as a teacher it can be incredibly difficult and stressful to provide the specialist teaching/strategies support that students deserve, but not always possible in mainstream settings. Fantastic when the support and specialism, training is there”.

Please indicate your personal views on this statement and their application to your choices.....

6. “More work. Guilt with regard to the needs of other students, students with real SEN problems should be in smaller schools – special schools are excellent and students make progress”.

Please indicate your personal views on this statement and their application to your choices.....

7. “Inclusion is an attempt to keep students within a school environment as long as possible despite their behaviour. It can only work if students are treated fairly and sanctions are imposed in accordance with their misdemeanours”.

Please indicate your personal views on this statement and their application to your choices.....

8. “Inclusion is a great concept in theory. I fully support the idea of giving each child the same educational opportunities; however for the approach to succeed teaching staff need to be empowered with effective training, have access to appropriate resources and be supported in classes”.

Please indicate your personal views on this statement and their application to your choices.....

9. “Excellent chances given to those who really need it and more importantly – WANT IT otherwise it’s no good”.

Please indicate your personal views on this statement and their application to your choices.....

10. “Where inclusion involves students with physical disabilities/learning difficulties it has been a positive teaching experience. Where inclusion has meant that students with acute emotional/behavioural difficulties have been allowed to hamper the life chances of a significant number of other students, it has been the single most demoralising aspect of the job”.

Please indicate your personal views on this statement and their application to your choices.....

'Looking at the listed sources below please rank how they have influenced your opinions towards types of SEN'

Personal experience

Professional experience

Training [PGCE]

In service [CPD]

Popular media [news coverage, magazine, newspaper]

Research

Academic sources

Literature/film

Other -please specify

Please indicate your personal views on this statement and their application to your choices.....

Thank you for your time; if you have any additional comments please leave them on the blank sheet which follows

Additional Comments.....

Personal Information (Optional)

Gender.....
.....

Key Stage

Taught.....
.....

Discipline [if

applicable].....

Type of Institution [Academy, State maintained, Independent, Faith School]

Region.....
.....

Length of

service.....
.....

Initial Training Route [PGCE, BA Education, Teach First,

other].....

Please return completed surveys as a word attachment to tania.watson@ncl.ac.uk

A17: The layers of data

Data Source	Quantity	Methods Used	Methods of Analysis
NUT Conference Diamond Ranking Questionnaires	60 Respondents	Self-complete Diamond Ranking Questionnaire	Simple SPSS compilation looking at frequencies and patterns
In School Diamond Ranking Questionnaire	25 *4 schools	As above	Thematic content analysis of additional annotated data
In School 'Quick and Dirty' Questionnaire	39 *4 schools		
	Total = 104	Self-complete Semi-Structured Questionnaire	Simple SPSS compilation of closed questions toward an overview of opinion and thematic content analysis of annotation
Face to Face guided Interviews – Special Education Needs Co-ordinators [SENCOS']	12	Audio taped semi-structured interviews, approximately of one hour duration	Narrative and thematic content analysis
Unstructured free narrative face to face interviews with parents'	11	Audio taped free narrative face to face interviews with parents' of approximately one hour duration	Combination of narrative synthesis report [what is said, unfettered by theory] and thematic content analysis
Guided re-visit interviews with parents'	5	Semi structured re-visit interviews of approximately one hour	As above
Guided interview Baroness M Warnock	1	Audio taped semi-structured interview of approximately one and a half hours long	As above
Guided interview with Leslie Henderson, founder of the Henderson Trust [Autism charity]	1	Unstructured unrecorded interview, approximately 1 hour	As above
Field notes from yearlong voluntary classroom assistant placement at a local special school	One academic year	Ethnographic Observation, field notes, informal conversations, tentative connections	Narrative and thematic content analysis
Field notes from yearlong voluntary classroom assistant placement at a local pupil referral unit	One + academic year	Ethnographic Observation, field notes, informal conversations, tentative connections	Narrative and thematic content analysis
Personal auto-ethnographic data, compiled historically	On-going	Reflexive auto-ethnographic observation, field notes, tentative connections	Reflexive narrative thematic content analysis

A18: Contribution of the data sets

Method of data collection	Data Objective
Autoethnography	Lived Experience
Participant Observation	How disability is negotiated in the specialist sector
SENCO Interviews [semi – structured]	Presentation, jurisdictions and staff expectations
NUT Conference (Teachers)[ranking exercise]	Validation of medical labels –would teachers rank?
Teachers (in-school)[1] [ranking exercise]	Validation of medical labels and invite to annotate. What is the impact of context?
Family interviews [open ended narrative]	How has disability response been experienced by families
Warnock interview [semi-structured]	Opinions at a policy level
Leslie Henderson Interview	Example of parental activism
Re-visit Parent – one year on	Have things changed?
Teachers (in-school) quick questionnaire	How does questionnaire format impact on response?

A19: Willig's (2008) Key Questions

Willig's Key questions

- How is the discursive object [be it disability per se, or individual pupil] constructed through language and social practices?
- What type of object is being constructed?
- What discourses are drawn upon?
- What is their relationship to one another?
- What do the constructions achieve?
- What subject positions are made available by these constructions?
- What possibilities for action are mapped out by these constructions?
- What can potentially be felt through and experienced from the available subject positions (Willig 2008 Pg 129).

A20: Braun's (2006) Five Stage Guide to Thematic Content Analysis

1. Familiarise yourself with the data
2. Generate initial codes
3. Search for initial themes
4. Review of themes
5. Defining and naming themes

A21: David Lupen illustration (2009)



A22: Codes and Themes

Codes	Themes	Meta Themes
Access to Services	Blame.	Knowing
Barriers	Lack	Accountability
Behaviour	Causation	
Change	Training	
Cultural/environmental explanations	Inclusion	
Diagnosis		
Difference between primary and secondary school		
Disability label challenge		
Expectations		
Familiarity with Disability		
Gender bias		
Hidden agenda		
History how things were done in the past		
Identification of disability		
Inclusion		
Jurisdictions		
Morale		
Parent/school relationship		
Pupil information-sharing and availability		
Range of disability in school		
Reference to (hidden) meanings behind disability		
Resistance to support		
Resources		
Response to disability		
Segregated education		
Tensions		
Training		
Volume of disabilities (expansion)		