Exploring Grandparenthood in the Context of Grandchild Disability: Intergenerational Perspectives

Hannah Marie Merrick

Doctor of Philosophy

Population Health Sciences Institute

Faculty of Medical Sciences

Newcastle University

May 2020

Abstract

Available evidence indicates that grandparents can play a crucial role in the support of their grandchildren with a disability, their adult children and the entire family unit. Shifts in family relationships and roles, demographics and broader contexts are placing greater importance on the role of grandparents. The lived experience of grandparenting in the context of grandchild disability has received scant attention in research, policy or practice, particularly in the UK, yet advances in neonatal and paediatric care have resulted in more children surviving with disabling conditions.

This qualitative study aimed to explore the role of grandparents in the lives of children with a disability from their perspective and that of the parents, and to understand the impact of ageing on the dynamics of intergenerational support. In-depth interviews were conducted with grandparents (n=21) and parents (n=11) of children aged 4-19 years with disabilities including autism spectrum disorder, cerebral palsy, and congenital disorders.

Three overarching themes were identified: *experiences of diagnosis and family adaptation*, *maintaining intergenerational harmony*, and *changes in the dynamics of care with age*. Grandparents were a vital source of support, aiding families to adapt and continually adjust to the needs of the grandchild. Grandparents, however, also recounted their own hardships, which included financial challenges, long hours of care, and lack of engagement in third age activities. Capturing both parent and grandparent perspectives demonstrated extensive intergenerational negotiation, and at times conflict, around employment, role boundaries, types of support, and the emotional work in maintaining intergenerational harmony. Intergenerational support shifted and was continually renegotiated across the lifecourse trajectory. As well as giving voice to a previously under-researched group, these findings inform key debates, such as how extending working life policies can impact on families with disabled children.

Acknowledgements

There are several people I would like to thank who have helped me with the completion of this thesis. Firstly, I would like to thank my supervisors, Dr Suzanne Moffatt, Dr Lindsay Pennington and Professor Janice McLaughlin for their guidance, support and patience with me over the last three years. You are all an inspiration to me, and I have felt very honoured to have worked with you all.

I would like to acknowledge the Economic and Social Research Council North East Doctoral Training Centre (ESRC NEDTC) for funding this PhD.

I should like to acknowledge and thank Jacqui Adams and Sarah Lewis, from Contact North East, who collaborated on this research. Their support and enthusiasm were a wonderful motivation to complete this research and hopefully make a difference to the families they work so closely with.

I am very thankful and appreciative of all the families who participated in this research and shared and entrusted their stories to me.

I am grateful to my progress assessors Professor Thomas Scharf and Professor Cathrine Degnen who provided helpful insights, critiques and praise.

During my time at the Institute of Health and Society I have received a wealth of support and encouragement from friends and colleagues. I would especially like to thank Professor Helen McConachie, Professor Ann Le Couteur and Professor Allan Colver who encouraged and supported my PhD application and gave me opportunities to build skills that prepared me for embarking on the PhD journey. I would also like to thank my fellow PhD colleagues in the PhD room for the peer support, encouragement, listening ears and constant provision of snacks.

Finally, I would like to thank my friends and family. Mum and Dad, I know you may not have always understood my return to be a student, but I thank you for your encouragement and emotional support. I owe a huge thank you to my friends, who have become my northern family. Their constant support, advice and belief in me has been invaluable. Last, but not least, I would like to thank Richard. Thank you for being patient with my time despite the distance between us, being the calm in the storms, and for believing in me when I did not.

Dedication

For my grandparents

Grandma and Grandad Leader, thank you for always being there
Grandma and Grandad Merrick, I miss you and think of you everyday

Table of Contents

List of Tables and Figures

Abbreviations

ASD	Autism spectrum disorder
ELSA	English Longitudinal Study
ESRC	Economic and Social Research Council
LSOG	Longitudinal Study of Generations
NHS	National Health Service
SHARE	Survey of Health, Ageing and Retirement in Europe
WHO	World Health Organisation

Terminology

Disabled child versus child with a disability:

When writing this thesis, I was aware of the meaning attached to the way disability was described in relation to the grandchild and how the use of the phrases '*disabled child*' or '*child with a disability*' hold different meanings. The social model of disability argues that the phrase '*child with a disability*' implies the disability is intrinsic to the child. While the phrase '*disabled child*' reflects the fact that disability is created as a consequence of the interaction between a person and their environment. Though I agree with this later meaning, in this context the phrase '*child with a disability*' is used as it is most often being used to refer to the grandchildren's specific impairments or specific diagnoses.

Formal support versus informal support

Formal support refers to support being provided by professionals, trained employees who are typically paid for their work. It may also be referring to the welfare benefits available to families of children with a disability.

Informal support refers to support being provided by the social network, in this context mostly by family members, who are not paid for their work.

Chapter 1. Introduction

The 21st century has been referred to as the 'grandparent century' (Timonen, 2019). The changing demographic, social and economic contexts in which grandparenting takes place mean the experience of grandparenting is evolving. Several publications in the last decade attest to the growing interest in contemporary grandparenting (Arber and Timonen, 2012; Moore and Rosenthal, 2016; Timonen, 2019). Alongside this, the diversity of grandparenting is being recognised, with research investigating custodial grandparenting, particularly in the United States (US) (Choi *et al.*, 2016; Hayslip *et al.*, 2017), step-grandparent and step-grandchild relationships (Christensen and Smith, 2002), grandparents who have lost contact with their grandchild through disrupted family relations (Drew and Smith, 2002), and bereaved grandparents who have lost grandchildren (Tourjeman *et al.*, 2015; Aho *et al.*, 2018).

In this thesis I focus on a group of grandparents who are currently under-researched (Findler, 2016): grandparents of children with a disability. Medical advances in neonatal care and child healthcare means, in developed countries at least, an increasing number of grandparents have grandchildren with a disability, more of whom are surviving into adulthood (Department of Health and Social Care, 2004; Liptak and Accardo, 2004; Department of Health, 2008). Families with children with a disability have an ongoing need for relatively intense, flexible and specialised care and support over the lifecourse. While most advanced economies provide some formal support for families of children with a disability, the types and amounts vary from country to country, and in the United Kingdom (UK) it varies considerably between local government areas. Following the financial crisis in 2007/8 in the UK (HM Treasury, 2009), the Conservative-led coalition government sought to reduce the deficit through austerity measures. These measures included heavy cuts to public expenditure rather than taxation, and included a major programme of welfare reform that effectively cut or froze many welfare benefits and tightened eligibility criteria (*Welfare Reform Act* 2012; Local Government Association, 2018). In recent years, through cuts to local government funding, families of children and adults with a disability are experiencing less state support, increasing the negative consequences arising from increased unmet need (Graby and Homayoun, 2019; Horridge *et al.*, 2019; Hoskin). Prior to these changes in welfare support, families with children with a disability were known to face additional caring responsibilities and increased financial demands, alongside unmet resource needs and lack of support networks (Wallander and Varni, 1998; Roberts and Lawton, 2001). These challenges have grown with the changes in welfare support which can, in turn, place a greater emphasis on the grandparents.

The rising importance of grandparents and their contribution to family life and society has resulted in an interest in grandparenting in the fields of sociology, demography, psychology, and also economics and anthropology. In this thesis I draw on psychological and sociological perspectives to explore the experience of grandparenting in the context of grandchild disability. In this introductory chapter I provide details on the increasing recognition of grandparents, their changing demography, and how this is shaping the experience of grandparenthood in the 21st century. Following on from this I describe the experiences of families of children with a disability, outlining the welfare support available to them in the UK, and how changes in formal support and policy contexts warrant the investigation of the experiences of grandparenthood in the context of grandchild disability.

1.1 The Rising Importance of Grandparenthood

Grandparents are an important part of contemporary families and society. In 1990, Age Concern (the main UK charity campaigning for older people) recognised the importance of grandparents with the introduction of 'Grandparents Day', celebrated on the first Sunday of October in the UK. There are approximately 14 million grandparents in the UK (Broad, 2007; Glaser *et al.*, 2013). Exact figures are hard to obtain due to this data not being collected in population surveys or census, such as the Family and Household Survey. However, surveys such as the English Longitudinal Study of Ageing (ELSA) are perhaps beginning to recognise the importance of understanding grandparents, with the latest wave in 2016 (Wave 8) asking questions about whether participants were a grandparent or not, and if they cared for grandchildren (Abell *et al.*, 2018).

The 'Being a Grandparent' report (Broad, 2007) noted the limited research that has been conducted on grandparenting in the UK, and the limited national statistics on grandparents, which still remains today. The author observed that much of the grandparenting research has been absorbed within other parenting, older people, and family support research. From 1990 there has been a renewed interest in the study of grandparents, for example the British Social Attitudes Survey (1998) included a one-off specially commissioned set of questions on grandparents, which was subsequently analysed to provide a baseline understanding of grandparents in the UK (Dench and Ogg, 2002; Social Community Planning Research, 2006). Following this, the UK's Economic and Social Research Council's (ESRC) major "Growing Older" programme included projects on the meaning and contribution of grandparenting (Clarke and Roberts, 2003) and the family lives of older people (Phillipson *et al.*, 2001). What was previously seen as a largely private 'family' matter was beginning to attract more political attention, as the impact of grandparent activities on family activities was becoming increasingly recognised. For example, across Europe, there are now numerous studies on the interaction of welfare support and grandparent involvement (Igel and Szydlik, 2011; Brandt and Deindl, 2013; Glaser *et al.*, 2013), and women's (mothers') labour participation (Hank and Buber, 2008; Bordone *et al.*, 2016). In particular, grandparents' role in childcare has become a dominant theme in literature on grandparents (Gray, 2005; Dunning, 2006; Share and Kerrins, 2009).

Changes in life expectancy, fertility and family structure shape the setting in which grandparenthood takes place. Trends in mortality rates and fertility rates have been given particular attention in the changing demography of the global population. There have been decreasing mortality rates, with marked survival rates in older age (Bongaarts, 2006; Christensen *et al.*, 2009). Since the beginning of the 20th century, life expectancy globally has been steadily increasing (Leeson, 2014; Leeson, 2017). The average life expectancy in the UK is predicted to reach 85.3 years for women and 82.5 years for men by 2030 (Kontis *et al.*, 2017), though these years may be with greater complex multi-morbidity, especially for women (Kingston *et al.*, 2018). Increased life expectancy means older adults could potentially spend more years as a grandparent. These gains in longevity may also help offset the later transition to grandparenthood resulting from women giving birth at older ages than before. In contrast to rising life expectancy, there has been an almost constant decline in fertility rates and a postponement of childbearing in advanced societies (Leeson, 2018; Roser, 2019). The shift from a pattern of high fertility / high mortality rates to low fertility / low mortality rates has resulted in a change from what was previously a predominantly young population to a predominantly older population. With an older population there are potentially also more grandparents in the population. However, the reduction in fertility rates means that these older adults will be grandparents to fewer grandchildren, will potentially transition to grandparenthood later than previous generations, but be grandparents for longer (Leopold and Skopek, 2015; Margolis, 2016).

This change in age structure of the population has also changed the structure of families from previously being described as a 'pyramid' shape (fewer older generations and more young generations), to a description of 'beanpole' families, where more generations are alive but there are fewer individuals within those generations (Myers, 1990; Bengtson, 2001). Alongside this, other sociodemographic changes, such as increasing divorce rates, have changed the structure of families, which in turn alters the experience of grandparenthood.

One aspect of contemporary grandparenting that has received a lot of attention is the role grandparents play in supporting their family with childcare. The number of grandparents providing childcare has dramatically risen, with nine million grandparents in the UK making up what has been referred to as a ‘Grandparent Army’ (International Longevity Centre, 2017). The foremost reason for grandparents’ increased involvement in childcare is their adult children’s involvement in the labour market, particularly women’s greater involvement (Glaser *et al.*, 2010; International Longevity Centre, 2017). This aspect of grandparenting has also raised the political attention paid to grandparenting, with estimates that grandparents are saving the UK more than £7 billion in childcare costs (Alexander, 2015). As well as this, grandparents are providing financial contributions to their grandchild’s upbringing, contributing to the costs of clothes, toys, leisure activities and education, all while receiving no payment for covering the costs of childcare (Dunning, 2006; International Longevity Centre, 2017).

These trends in grandparenting practice are seen in other developed nations across the globe. In the US, Meyer and Kandic (2017) have highlighted the increasing assistance of grandparents in providing childcare for working families due to a paucity of federal and employer supports. Across Europe, numerous reports using data from Survey of Health, Ageing and Retirement in Europe (SHARE) have highlighted the important role of grandparents in providing childcare, and the influence of women’s labour market participation, family policies (i.e. level of formal childcare provision) and changing family demographics on grandparent involvement (Glaser *et al.,* 2010; Glaser *et al.,* 2013; Glaser *et al.,* 2014). On the other side of the world, research in Australia is also recognising the important role of grandparents in supporting parents with childcare, acting as either the primary form of childcare or a ‘back-up’ to formal childcare (e.g., when the grandchild is sick) (Jenkins, 2010; Craig and Jenkins, 2016). This research raises the question of how much choice middle generations have in asking for grandparent support due to the costs of, and access to formal care.

Grandparents are playing an important role in family life, and potentially an even greater role in families with children with a disability. In order to understand grandparenthood in this context I provide next some details on the welfare context for older adults and families of children with a disability in the UK and draw attention to the North East of England, where this study took place.

1.2 Policy, Grandparents and Employment

Despite the rising awareness of the contribution of grandparents to the provision of childcare, there is very little policy on grandparenting in the UK. In April 2011, ‘Specified Adult Childcare credits’ were introduced for grandparents or other family members who care for a child under 12 years of age (Department for Work and Pensions, 2019c). This was created to help build up the National Insurance contributions of grandparents who give up work before reaching State Pension age to help with childcare for working parents. National Insurance credits attached to Child Benefit (see Table *1*) are transferred from the Child Benefit recipient to a specified adult. However, despite the availability of this scheme, it has been reported that only a small proportion of eligible grandparents have claimed the credits despite increased advertising, indicating many families are still unaware of the scheme (McFaul, 2017; Hughes, 2019). Other than this, there are currently no other policies that financially support or recognise the contribution of grandparents to childcare in the UK.

In fact, policy changes are potentially making it harder for grandparents to be involved in childcare support. The ageing population has drawn policy attention on how to support the associated rising costs of pensions, health and social care (Organisation for Economic Co-operation and Development, 2006). The average age of leaving the labour market has increased over the past two decades, although is still lower than it was in the 1950s and is not keeping pace with increases in life expectancy. The ageing workforce and scale of early exit (though not all voluntary exit) from the labour market means the UK economy is facing a significant challenge in maintaining a supply of labour. In response to this, the UK government has been introducing policies to retain older workers by increasing the State Pension age in tandem with discouragement of early retirement (Ginn and MacIntyre, 2013). The *Pensions Act* (1995) introduced the gradual equalisation of men and women's State Pension age. Until this point State Pension age was 60 years for women and 65 years for men. The *Pensions Act* (2011) confirmed this equalisation of State Pension age by November 2018, raising to 66 years for all by October 2020. A review of the *Pensions Act* (2014) then brought forward further increases in State Pension age by eight years, with State Pension age due to reach 68 years by 2037/38 (Department for Work and Pensions, 2014).

There has also been a marked effort to encourage 'Fuller working lives' (Department for Work and Pensions, 2017a). As well as increasing the age at which State Pension can be claimed, there have been efforts to improve incentives to stay in work for longer. This has included measures to improve training, expand flexible working, and improve workplace environments for older workers. Policy makers have depicted extending working life as a way for older adults to take control of their retirement (Altmann, 2015), however there has been considerable criticism due to far less consideration of older adults who have no option but to stay in work for financial reasons (Phillipson *et al.*, 2016; Lain, 2017; Lain *et al.*, 2019a). Questions are being asked about how feasible, or even ethical, it is for all people to work for longer. Older workers' health, the physical demands of their job, and the likelihood of caring responsibilities to family members all affect an individual's ability to engage in extended working lives, and means the matter of 'choice' is unevenly distributed among older workers (Porcellato *et al.*, 2010; Loretto and Vickerstaff, 2015; Lain *et al.*, 2019b). For example, The Marmot Review highlighted the steepness of the social gradient in morbidity in the UK, with the lowest socioeconomic group at ages 45-64 having illness rates comparable to higher socioeconomic groups aged 65 and over (Marmot *et al.*, 2010). Extending working life policies could potentially further increase inequalities in later life, with the more advantaged with better employment histories and prospects being more likely to benefit from extending working life than those in a lower socioeconomic position who cannot afford to stop working and have had less opportunity to accrue a private pension over the lifecourse (Cridland, 2016; Lu *et al.*, 2017; Carr *et al.*, 2018).

Most critical to the topic of this thesis have been concerns raised for groups such as older women, due to inequalities within the workplace and home (Lewis, 2006). Women earn less for equivalent jobs, are more likely to take a career break to care for children, and are more likely to be an informal carer for disabled and older family members (Bracke *et al.*, 2008; Bauer and Sousa-Poza, 2015). There have been several campaign groups fighting against the changes in State Pension Age for women. One such group is the *Women Against State Pension Inequality (WASPI)* campaign, which was founded in the UK in 2015 with the aim of fighting for justice for women, particularly those born in the 1950s (Women Against State Pension Age Increase, 2019). The acceleration of the change in State Pension age and the lack of notice given about the changes mean women within this age group have been left unable to adequately prepare (Ginn and MacIntyre, 2013). In June 2019, two women, with the support of the campaign group *Back to 60,* took the government to High Court to ask them to answer questions about whether the decision to raise State Pension Age amounted to age and equality discrimination. On the 3rd October 2019 the outcome of the judicial review was announced, stating there was no discrimination on the basis of age or equality (Peachey, 2019). However, academic research suggests that this shift to individual responsibility for pension provision may further exacerbate gender inequalities due to women having limited access to opportunities to save (Ginn and MacIntyre, 2013), and still undertaking the majority of caring responsibilities for older parents and for grandchildren (Wellard, 2011).

Critics have highlighted the danger of raising State Pension age without considering a broader set of policies to support both women and men at different phases of the lifecourse (Price and Ginn, 2004; Vickerstaff, 2010; Phillipson *et al.*, 2016). The impact of these changing policies on grandparent availability is explored further in the following chapter.

1.3 Grandparents in North East England

Here I briefly outline some details of the population in North East England to provide some context of how older adults (and grandparents) differ from the rest of the country. Up until the 20th century, the North East's economy had been dominated by mining, shipbuilding, heavy engineering, and manufacturing. However, in the later decades of the 20th century deindustrialisation resulted in the closure of most of these industries in the North East. Mass long-term unemployment, disability, and increased welfare dependency resulted. In recent years, the region has seen some economic growth, with a growth in the energy sector, world leading clinical research, and a rapidly growing digital and creative sector (North East Local Enterprise Partnership, 2019).

Despite the economic growth, the economy and infrastructure of the North East lags behind many other regions of the UK. The North East has the largest unemployment rate at 5%, compared to 3.8% in England and the UK (Watson, 2019). Regional differences in employment rates in older adults have been demonstrated in England (Banks *et al.*, 2010). Employment rates of older adults aged 50-54 and 60-64 years in the North East are lower than the rest of the UK, however they have been rising (Round, 2017). Of those that are working, older workers in the North East are more likely to be working full time than part time, potentially reflecting an increased need to continue to stay in employment in order to support themselves financially due to lower rates of wealth (Round, 2017). Compared to other English regions, the North East includes higher numbers of pensioners living with lower general wealth and pension income as age advances (Round, 2017).

Longevity in the north of England has increased, but the average life expectancy remains below the national rate, with the North East having the lowest life expectancy at birth for men (77.9 years) and women (81.6 years) in England and Wales in 2015 (79.4 years in men, and 83.1 years for women) (Office for National Statistics, 2015). As well as lower life expectancy, the average healthy life expectancy at birth is lower in the North East at 59.7 years for men and 59.8 years for women (i.e. below State Pension age). Within the region, healthy life expectancy at 65 years of age ranges from 7.1 years in the poorest areas to 14.9 years in the most affluent (Public Health England, 2018). When looking at self-reported health in 2011, the North East had some of the lowest rates of self-reported 'good' (33.3% vs. 34.1%) or 'very good' (44% vs. 47.1%) health and the highest rates of 'fair' (15.2% vs. 13.2%), 'bad' (5.7% vs. 4.3%), or 'very bad' (1.7% vs. 1.3%) health than other English regions and Wales (Office for National Statistics [ONS], 2013d). The north of England also has relatively high rates of potentially life-limiting illness and long-term condition (Ellis and Fry, 2010). As a result of higher levels of poor health, older adults in North East England are more likely to have to involuntarily leave the labour market before State Pension age or try to find paid employment that accommodates their health needs. This, therefore, is the economic and employment context that may influence grandparents' available resources, time and energy to provide support to grandchildren.

1.4 Families of Children with a Disability

The most recent UK Family Resource Survey 2017/18 reported 21% (13.3 million) of people described themselves as having a disability, of which 8% (over 1 million) were children (Department for Work and Pensions, 2019b). Nearly all children with a disability are cared for within the family home. Families of children with a disability may have to contend with many unexpected challenges in relation to the child's disability and impairments, as well as challenges caused by balancing parenting and caring, maintaining a family life (Beresford *et al.*, 2007), managing the additional costs of raising a child with a disability (Dobson and Middleton, 1998), and negative social responses and social arrangements (Dowling and Dolan, 2001; Green, 2007). Families of children with a disability will typically be involved with health, educational and social support services. It is widely reported that many families of children with a disability struggle with accessing and navigating these multiple support services, which are often fragmented and/or poorly resourced (Rodger and Mandich, 2005; Reichman *et al.*, 2008; McManus *et al.*, 2011). Much of the psychology literature on families of children with a disability has focussed on parents and the impact having a child with a disability has on their financial situation, time for themselves, and family relationships. Mothers of children with a disability are reported to have higher levels of depression, anxiety and isolation (Bailey *et al.*, 2007; Montes and Halterman, 2007; Emerson *et al.*, 2010). These additional challenges mean that social support, and in particular family support, is important for parent coping and adaptation.

One of the main challenges identified for families of children with a disability is the additional costs of raising a child with a disability. A recent report from the UK charity Scope, The Disability Price Tag 2019 (John *et al.*, 2019), indicated that families with children with a disability face average extra costs of up to £581 (≈ $745, €672,) per month for one child and up to £823 (≈ $1056, €953,) if there are two or more children with a disability in a family. The extra costs are put into three categories. Firstly, there are extra costs in acquiring specialist goods and services, which includes equipment and home adaptations, therapies (especially accessing private services, if affordable, to avoid long NHS waiting lists), and specialist toys or play equipment (e.g., sensory toys). Secondly, extra costs are incurred through greater use of non-specialist goods and services. These costs include increased transport costs, such as taxi and private-hire vehicles due to inaccessible public transport, and greater energy costs such as extra heating or extra electrical costs to charge equipment such as assistive technology or powered wheelchairs. Finally, extra costs are incurred through the higher costs for non-specialist goods and services such as insurance costs being higher, or insurance cover being denied. Extra costs mean that many families with a child with a disability are unable to achieve the same standard of living as those without disability (Buckner and Yeandle, 2017). Given that many families of children with a disability are on lower-than-average incomes, being able to manage the extra costs becomes even harder (Blackburn *et al.*, 2010; Shahtahmasebi *et al.*, 2011). Previously, means-tested benefits and tax credits systems helped with some of the additional costs families of children with a disability faced. The next section describes the welfare support available to families and the current changes to welfare systems affecting families with children with a disability.

1.4.1 Support to families of children with a disability

Support for children and young people with a disability and their families comes from multiple agencies, including the National Health Service (NHS), education, and the Local Authority. The *Children and Families Act* (2014) was designed to facilitate greater cooperation between education, health and social care. Health services such as general practitioners, hospital services and health visitors are often involved in identifying the child's disability, but also provide ongoing specialist and therapeutic services as needed. The *Children and Families Act* (2014) has placed a duty on Clinical Commissioning Groups[1], NHS Trusts and NHS Foundations to inform a child's parents and the Local Authority of any child with special educational needs and/or a disability. Within education at all levels (including nursery, school and college) most children with a serious disability will be assessed for special education needs. Following assessment, a plan for support should be agreed between the school and family, which is regularly reviewed. Examples of education support may include access to a speech and language therapist, support staff in the classroom or equipment to aid any sensory or physical impairments. All Local Authorities have a responsibility to provide support to families of children with a disability, however, as already mentioned above, the availability and accessibility of this support is very fragmented and under-resourced. Families of children with a disability can access financial support, respite services and other social care services, but

---

[1] Clinical Commissioning Groups (groups of local primary care practitioners) are clinically led statutory NHS bodies responsible for the commissioning of health care services for their local area, including mental health services, urgent and emergency care, elective hospital services and community care. They were created following the *Health and Social Care Act (2012).*, and replaced Primary Care Trusts in April 2013 (NHS Clinical Commissioners *About CCGs*. Available at: https://www.nhscc.org/ccgs/ (Accessed: 17th October 2019).

access depends on local availability. Table 1 and Table 2 provide lists and descriptions of the types of financial and other support schemes available.

Whilst in principle a wide range of services are legally due, in practice there is a wide disconnect between what is described as available to families and what families can access and utilise. In response to this, the Disabled Children's Partnership was established, which is a coalition of over 70 organisations (including Contact, Council for Disabled Children, National Autistic Society). The partnership exists to address the lack of health and social care services for families of children with a disability (Disabled Children's Partnership). They have concluded there is currently a £433.9 million gap in funding for social care services by Local Authorities for children with a disability. The number of children with a disability receiving social care has reduced, this is despite the fact the number of children with a disability in the UK has been increasing over the past 10 years, with their needs becoming more complex (Davies, 2012). This underfunding means that local authorities are restricted in who and how many people they can help, meaning typically families do not get support until they are in crisis. The needs of children with a disability are not being met by current social support services, with 9 in 10 parents reporting they have had to fight to get the services they need (Disabled Children's Partnership, 2017).

Important to acknowledge are the changes that are currently happening in terms of benefits and welfare support to families of children with a disability. In 2013, Universal Credit was introduced as a flagship component of the UK government's welfare reforms for working-aged individuals (16-64 years), aiming to 'encourage' those not in work to move into employment. The aim was to simplify the benefits system by replacing six existing means-tested benefits and tax credits into one monthly payment[2] (Department for Work and Pensions, 2018). Universal Credit was incrementally introduced, and in 2017 it was rolled out in both Gateshead and Newcastle in the north of England. Universal Credit has been met with criticism, in particular the impact it is having on more vulnerable people, such as those with physical and mental health problems, and on lone parents (Seddon and O'Donovan, 2013; Cain, 2016; Cheetham *et al.*, 2019). The experiences of those who have applied for Universal Credit indicate frustrations with the application process, difficulties in managing their incomes, serious financial consequences of the minimum 5-week payment delay for new claimants, and negative social, physical and mental health impacts (Schmuecker, 2017; Cheetham *et al.*, 2019; Stinson, 2019).

---

[2] Benefits and tax credits being combined into one-monthly payment include: housing benefit, Child Tax Credit, Income Support, Working Tax Credit, Income-based Job Seekers Allowance, and Income-related Employment and Support Allowance

Table 1: Financial benefits available to families of children with a disability in the UK 2019

Type of Benefit	Description	Amount[1]	Eligibility
Disability Living Allowance[2]	Designed to meet the extra costs families might have in relation to the child's disability. Made of two components: 1. Care Component- if child needs a lot of extra watching over or help with personal care. Different rate depending on level of extra care child needs. 2. Mobility component- paid to children who need help in getting around. Paid at two rates depending on nature of mobility problem.	Care component (per week): Lowest rate - £23.20 Middle rate - £58.70 Highest rate - £87.65 Mobility Component (per week): Low rate - £23.20 Higher rate - £61.20	Any child with a disability or chronic illness qualifies, even without a formal diagnosis. An application needs to be made that demonstrates the child needs substantially more care and supervision than other children of the same age. Applicants may be assessed in person before a decision is made. Payment suspended if child spends more the 28 linked days in residential accommodation.
Personal Independence Payment[2]	Replaces Disability Living Allowance for adults aged 16-64 years. Uses a points-based system to decide if an individual qualifies. Paid in two components: 1. Daily Living Component - ability to carry out key activities necessary to participate in daily life (e.g., preparing food, eating and drinking, managing treatment, communicating verbally, mixing with other people). 2. Mobility Component - ability to get around.	Daily Living Component (per week): Standard rate - £57.30 Enhanced rate - £85.60 Mobility Component (per week): Standard rate - £22.65 Enhanced rate - £59.75	Whether an individual qualifies will depend on the difficulties they have in carrying out certain tasks essential to independent living and the problems they have in getting around out of doors.
Carer's Allowance	Parents qualify for this if they provide at least 35 hours of care per week to someone who gets one of the following: - The care component of Disability Living Allowance at the middle or highest rate. - The daily living component of Personal Independence Payment at either rate.	£66.15 per week	Only one parent/carer qualifies for carers allowance for a child. Only one award is given per family even if a parent is looking after more than one child with a disability. If a parent/carer is working, they can only get Carer's Allowance if earnings after deductions are no more than £123 per week.

Tax Credits Being replaced by Universal Credit (between July 2019 and 2023)	Working Tax Credit: Means tested payment for working people on low-income Child tax credit: Means tested payment for people with children. Paid to all families who have at least one dependent child. You get extra child tax credit payments if you have a child with a disability who gets Disability Living Allowance, Personal Independence Payment or who is registered blind. Childcare costs can be included only for: - Lone parents who are working at least 16 hours a week. - Couples who are both working 16 hours. - Couples where one partner works 16 hours and the other is entitled to Carer's Allowance or either incapacitated or in hospital/prison.	The amount received depends on your family circumstances and your annual income.	If you have children, you qualify if your income is low enough and: - You are a lone parent and work at least 16 hours per week. - You are part of a couple in which one partner works at least 16 hours per week and you work at least 24 hours per week between you. However, a couple with children need only work 16 hours per week between them if: - One partner works at least 16 hours per week and the other partner is entitled to Carer's Allowance. - One partner is disabled or over 60 and works at least 16 hours per week.
Child Benefit	Claiming Child Benefit gives the recipient National Insurance credits which count towards a State Pension. Paid every 4 weeks. Payments may be affected if the child goes into care for more than 8 weeks or in hospital or ‘residential care’ for more than 12 weeks.	Eldest child - £20.70 per week Additional children - £13.70 per child per week	Child Benefit can be claimed by anyone responsible for a child who is either under 16 years or under 20 if they stay in approved education or training. Only one person can get Child Benefit for a child, and there is no limit on how many children you can claim for. Some of the Child Benefit may have to be paid back in tax if claimant or their partner’s individual income is over £50,000.

[1] Figures are true as of October 2019. [2] Available to all individuals with a disability, not just families of children with a disability

Data sourced from: www.contact.org.uk (Contact), Disabled Children: A legal handbook (Broach *et al.*, 2016), www.gov.uk/help-for-disabled-child (Gov.uk, 2019)

Table 2: Government Support Schemes available to families of children with a disability in the UK 2019

Type of support	Description
Short breaks	Local authorities have a legal duty (*Children Act*, 1989) to provide short breaks for families with a child with a disability. These breaks can include day care at home, overnight short breaks, day care away from home, residential breaks and family link schemes. However, these schemes have been subject to substantial cuts (Every disabled child matters, 2015)
Childcare Support	
Funded childcare for 2-year olds	15 hours a week for 38 weeks a year for parents in receipt of benefits (including in-work benefits) or children who are disabled or looked after children (children in the care of the local authority)
Universal funded childcare for 3- and 4-years olds	15 hours a week for 38 weeks a year for all 3- and 4-year olds
Funded childcare for 3- and 4-years olds with working parents	Entitled to an extra 15 hours a week funded childcare for 38 weeks of the year, equating to 30 hours a week in total. Parents must earn at least the equivalent of 16 hours a week at national minimum wage or national living wage, and not earn over £100,000 per year
Tax Free Childcare (aged under 12, or under 17 if child has a disability)	Covers 20% of the childcare costs up to a maximum of £4000 for children with a disability
Universal Credit (replacing tax credits)	Pays up to 85% of childcare costs up to £175 per week for one child and £300 for two or more children
Personal budget and direct payments	Personal budget is an allocated amount of money that the local authority considers sufficient to meet all of your child's eligible needs. Once amount is agreed, family can decide how to make best use of it. Direct payments are payments by local authorities that allow disabled people and carers to buy in and arrange the services they been assessed as needing themselves rather than being provided by the local authority.
Disabled Facilities Grants	Grant from the local council if adaptations need to be made to the home e.g., widen doors or install ramps, improve access to rooms and facilities
Motability Scheme	Can exchange Motability allowance to lease a new car, scooter or powered wheelchair
Education, Health and Care Plan (EHC)	Plan for children and young people aged up to 25 who need more support than is available through special education needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.

Data sourced from: www.contact.org.uk (Contact), Disabled Children: A legal handbook (Broach *et al.*, 2016), www.gov.uk/help-for-disabled-child (Gov.uk, 2019)

A concern has also been raised over how these major changes to the UK welfare system affect the income of families of children with a disability. UK charity Contact (2017), who support families of children with a disability, have highlighted a number of ways Universal Credit could impact on families of children with a disability. These include suspending payments for children who are away from home for more than six months (such as children in hospital), expecting full-time carers to look for work when they share the care of a child with a severe disability with a partner, and expecting full-time carers to look for work while they wait for a decision to be made on their child's claim for Disability Living Allowance. Prior to Universal Credit, parents received an additional amount if their child was awarded Disability Living Allowance through the disability element of child tax credit, worth £57 (≈ $73, €66 a week. The principle of the payment being made at two rates is replicated in Universal Credit, with the higher rate remaining the same, however, the lower rate is being cut by more than 50% (£60.90 to £29.05 per week, equivalent to $74.82-$35.69 or €68.49-€32.67 per week). This has serious implications for families who are unable to work and who only qualify for the lower rate, potentially being £1,656 (≈$2139, €1920) worse off a year. It was intended that this loss in income could be offset by parents moving into work, however many families report that it is very difficult to find work that fits around the care needs of their child with a disability (The Children's Society, 2012). Therefore, it will be more difficult for these families to supplement the loss in income. Another issue is the two-child limit introduced to families who have a third child born after April 2017 (Department for Work and Pensions, 2017b). Under this limit, the third child and any subsequent children are not allocated a child element allowance under Universal Credit. This could result in a loss on average of £374.10 (≈ $483.23, €434.03) per year for in-work households and £261.84 (≈ $338.27, €303.79) per year for out-of-work households. A report attempting to analyse the impact of changes in Universal Credit to families of children with a disability indicated that the cuts in benefits could be devastating for some families, in particular for lone parent families (The Children's Society, 2012). Contact's report had two main recommendations: to protect children on the mid-rate care component of Disability Living Allowance and to provide additional support with childcare for families of children with a disability (Contact, 2017).

Alongside all of this, in April 2016 a 'benefits freeze' was announced, meaning that all working-age benefits would not rise with inflation for four years (HM Treasury, 2015; McInnes, 2019). The value of working age benefits has fallen by 6.4%, with lower income families being impacted the most by these changes (Corlett *et al.*, 2017). There have been calls from multiple organisations to end the benefits freeze, with over 400,000 families being swept into poverty and made £340 (≈ $439, €395) a year worse off (Barnard, 2019).

In addition to prolonged austerity, the UK has seen major unprecedented changes to state welfare provision that will impact on children with disabilities and their families throughout their life. This reduction in state welfare support has serious implications for grandparent support and involvement within families of children with a disability in the UK. Particularly for those families on the middle- to low-care component rates of Disability Living Allowance, grandparents may become an increasing source of financial help as well as practical support. However, this is all coming at a time when grandparents are being encouraged to stay in work for longer or may need to stay in work for longer to financially support themselves and potentially their family in later life. A greater understanding of the role and experience of grandparenthood in this context is needed to fully understand the impact of these changes on families of children with a disability.

1.5 Research Collaboration with Contact

For this research, I collaborated with Contact North East. Contact is a charity for families with children with a disability. The organisation provides guidance and information, as well as opportunities for families to come together to support each other through workshops and support groups. The charity was founded in 1970 when a group of families recognised that despite their children having different disabilities, they still had common experiences and could support each other. The charity's vision is "that families with children with a disability feel valued and are strong, confident and able to make the decisions that are right for them" (Contact, 2019). The charity provides numerous resources for families on their website, including information about diagnosis, financial support, education and information on work and childcare. In Contact's latest Annual Report it was reported that over 44,000 parents took part in parent workshops, over 11,000 calls were answered by their Helpline advisors and 2,700 parents were supported while their child was in hospital (Contact, 2018). Over the last year they have also been involved in a number of campaigns with families to improve school transport, helping parents challenge the closure of a respite centre, and working with the University of Leeds in publishing their report 'Caring More than Most'.

Contact is a national charity with multiple offices across the UK, as well as a central office in London. The North East branch of Contact were asked to collaborate on this research following their involvement in a previous Masters research project looking at grandparenthood in the context of grandchild disability (Moffatt *et al.*, 2019). I worked closely with Jacqui Adams, who was the Regional North East & Cumbria Manager, and with Sarah Lewis, the Regional Information Officer. Jacqui and Sarah were involved in the research from the very beginning, including looking at the research proposal, contributing to the design of the research questions, and approving all the research adverts, information sheets and consent forms. As part of the collaboration, recruitment for the study was conducted through Contact North East. Jacqui and Sarah were also part of an Advisory Group for the research, contributing to discussions about the methods and results emerging from the analysis. Unfortunately, Contact North East were unable to continue due to cuts to their budget and local funding in June 2018 and had to close. Following this Jacqui remained involved in the Advisory Group, has commented on the results of the project, and has helped with planning the dissemination activities for the research, both with Contact and other organisations. The closure of this local branch is indicative of the impact of prolonged austerity-driven budget cuts and is a serious loss of support for families with children with a disability in North East England.

1.6 Aims and Objectives

The overall aim of this study was to explore the experience of grandparenthood in the context of grandchild disability, from grandparent and parent perspectives. There were three objectives for this research:

1) To understand the lived experiences of grandparents of children with a disability and how this affects their identity and grandparenting role.
2) To explore the current caring relationships between grandparents, their adult children, and their grandchildren with a disability, from two generation’s perspectives.
3) To understand the impact of ageing on the grandparent-grandchild relationship, and the components and dynamics of care.

1.7 Thesis Overview

In this first chapter I have outlined the increasing importance of grandparents and given some details of the context in which this research is taking place. Chapter 2 is a narrative review of the current literature on ageing and intergenerational relationships, outlining the current theoretical perspectives and the influences on grandparent-parent-grandchild relationships. Following this there is a narrative review of the current literature that has investigated the experience of grandparenthood in the context of grandchild disability. Chapter 3 describes the methodology and research methods and I reflect on some of the processes of carrying out this research. In Chapters 4 to 6 I present the three overarching themes that emerged from the analysis. Chapter 4 starts where most of the participants’ stories began, with the experience of diagnosis and the family adjustment. Chapter 5 explores the intergenerational support provided, the ways in which this support is provided, and the factors within and outside the family that influence intergenerational support. In Chapter 6 I explore some of the changes in the grandparent role as each generation ages, and then discuss some themes that emerged in thinking about future intergenerational support. Chapter 7 draws together the main findings and provides unique perspectives on grandparenting in the context of grandchild disability. The overarching implications and impact for research, policy and practice are discussed.

Chapter 2. Narrative Literature Review: Ageing, Intergenerational Relationships, and Grandparenting Children with a Disability

2.1 Introduction

Chapter 1 provided an outline of the demographic and welfare contexts in which grandparenting a child with a disability currently takes place in the UK. In this chapter I review the literature of the theoretical frameworks on ageing, theories of intergenerational relationships, and then move on to provide a more detailed review of the current literature on the experience of grandparenthood in the context of grandchild disability. Grandparenthood is a role that comes with ageing; therefore, we must consider what grandparents' experiences of ageing have been over the lifecourse. Along with this, grandparenthood takes place within the family context, therefore the role and experience of grandparenthood will be influenced by the quality of these intergenerational relationships and how expectations are negotiated within each family. This may be especially true in families of children with a disability where there may be greater expectations of, and need for, intergenerational support.

2.2 Ageing Population and Care Availability

The trends of decreasing fertility rates and increasing life expectancy discussed in the Introduction chapter means the global population is ageing (Finch, 2017). At both a population and individual level, ageing results in challenges and opportunities for governments, families, communities, and individuals (Harper, 2006; Leeson and Harper, 2007; Leeson, 2018). In the UK, there has been an increasing focus among government and policy makers about the 'cost' and 'burden' of an ageing population (Phillipson, 2015). At the same time, it is suggested that the older population (65 + years) is on average, healthier, wealthier, and more economically active than previous generations (Women's Royal Voluntary Service, 2011), although serious inequalities persist in how ageing is experienced (Dannefer, 2003). Important questions are being asked within academia, policy, and healthcare about how people age and how to support an ageing population, and concerns have been raised about the trends in older adults' health and social care needs.

Different approaches to dealing with an ageing population in the UK, and across Europe, have included individuals taking greater responsibility for their own old age (e.g., planning for retirement, "active" ageing), and through changes at the macro level in terms of policy and welfare provision. However, these approaches assume a level of increased prosperity for all post-retirement, neglecting empirical evidence for the inequality, social exclusion, and deprivation experienced by some in their later life, potentially leading to even greater inequalities (Nazroo *et al.*, 2008; Marmot and Bell, 2012). Over time, different generations have had differing amounts of access to opportunities for economic success, personal security, and family development. More recently in the UK, there has also been evidence of a deceleration of the increase in life-expectancy in both men and women, and it is long established that there are considerable differences in life expectancy based on levels of deprivation (Hiam *et al.*, 2018). These inequalities and the ways ageing are experienced have implications for how grandparenthood may be experienced in terms of availability, obligation, and capacity to support grandchildren.

Some of the current interest in grandparents may be because members of the Baby Boom generation are beginning to experience life with grandchildren. The Baby Boom generation refers to individuals born between 1946 and 1964, currently aged in their 50s-70s. In Western Europe and North America, this generation are described as having experienced significant change in terms of gender roles, ethnic diversification, changes in traditional household and family structures, and have seen enormous technological advancements over their lifecourse. Early Baby Boomers were children in a period of post-war austerity and then entered adulthood during a time of increasing consumerism, changes in employment opportunities, and changes in pension opportunities (Biggs *et al.*, 2008). In contrast, the later Baby Boomers were born during a time of prosperity, however when they came to enter the labour market the economy was entering a recession. This has resulted in different expectations of employment, welfare state and lifestyle from each cohort (Evandrou and Falkingham, 2000), which in turn is potentially altering their experiences of grandparenthood.

2.2.1 Changing experience of ageing

In the UK, there have been substantial changes in the overall health of the population due to medical advances and changes in the national wealth that have all affected how the process of ageing and ‘old age’ have been experienced and perceived. Policy has a central role in providing and shaping opportunity structures (e.g., access to healthcare, housing and employment) for the ageing population. Phillipson and Baars (2007) have described European and North American perspectives of ageing evolving over the past half-century in three phases. Firstly, in the 1950s and 1960s ageing was seen as the social problems of the individual arising from their disengagement from the labour force and greater dependence on family members for support and care. At this time, Cumming and Henry (1961) posited one of the first theories of ageing: Disengagement Theory. This theory described individuals as gradually withdrawing from their roles and commitments in society (e.g., leaving work, fewer parental responsibilities). Ageing was largely viewed as a negative experience, with increased levels of poverty due to loss of income and an inevitable decline in health. Disengagement theory has been widely criticised for a narrow focus on the influence of social structures and for not allowing for heterogeneity in the way individuals age (Hochschild, 1975). A discourse of disengagement is very different to the current discourse of ageing, which emphasises engagement (including civic, social, and labour market engagement) in older age. However, Disengagement theory did begin to emphasise the gender difference in the experience of ageing, as the process of disengagement was hypothesised to be harder for men who were more engaged in the labour market than women (Zaidi and Howse, 2017).

The second phase of perspectives of ageing began to challenge the dependency view of the Disengagement theory and focussed more on the positive experiences of later life. Increased life expectancy, improved health status, and a compression of morbidity rates, which delay the onset of ill-health and disability, provided individuals with the opportunity to enjoy life after work, and maintain some roles and social activities (Erlinghagen and Hank, 2006). The idea of a ‘third age’ emerged where individuals were no longer limited by work or child rearing commitments and had the opportunity and economic resources to enjoy life before reaching ‘old age’ (Laslett, 1991). Social science theories of ageing were starting to take into account the positive aspects of ageing. For example, the psychosocial approach of Continuity Theory highlighted how, as people aged, they maintained some of their roles and commitments (e.g., volunteer work, hobbies) in later life and positively adapted to the changing external structures such as leaving the labour force (Atchley, 1989). Attention was drawn to social and economic advantages or disadvantages (in terms of health, income and social support) established over the lifecourse that influenced the ability of individuals to take up opportunities and experience a ‘third age’. Feminist theory in particular, which focusses on the experiences of women and gender inequalities, highlighted the disadvantages women accumulate over the lifecourse. Women are more likely to take career breaks for childcare or other caring responsibilities and be in part time work (Ginn and Arber, 1991; Lewis, 2006). In the UK, this impacts women’s ability to contribute to National Insurance and save for later life, all of which means they are more likely to rely on a (inadequate) State Pension for income in later life, or on a male partner’s pension (Kingsmill, 2001; Price and Ginn, 2004). Grandmothers may not be able to leave work to help with childcare needs and mothers may face financial difficulties in their own later life.

The final phase of perspectives on ageing (1990’s onwards) described by Phillipson and Baars (2007), was a shift in the perspective of ageing from an individual to a global issue and concern. The concept of “successful ageing” was developed as a research tool to try to explain why some individuals are able to age better than others (Rowe and Kahn, 1997). In Rowe and Kahn's (1997) model of “successful ageing” it is defined as “the avoidance of disease and disability, maintenance of high physical and cognitive function, and sustained engagement in social and productive activities” (p. 439). Recently, there has been an emphasis in policy on what has been termed “active” and “healthy” ageing, emerging from the European Commission Policy frameworks (European Commission, 2017) and from the World Health Organisation (WHO) Global Strategy on Ageing and Health (World Health Organization, 2016), in response to the challenges of an ageing population (Foster and Walker, 2015). “Active ageing” has been defined by WHO as “the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age” (World Health Organization, 2002, p. 12).

However, while these concepts have encouraged a move away from a largely negative discourse around ageing, there is the implication that concepts such as “active” and “successful” ageing are assumed to be achievable for all, putting the responsibility of ageing on the individual rather than society (Dillaway and Byrnes, 2009; Rubinstein and de Medeiros, 2014). There are multiple definitions of “successful ageing” used and applied in the literature (Cheng, 2014; Cosco *et al.*, 2014). Many of these definitions operationalise ageing as a binary outcome (successful or unsuccessful) and include an absence of physical disability which automatically puts many individuals in the “unsuccessful” group (Depp and Jeste, 2006; Cho *et al.*, 2012). The traditional concepts of “successful ageing” also assume a high degree of individual control, neglecting the inequalities in ageing and the influence of social and cultural location (Katz and Calasanti, 2014; Timonen, 2016). Definitions of “successful ageing” that include the perspectives of older individuals show that factors such as optimism, effective coping-styles, and social and community involvement are more important to their perception of “successful ageing” (McCann Mortimer *et al.*, 2008).The usefulness of using terms of “successful” and “active” ageing is called into question when only 8.5-12% of people over 65 years in US and Europe were identified as “successful agers” using Rowe and Kahn’s definition (McLaughlin *et al.*, 2010; Hank, 2011). Individual factors such as being of advanced age (over 75 years) or female, have been associated with decreased opportunities of ageing “successfully” (McLaughlin *et al.*, 2010), and structural factors at the societal level (e.g., welfare state policies and access to healthcare) influence patterns of “successful ageing” in different countries (Hank, 2011). For some, a form of “successful ageing” may be achievable, but the serious inequalities that exist in later life based on social class, gender, ethnicity and health mean for others it is unattainable and they will continue to require the support of society in later life (Dillaway and Byrnes, 2009). Concepts of “active” and “successful” ageing put responsibility for ageing on the individual, underplaying the importance of macro level influences on the experiences of ageing.

Where previous theories have not accounted for the heterogeneity of ageing, Cumulative Advantage and Disadvantage theory (CAD) postulates that inequalities in ageing are initiated early in life and social processes allow for the accumulation of advantages (or disadvantages) over the lifecourse (Dannefer, 2003). Evidence of a cumulative advantage or disadvantage effect has been found for measures of IQ, income, and status (O'Rand, 1996; Crystal *et al.*, 2016). There is also increasing evidence for a cumulative disadvantage effect on health in later life, with data from 10 European countries finding evidence for a continuation of education-based, occupation-based and wealth-based gaps in health (Stolz *et al.*, 2017). In North East England, The Thousand Families Study has provided significant understanding of lifecourse predictors of health (Lamont *et al.*, 1998; Pearce *et al.*, 2008). The study has followed 1142 babies born between May and June 1947 in Newcastle upon Tyne. The cohort has been followed-up several times over their childhood, in their 20s, 30s, 50s, and most recently in their 60s. The impact of factors over the lifecourse including child health (e.g., birthweight), socio-economic status and changing social trajectories on oral health (Mason *et al.*, 2006), respiratory health (Tennant *et al.*, 2008) and mental health (Tiffin *et al.*, 2005) have been investigated (along with several other outcomes), and have indicated the cumulative effect of these variables on later life outcomes. For example, Forrest *et al.* (2011) found that childhood IQ and education level were positively associated with upward social mobility (which has been associated with better health) between the ages of 5 and 49-51 years.

The social inequalities rooted in family origins has resulted in an interest in how inequality is expressed through generations. There is a body of research that has begun to investigate how grandparents class, resources and own social mobility influence grandchildren’s outcomes. The majority of this work has been completed in the US and Western Europe, with many studies finding a positive grandparental effect on grandchildren’s outcomes (Anderson *et al.*, 2018). Across several social contexts, grandchildren with higher educated grandparents are reported to perform better in language and mathematical classes (Ferguson and Ready, 2011; Møllegaard and Jæger, 2015). These influences are found to persist into the grandchild’s labour market participation and social class in adulthood (Chan and Boliver, 2013; Dribe and Helgertz, 2016; Knigge, 2016). In the UK, using data from the British Household Panel Study and the UK Household Longitudinal Study, Zhang and Li (2019) found evidence for a positive grandparental effect across the lifecourse, from the occupational aspirations of teenage grandchildren, to the educational attainment of young adults and finally grandchildren’s occupation as an adult. These effects were found after controlling for the parents’ socioeconomic and cultural resources, as well as demographics including gender and ethnicity.

Grandparents can play an important role not just in supporting families but also potentially in shaping the grandchild's life chances over the lifecourse.

The implications of inequalities in later life are important for consideration in policy to ensure groups are not further disadvantaged in later life, especially when there has been an increased emphasis on private (individual) rather than public (collective) provision of support and care for older individuals (Judt and Snyder, 2010). One UK example of this has been the increase in the age at which people can access their State Pension and the introduction of measures to reduce age discrimination in the workplace, such as the UK's 'Fuller Working Lives' strategy (as described in Chapter 1, section 1.2) (Department for Work and Pensions, 2017a). The changes in access to State Pension are likely to be much more detrimental to low-income workers, carers, and those with disabilities, who have limited opportunities or choice about how long they can remain in the workforce (Angel and Mudrazija, 2011; Phillipson *et al.*, 2016; Lain *et al.*, 2019b).

Recent epidemiological research indicates that increased life expectancy among adults is accompanied by only small gains in disability-free years, and smaller gains for women than for men (Jagger *et al.*, 2016). Even though we are living longer, these extra years are not necessary equating to a delay in the onset of disability or ill-health, and again the effect is not seen across all populations with issues of inequality also increasing. Comparisons made using data from the UK's Cognitive Function and Ageing Study I (1991) and Study II (2011), indicated that while life expectancy increased over the decade, in 2011 on average participants over 65 years of age were spending two more years in low dependency (care less than daily) and one year more in high dependency (24 hour care needed) (Kingston *et al.*, 2017). If these trends, particularly in low dependency, were to continue it would have important implications for families who generally take responsibility for this type of care need (e.g., help with household tasks and shopping), influencing interpersonal relationships within families. Longer lives are not necessarily equating to longer lives in good health, which has implications for older adults' capacity to remain in the paid work force and to provide family care for grandchildren, partners, or indeed, ageing parents.

A further implication of the level of dependency in later life, and an issue that has been raised in the media as well as academic research and policy debates, is how to support the social care needs of an ageing population. In the UK, the majority of adult social care, similar to support for children with a disability, is provided informally by family members or friends (Carers UK, 2019). Looking at predictions for informal care in England up to 2032, it has been calculated that the supply of informal care will not be able to keep pace with the demand for it (Pickard, 2015). Rather than being met with increased investment, the increased demand for adult social care has been met with a decrease in net expenditure by 11.4% between 2010 and 2015 (Burchardt *et al.*, 2015). This increase in demand for adult social care is suggested to be due to an increase in the number of working-aged adults requesting support due to disability, a growing number of older people, and a significant level of unmet need (Bottery *et al.*, 2019). Age UK, a major charity highlighting the crisis in social care for older adults, have reported that over 1.2 million people aged 65 years and over do not receive all the care and support they need to complete essential daily living activities, and tightened eligibility criteria have led to an approximately 25% reduction in the number of older people accessing publicly funded care since 2009/10 (Age UK, 2018). Of those that are managing to access formal care, 1 in 5 social care providers are rated as inadequate or requiring improvement (Care Quality Commission, 2017).

There is an increased demand for informal care for both younger (grandchild care) and older generations that leaves many middle-aged and older adults in a precarious position of managing the care needs of others, as well as their own employment roles and social activities (Carmichael *et al.*, 2010; Michaud *et al.*, 2010; Bauer and Sousa-Poza, 2015). The experience of ageing has changed greatly over the last half-century. These changing experiences of ageing are highlighting the persistent inequalities that exist over the lifecourse and need addressing and consideration in current and future policy surrounding ageing.

2.2.2 Grandparenthood and ageing

As outlined above, the cultural representations and notions of older people’s place in society has changed considerably over the last decade. In turn, these social representations have changed the way in which values and notions of the grandparent role are constructed. With an ageing population, there has been an increase in the number of people experiencing grandparenthood in later life and an increase in the length of time individuals experience grandparenthood (Uhlenberg, 2005; Muller and Litwin, 2011). These changes have implications for our understanding of contemporary grandparenting. Contemporary ageing populations (including grandparents) are diverse; individuals balance multiple roles and responsibilities. The recent focus on a “third age” vision of life post-retirement, and agendas of “active”, “successful”, and “healthy” ageing has been critiqued for their narrow focus on labour force participation, life-long learning, and participation in leisure activities (Katz, 2000; Clarke and Roberts, 2003; MarhÁNkovÁ, 2018). Caregiving activities are rarely included in “healthy” or “successful” ageing agendas, yet more and more evidence highlights the increasing role grandparents are playing in families (e.g., childcare support). The Active Ageing Index (EU) includes caregiving activities (including for grandchildren and older adults) under

‘Participation in Society’(Zaidi *et al.*, 2013; Zaidi, 2015). Recent grandparenting literature has begun to investigate how the transition to grandparenthood impacts on aspects of active ageing such as labour force participation, grandparent health and wellbeing, and grandparents’ social activities and engagement. However, there are still some gaps in understanding how grandparenting, let alone intensive grandparenting (such as that provided by grandparents of children with a disability) fits in with contemporary attitudes towards ageing.

One area receiving increasing attention is how the transition to grandparenthood impacts decisions about labour force participation and retirement. A report commissioned by UK charity Grandparents Plus, using data from the British Social Attitudes Survey from 1998-2009, reported that 44% of grandparents (including those with adult grandchildren) are aged under 65 years and 29% were working (Wellard, 2011). An increasing number of middle-aged and older women in the labour market implies that many contemporary grandmothers, and grandfathers, are still working (Department for Work and Pensions, 2019a). Therefore, it cannot be assumed that grandparents are older people, no longer in paid employment. Using data from SHARE Hochman and Lewin-Epstein (2013) found across Europe, grandparents aged 50-64 years had a stronger preference for early retirement than middle-aged adults without grandchildren. Van Bavel and De Winter (2013), using data from the European Social Survey, also found a similar effect of grandparenthood stimulating early exit from the labour market, especially for women. In Germany, in a sample of 152 maternal and paternal grandparents, being a grandparent was associated with less psychological involvement in work, more family-related hopes for retirement, and fewer retirement related concerns than a control group of non-grandparents, especially for maternal grandparents (Wiese *et al.*, 2016). Grandparenthood stimulating early exit from the labour market, may be in direct conflict with policy agendas to retain older adults in the workforce (Lumsdaine and Vermeer, 2015).

As described in Chapter 1, grandparents are filling a childcare need of parents. In the UK, using data from the British Social Attitudes Survey (1998-2009) and the ELSA, two thirds of grandparents (grandmothers in particular) provide at least ten hours of care a week for their grandchildren aged 16 years and under (Wellard, 2011; Glaser *et al.*, 2013; Glaser *et al.*, 2014). Across Europe, grandparents are more likely to provide care in countries that have limited affordable childcare and low support payments to parents who stay at home, such as Spain and Portugal (Glaser *et al.*, 2013). However, among parents who can afford formal childcare some may not access it due to poor quality or lack of availability (Rutter, 2015). The changing availability of grandparents to provide childcare in the UK, due to rising employment rates in older people, has been found to have an influence on whether mothers of young children return to employment or not, particularly for low income families where the grandparent may have no private pension provision and where the parent cannot afford ‘formal’ childcare (Gray, 2005). Across Europe, Glaser *et al.* (2010) reported a significant association between patterns of female labour force participation and rates of childcare by grandmothers, independent of the policy context. Requiring grandparents to work for longer is likely to have profound effects on the supply of informal childcare, maternal employment rates and intergenerational relationships within families (Wellard, 2011). This implies a conflict for UK policies, which on the one hand are aiming to increase employment rates of older people and on the other, are aiming to increase the proportion of mothers in the work force (Gray, 2005; Glaser *et al.*, 2010). Intergenerational ties and grandparents’ needs and desires to care for grandchildren may conflict with policy aims to keep older people working for longer.

Attention has also turned to how grandparenting can contribute to ageing health. Grandparent involvement, such as providing childcare, potentially results in increased activity levels or cognitive stimulation, which may in turn improve grandparents’ health and wellbeing, consequently reducing mortality (Burn and Szoeke, 2015b; Hilbrand *et al.*, 2017). Using longitudinal data from SHARE, Di Gessa *et al.* (2016b) found grandmothers who provided intensive and non-intensive childcare had better physical health than grandmothers who did not provide any childcare, even when accounting for lifecourse characteristics (such as baseline health, socioeconomic status and demographic characteristics) which are associated with increased likelihood of providing grandchild care. Similarly, the available research has demonstrated a positive influence of grandparenting on cognitive health. Arpino and Bordone (2014) found grandmothers in Europe aged 50-80 years from the SHARE who provided childcare had better verbal fluency than those who did not. Data from the Women’s Healthy Ageing Project in Australia also indicated that grandmothers providing childcare have more optimal cognitive functioning (Burn and Szoeke, 2015a). Danielsbacka *et al.* (2019) used data from SHARE to look at the longitudinal effect of grandchild care on health outcomes including self-rated health, difficulties with activities of daily living, depressive symptoms, life satisfaction, and meaning of life scores. They found that while there were between-subject differences indicating a positive effect of grandchild care on grandparent health, these differences did not remain when looking at within-subject changes. Grandparents who experienced changes in the amount of childcare they provided did not demonstrate any changes in health outcomes. There is also research demonstrating the negative effect of grandparenting on health, particularly when the intensity and frequency of contact with grandchildren is too low, such as loss of contact with grandchildren (Drew and Smith, 2002; Drew and Silverstein, 2007), or when it is too high, such as custodial grandparenting (Grinstead *et al.*, 2003; Baker *et al.*, 2008).

How grandparenting fits in with “active ageing” or “successful ageing” frameworks, in particular the ability of older people to combine grandparenting with social activities, has been highlighted (Kohli *et al.*, 2009; Bulanda and Jendrek, 2016). Some research has suggested being a grandparent may act as barrier by restricting grandparents from pursuing other activities, reducing their social networks and threatening their financial security (Arpino and Bordone, 2015). While others have suggested being a grandparent may also contribute to “active ageing” by providing a sense of purpose (Coall and Hertwig, 2010) and encouraging continued involvement in social activities (Hank and Stuck, 2008; Engelhardt *et al.*, 2010). Grandparenthood is a significant transition experienced by many in later life. This transition potentially has an impact on individuals’ experiences of ageing through effects on their labour force participation, health, and engagement in social activities, depending on the intensity of their involvement with grandchildren. The extent of the impacts of grandparenthood on the experience of ageing needs to be further assessed in terms of inequalities over the lifecourse and the family and social contexts in which it takes place.

2.3 Theories of Intergenerational Relationships

The ageing population and the changes discussed above also impact intergenerational relationships through changing family structures and more years spent together. This has led to an increased interest in intergenerational relationships among families, and in particular the role of grandparents (Gray, 2005; Dunning, 2006). Reviewing the literature on grandparenting and family relationships three prominent theories were identified that describe and explain the relationships between generations. Each of these theories have been applied to the adult child and parent relationship, and to the grandparent-grandchild relationship.

2.3.1 Generativity

In the field of psychology, researchers have explored the grandparent relationship by drawing on the concept of generativity, coined by developmental psychologist Erik Erikson, as part of his model of the human life span (Erikson, 1963). The model divides the human life span into eight stages, each of which is characterised by a challenge or developmental crisis. ‘Generativity versus stagnation’ is the challenge described for the later stages of the lifespan. Generativity describes a concern for and care of future generations that develops during middle age including an older adult’s need to contribute to and make a difference to the community (Erikson, 1963). Generativity may be expressed through activities such as parenting, mentoring, and civic or political engagement (de St Aubin *et al.*, 2004). Initially, generativity was a challenge associated with the mid-life stage; however, more recent research indicates that generativity exists across the lifecourse, including in adolescence and in later life (Lawford *et al.*, 2005; Frensch *et al.*, 2007; Villar and Serrat, 2014). Generativity may therefore play a significant role in intergenerational relationships, at both the parent-adult child level and the grandparent-grandchildren level.

The term ‘grand-generativity’ was coined to refer to the concern of older generations to nurture, guide, and care for younger generations, where specifically grandparenthood would be the best opportunity to be generative (Erikson *et al.*, 1986). It is this expression of generativity later in life that has been used to describe and explain intergenerational relationships, such as the relationships between grandparents and grandchildren. For example, in grandparents’ stories of teaching their grandchildren (Norris *et al.*, 2004) or in the stories from adolescent grandchildren of grandparents passing important values on to them (Pratt *et al.*, 2008).

Generativity has been suggested to explain both the satisfaction grandparents’ (most commonly grandmothers) gain from their role and their motivation to be involved in looking after their grandchildren. Studies using quantitative measures of generative concern have found greater generative concern to predict greater satisfaction with the grandparent role in non-custodial grandparents (Thiele and Whelan, 2008), and has been associated with increased feelings of being important and useful to family (Gattai and Musatti, 1999). Many of the rewards grandparents describe from the role are suggested to be linked to generativity, such as having an influence on their grandchildren’s growth and happiness, a sense of being needed and sharing important values (Villar *et al.*, 2012). There is mixed support from research investigating the relationship between generativity and providing childcare for grandchildren. While some have found generative goals to be positively associated with grandparents’ desire to provide childcare (Hoppmann and Klumb, 2010), others have failed to find such associations in relation to spontaneous offers of childcare (Materne and Luszcz, 2010). Others have suggested that while generativity may be involved in the motivation to provide care, the generativity was still focussed on the grandparents’ own adult children rather than the grandchildren (Villar *et al.*, 2012). Grandparents offered help as a way of supporting their adult child’s wellbeing and was seen as a continuation of good parenting.

Though it has been argued that generativity has relevance in understanding why individuals engage in intergenerational relationships, some limitations have been identified (Villar and Serrat, 2014). Firstly, generativity has mostly been treated as a personality trait in psychological research, ignoring the social context and relationships that can aid or hinder the expression of generativity (Villar and Serrat, 2014). Generativity has also been mainly focussed on older generations, with the younger generation only described as recipients of generativity. However, grandparents can gain just as much from their grandchildren as grandchildren do from their grandparents (Drew and Smith, 2002; Kaufman and Elder, 2003). This focus on downward, rather than also upward support may not account for the complexities of support between generations.

2.3.2 Intergenerational solidarity

Whereas generativity focuses on the individual’s desire to enact the grandparent role, sociological theories have highlighted that grandparenthood is a construct influenced by numerous factors (Ben Shlomo and Taubman – Ben-Ari, 2016). The Intergenerational Solidarity Model (Bengtson and Roberts, 1991) has tried to account for the complex relationships between generations with elements derived from social theory, social psychology and family sociology. Intergenerational solidarity is described as interactions in the family that represent sentiments, attitudes and behaviours that bond family members across generations (Bengtson and Roberts, 1991). The intergenerational solidarity model includes six dimensions of parent-adult child solidarity; affectual (quality of the relationship, measured in terms of emotional closeness and conflict), consensual (the amount of agreement in values and beliefs), structural (the structure that forms the specific ways the family interacts, e.g., geographical distance), associational (the amount and kind of intergenerational contact, e.g., frequency of contact), functional (forms of financial, instrumental and emotional support exchanged between generations) and normative solidarity (extent of commitment to filial and parental obligations).

Much of the evidence for the intergenerational solidarity model comes from the Longitudinal Study of Generations (LSOG), which is the longest of such studies in existence and which aims to conceptualise and measure intergenerational relationships (Bengtson, 1975). The study began in 1975 as a cross sectional study of 300 three-generation families in Southern California, then extended into a longitudinal study with families followed up every three years. In 1991, a fourth generation of great-grandchildren was added to the study (Bengtson *et al.*, 1996). Using data from LSOG, Giarrusso *et al.* (2005) found parents over-estimated ratings of intergenerational solidarity compared to their adult children over a 20-year period. The “intergenerational stake hypothesis” postulated that this over estimation is due to parents investing more in their children than their children do in them. Parents are potentially able to invest more in the relationship than their child by virtue of lineage and greater resources (such as finances), therefore this greater investment may motivate them to perceive the parent-child relationship to be stronger than their children do (Giarrusso *et al.*, 1995).

The intergenerational stake hypothesis has also been applied to the grandparent-grandchild relationship, especially as both the grandparent and grandchild grow older and the grandchild enters adolescence (Bengtson *et al.*, 2000). While Harwood (2001) found in 135 grandparent-grandchild dyads grandparents reported a closer relationship than their adolescent grandchildren did, others have found grandparents report a more pessimistic view of the relationship than grandchildren (Villar *et al.*, 2010). Some dimensions of intergenerational solidarity, such as emotional closeness, may improve as both grandparents and grandchildren age, however other dimensions may become more dissatisfying for one member of the dyad (Block, 2000). For example, grandparents may perceive a lower level of contact than their grandchild and have a greater desire to increase it, leading to a more pessimistic view of the relationship than grandchildren. Spalding and Carpenter (2018) replicated Harwood's (2001) study in 79 grandparent-grandchild dyads to investigate if the hypothesis still holds in a more contemporary sample. Self-report measures of closeness found evidence for the intergenerational stake hypothesis, however proxy measures indicated that grandparents recognised that grandchildren felt less close than they did. The authors concluded that the intergenerational stake hypothesis does not fully capture the nuances within grandparent-grandchild relationships.

Various factors have been found to influence intergenerational solidarity, including gender (Lawton *et al.*, 1994), culture norms and practices (Nauck and Suckow, 2006), and age of grandparents/grandchildren (Mills, 1999). The complexity of factors influencing intergenerational solidarity was demonstrated by Giarrusso *et al.* (2001) study of Euro-American grandparent-grandchild dyads, from the LSOG study, and Mexican American grandparent-grandchild dyads, from the Study of three-generation Mexican American families (Markides and Krause, 1985). Both groups demonstrated strong grandparent and adult grandchild relations, yet the intergenerational stake phenomenon (i.e., grandparents reporting higher rates of affection and higher perceived consensus than grandchildren) was only seen in the Euro-American dyads. Among the Euro-American sample, the grandparent being older, the grandchildren being female, and the grandchild’s perception of a low level of consensus in attitudes and values were found to contribute to the gap between the generations in their ratings of affectional solidarity within their relationship. In contrast, among the Mexican American group, the grandchild being male, the grandchild’s low perception of the level of consensus in attitudes and values, and high levels of acculturation (adopting values and practices of another culture) contributed to the gap between grandparents and grandchildren ratings of affection for each other. The authors suggested that a higher level of filial piety (duty of respect and care to parents and elderly family members) in Mexican American culture may mean grandchildren within these families feel a stronger obligation to maintain continuity in their relationship with the grandparent. Levels of intergenerational solidarity were high across both groups, though both gender and culture were influencing how the intergenerational stake hypothesis was expressed in different ways within the two groups.

The construct of intergenerational solidarity is criticised for not being able to address issues of tension and conflict (lack of solidarity) across generations (Hammarström, 2005; Lowenstein, 2007). Following this critique, Bengtson *et al.* (2002) added “conflict” as a further dimension to the intergenerational solidarity model. The new model highlighted that both positive and negative valences can be placed on the six dimensions, and that they can coexist in different directions. Economic downturns, uncertainty in employment and benefits, as well as societal transformations may lead to greater intergenerational tensions on the one hand, and a greater need for intergenerational solidarities on the other. Cumulative advantage and disadvantage gained over the lifecourse may affect intergenerational solidarities within families (Szydlik, 2012), with the socio-economic status of families, practices within families, and the interaction of the welfare state potentially influencing intergenerational solidarities among families (Timonen *et al.*, 2013). These conflicts and tensions may arise more between grandparents and their families as grandparents juggle multiple roles or struggle to support younger generations as well as themselves in later life.

Intergenerational solidarity across generations rather than just within families has become an increasingly prominent topic within political, sociological and media contexts. The concepts of intergenerational justice and intergenerational equity have been raised as a concern for the reciprocity of intergenerational solidarity in contemporary societies that are facing the challenges of an ageing population, individualisation, economic recession and globalisation (Pickard, 2019). While the media may portray a distancing between ‘old’ and ‘young’ generations, with a narrative of the older generations taking a bigger stake in welfare support and leaving younger generations with less opportunities and chances to ‘get on’ in life, sociological research does not find support for such distancing (Higgs and Gilleard, 2010; Scharf *et al.*, 2013; Shrimpton *et al.*, 2017). Rather, it has been argued that between-generation contact that leads to empathy and more flexible criteria for reciprocity helps moderate the potential for conflict between age-groups (Bengtson and Putney, 2006; Thijssen, 2016).

2.3.3 Intergenerational ambivalence

Following on from criticisms of the intergenerational solidarity model the concept of intergenerational ambivalence was proposed to account for both the positive and negative (or conflict) feelings expressed in family relationships (Lüscher and Pillemer, 1998). Rather than there being ‘love-hate relationships’ between individuals, intergenerational ambivalence sees ‘solidarity’ and ‘conflict’ as co-existing features of family relationships (Connidis and McMullin, 2002). It is important to clarify that, in this context, the terms ambivalence and ambiguity cannot be used interchangeably as they would be in lay language. Ambivalence in this context refers to the tensions between two positions, while ambiguity holds its definition as describing an uncertain situation where there can be more than two meanings.

Intergenerational ambivalence is described at both the structural (sociological) and individual (psychological) level. Structural ambivalence includes ambivalence resulting from social position and socially constructed contradictions such as competing roles and demands. For example, particular attention has been given to gender and how gendered aspects of intergenerational relations may result in women experiencing greater ambivalence due to competing demands between their family needs, work obligations, and other societal demands (Connidis and McMullin, 2002). Individual ambivalence describes contradictory feelings, motivations or thoughts (Lüscher and Pillemer, 1998). Individuals may experience intergenerational ambivalence differently depending on individual traits. The concept of intergenerational ambivalence describes how these conflicting obligations and mixed feelings are continuously negotiated within family relationships (Connidis and McMullin, 2002). In order to fully understand the quality of the family relationships both the positive and negative aspects need to be measured and assessed (Bengtson *et al.,* 2002; Connidis and McMullin, 2002; Fingerman, 2004).

Research on intergenerational ambivalence has mainly focussed on the adult child and parent relationship, although some literature has begun to describe how the grandparent role may be a cause of ambivalence in this relationship (Neuberger and Haberkern, 2013; Hebblethwaite, 2015). The role of grandparents is not formally described but is associated with a number of social norms such as “being there but not interfering” (Mason *et al.*, 2007; May *et al.*, 2012). Structural ambivalence may occur when there is a contradiction between the grandparents’ behaviour (e.g., providing or not providing care) and the normative expectations of grandparents in that country/society (Hillcoat-Nallétamby and Phillips, 2011). Work by May *et al.* (2012) with 61 grandparents in the UK highlighted paradoxes grandparents experience including ‘not interfering’ and being a good parent, and between ‘being there’ and exercising self-determination. Grandparents in their study expressed their desire to have an independent existence, rather than needing to be there when called upon when parents need them (May *et al.*, 2012).

Ambivalence may become of increasing importance in the context of contemporary grandparenting with the policy changes associated with extending working life and the effects on grandchild care availability described earlier. Grandparents, in particular grandmothers, may be less able to meet grandparental obligations and may therefore face increasing ambivalence as the expectations of working and providing grandchild care cause conflict. There may be increased negotiations within families about family members' duties and individuals' economic obligations to manage this structural ambivalence (Neuberger and Haberkern, 2013).

2.3.4 Factors influencing the grandparent-grandchild intergenerational relationship

One common finding between theories of intergenerational relationships (generativity, intergenerational solidarity hypothesis, and intergenerational ambivalence) is that these relationships are multidimensional and the wider context in which they exist must be considered. The relationship between grandparents and grandchildren is often mediated by the middle adult generation, therefore the quality of the grandparent-parent relationship can have a powerful influence on the grandparent-grandchild relationship. Grandparents who are close to their adult children more often have a closer relationship with their grandchildren (Mueller and Elder, 2003). However, parents can also prevent or even sabotage a relationship with grandchildren (King and Elder, 1995; Sims and Rofail, 2013).

Factors outside the family context including the age of the grandparent and grandchild, the number of additional grandchildren, geographical proximity, gender, and lineage are found to influence the grandparent-grandchild relationship. Close geographical proximity has been found to have a positive effect on grandparent-grandchild relationships, through increasing the frequency of contact and feelings of closeness (Kivett, 1991; Uhlenberg and Hammill, 1998). However, modern developments in communication technology may reduce these barriers for those to whom it is available to and accessible (Tarrant, 2012).

In terms of the age of the grandparent and grandchild, the relationship between them is likely to change over time. Younger grandparents have been found to be associated with fun activities and childcare, while older grandparents offer their older grandchildren support and advice (Ben Shlomo and Taubman – Ben-Ari, 2016). With the population ageing, transition to grandparenthood starting later and grandparents spending longer in grandchildren's lives, grandchildren are more likely to experience having grandparents with ill-health. Some research has explored how this effects adolescent and adult grandchildren's perception of the relationship with grandparents, in particular the effect of grandparents being diagnosed with dementia (Werner and Lowenstein, 2001; Celdrán *et al.*, 2014). Grandparent ill-health and disability has been associated with negative consequences for the grandparent-grandchild relationship, such as increased stress for the grandchild, less satisfaction and less interaction (Howard and Singleton, 2001; Werner and Lowenstein, 2001). However, some research has suggested some positive outcomes including long-lasting positive memories and increased contact (Silverstein and Long, 1998; Dellmann-Jenkins *et al.*, 2000). The grandchild's knowledge of the disease and perceptions of the consequences of the disease on them and their family possibly mediate the affect of grandparent illness and disability on intergenerational relationships (Boon *et al.*, 2008).

In terms of gender and lineage, maternal grandparents are often reported to be more involved than paternal grandparents (Wheelock and Jones, 2002). Most studies consistently report that grandmothers are more involved in caring for grandchildren than grandfathers (Hank and Buber, 2008; Horsfall and Dempsey, 2015). Many of the studies looking at gender and grandparenting suggest that grandfathers' involvement in grandchild care is through supporting the grandmother and in more practical activities such as picking children up from school (Craig and Jenkins, 2016). More recent research suggests that the increasing awareness of the importance of fathers being involved in the care of their children may be reflected in changes in grandfathering practices as well (Mann *et al.*, 2015).

Much of the literature on grandparenting has focussed on grandmothers or has grouped together grandmothers and grandfathers into one homogenous group (Dench and Ogg, 2002). However, there has been a growing recognition of the need to understand specifically grandfathers' experiences separately from comparisons with grandmothers and examine how gender plays out in both grandmothers' and grandfathers' roles (Tarrant, 2010). Mann (2007) suggest that findings of grandfathers as being "uninvolved" can be attributed to a failure to consider the role of masculinity in how men present themselves in research contexts. A study of 31 grandfathers, aged 51-88 years in North West England has contributed the understanding of contemporary grandfather experiences (Tarrant, 2010; Tarrant, 2016). This research has shed new light on the understanding of grandfatherhood, in particular how men's family practices are structured in relation to masculinity, ageing and generation. More contemporary grandfathers, especially those who transition into their role in their 50s and 60s, have been found to adopt more nurturing and mentoring roles (Harper, 2003; Mann and Leeson, 2010). Two factors have been suggested to influence the varied expression of grandfatherhood (Mann *et al.*, 2015; Tarrant, 2016). The first is the number of social influences that have shaped many generations' attitudes towards men's role within the family and work. Patterns of the male breadwinner and providing for family were conventional for nearly three decades of the 20th century. These patterns are not easily changed and some men continue to recognise women as central to family relationships

(Mann and Leeson, 2010; Goodsell *et al.*, 2011). Nevertheless, men are creating new patterns of behaviours for themselves, with new nuanced understandings of men's emotional expressions (Roger *et al.*, 2012) and more flexible understandings of masculine characteristics and roles (Doucet, 2004; Sorensen and Cooper, 2010). The second factor is the events of the lifecourse. For example, retirement in relation to the timing of grandfatherhood results in variation of the expression of grandfatherhood. For those where the transitions to retirement and grandfatherhood co-occur, there may be a changed orientation to family where men have more time to engage with grandchildren than they did when they were working fathers (Mann *et al.*, 2015). Therefore, the gendered understanding of grandparent-grandchild relationships may be changing.

Within the sociology field, the interaction between welfare support and intergenerational solidarity has often been discussed more in relation to providing care to older generations (Daatland and Lowenstein, 2005; Lowenstein and Daatland, 2006). However Igel and Szydlik (2011) have discussed this interaction in relation to grandparent support to younger generations. They describe concepts of 'crowding in' and 'crowding out' to demonstrate the ways in which the two components interact. 'Crowding in' refers to high service levels (welfare support) and high levels of family support. Access to services is said to stimulate, or at least not discourage, family involvement. In this scenario family support and welfare support can complement each other, adding to the completeness of support needs. Whereas 'crowding out' refers to countries where service levels are high, but family help is low. In this scenario, the welfare support is compensating for lower levels of family support or is substituting out family support. With crowding out, welfare support and family support are an either/or whereas with crowding in the two work together, potentially reducing the dependence and obligation for family support to be provided. Igel and Szydlik (2011), using data from SHARE, concluded that increased expenditure on the welfare provision of childcare would 'crowd in' the occurrence of grandparent childcare and intergenerational support but could 'crowd out' the intensity of the role.

A final important factor to consider is the role of culture in influencing the amount and type of grandparent involvement in the care of grandchildren. Much of the literature so far has focussed on grandparents in Western cultures, with only a few small studies being carried out with Asian or African grandparents (Van der Geest, 2004; Chan, 2007; Shaibu, 2013). As well as differences across cultures, cultural norms within societies are also changing. For example, in the UK, the 'baby boomers' are entering later life with different sets of cultural values, such as being more orientated to leisure activities, than previous cohorts (Arber and Timonen, 2012).

Therefore, different cultures, and different generations within those cultures will practice grandparenthood in different ways and this must be considered when exploring grandparent-grandchild relationships. We must also take into account how the changing cultural norms for the expectations of being a grandchild will also affect the grandparent-grandchild relationship (Kemp, 2005).

The research to date on ‘traditional’ grandparenting (i.e., non-custodial, grandchildren without disability) highlights the complexity of contemporary grandparenting, the multidimensional influences on grandparents’ relationship with their grandchildren, and the importance of researchers taking all these factors into account when examining intergenerational relationships (Arber and Timonen, 2012). It is perhaps necessary, although challenging, to understand the grandparent-grandchild relationship from all three generations’ perspectives (grandparent, parent and grandchild), in order to see the expectations each brings to the relationship, and how each party influences the relationships (Hagestad, 2006).

2.4 Grandparenting: Role, Identity and Meaning

Grandparenting is one of the few new roles acquired later in life and it is assigned rather than chosen, with little or no choice over the timing. In general, the role is seen as important and rewarding (Clarke and Roberts, 2003). The grandparent role is evolving with demographic changes and changes in family structure meaning that the norms previously associated with grandparents are becoming increasingly inappropriate (Gauthier, 2002). The previous chapter and sections of this review have indicated the importance of grandparents, however the literature theorising grandparenthood, in terms of typologies, identity and meaning of grandparenthood, is relatively limited. Much of this may be due to the constant changes and diversity of grandparents in the 21st century.

In the US, Neugarten and Weinstein (1964) undertook some of the earliest research on grandparents. Based on 70 sets of grandparents they derived a five-fold typology of grandparenting: formal, fun-seekers, distant, surrogate-parents, and reservoirs of family wisdom. These typologies are often cited and used still in current research on grandparenting (e.g., Woodbridge *et al.*, 2011). However, these typologies have been criticised for being too inflexible and not accounting for the interaction of grandparents’ personalities and changing family situations. The typologies have been built on by other researchers describing roles or styles of grandparenting that are more flexible and which may change over the lifecourse. For example, Cherlin and Furstenberg (1985) from their data of 510 men and women, described five styles of grandparenting (detached, passive, supportive, authoritative, and influential), and later Kornhaber (1996) described 11 grandparent roles from a longitudinal study of 300 grandparents and grandchildren. These fell into six categories: nurturer/supporter, kin-keeper/value transmitter, teacher/mentor, friend/playmate, magic maker, and special role (e.g., care and support provided to a grandchild with a disability). Kornhaber (1996) also described several theories of grandparenting: Grandparent Drive (biologically rooted motivation to grandparent), Latent Grandparent Identity (individual's 'theoretical' expectations and beliefs about the grandparenting role), and Functional Grandparent Identity (actual styles and behaviours adopted by grandparents). Even though these typologies and theories have gone some way to show the variety of ways grandparenting can be enacted and help with trying to understand some of the variation in grandparent-grandchild relationships, they are likely to reflect grandparents between the 1960s and 1990s. More contemporary perspectives on grandparenting highlight how the many diverse forms of grandparenting cannot, and potentially should not, be reduced down to a small number of types (Arber and Timonen, 2012). The influence of family structures and policies needs to be taken into account when describing and theorising about contemporary grandparents (Moore and Rosenthal, 2016).

Much of the current psychology literature uses Hurme's (1991) framework of grandparenthood which splits it into four dimensions: grandparent behaviour, meaning of grandparent role, satisfaction with role, and grandparents' expectations and attitudes (cited in Thiele and Whelan 2008). In terms of grandparent behaviour (or role), most literature describes grandparents as providing practical instrumental support (e.g., financial help, caring for grandchildren), and emotional support (Dunning, 2006; Glaser *et al.*, 2014; International Longevity Centre, 2017). In Hurme's framework the behaviour/role of grandparents is suggested to be influenced by how important the role is to the individual and how much meaning they place on the role (Miller and Cavanaugh, 1990; Silverstein and Marenco, 2001; Sorensen and Cooper, 2010). In general, those grandparents who are more involved describe grandparenthood as a more central and meaningful part of their identity than those who are described as 'passive' or 'remote' grandparents.

Kivnick (1982) has postulated five dimensions that have most comprehensively described the meaning of grandparenthood: centrality, valued elder, immortality through clan, re-involvement with personal past, and indulgence. 'Centrality' refers to how fundamental, salient or important the role is to grandparents' sense of identity, behaviour and feelings. 'Valued elder' relates to how important grandparents feel it is to be remembered and esteemed as a source of knowledge and of emotional and instrumental support to grandchildren. 'Immortality through clan' refers to the sense of continuity derived through having descendants, identifying with them and feeling responsible for them. 'Re-involvement with personal past' represents the meaning derived from reliving experiences from grandparents' earlier life and thinking about one's own grandparents. 'Indulgence' refers to how much grandparents value being allowed to spoil and be lenient toward their grandchildren. Some work has been done more recently to look at these five dimensions of the meaning of grandparenthood, however with mixed support for Kivnick (1982) model. In particular, research has focussed on role centrality and its positive link to psychological wellbeing (Muller and Litwin, 2011) and grandparent satisfaction (Reitzes and Mutran, 2004; Thiele and Whelan, 2008). In Australia, Thiele and Whelan (2008) found evidence for a multidimensional model of grandparent meaning in 149 non-custodial grandparents, yet in the US Hayslip *et al.* (2003) found only a one-dimensional factor in their confirmatory factor analysis of data from 102 grandparents. Nevertheless, the two studies did find that greater role meaning was positively associated with greater role satisfaction.

Looking at another aspect of Hurme's (1991) framework, the degree of satisfaction grandparents derive from the grandparent role has been found to be varied. Some research presents grandparenthood as potentially burdensome and an obligation that takes grandparents away from their own interests (Arpino and Bordone, 2015; Noy and Taubman–Ben-Ari, 2016), while others describe the rewarding aspects of the role such as feeling useful, learning new skills, and personal growth (Silverstein and Marenco, 2001; Taubman-Ben-Ari, 2012; Moore and Rosenthal, 2015). It has been postulated that women gain more satisfaction from the role than men due to socialisation processes (Thiele and Whelan, 2008), however these gender differences are suggested to have reduced over the last few decades and have been less commonly found in more recent research (Peterson, 1999; Reitzes and Mutran, 2004). As described in section 2.3.4, the understanding of grandfatherhood is changing as they are focussed on separately to grandmothers. Thiele and Whelan (2008) highlighted the importance of intrinsic and psychological processes, such as centrality meaning and valued elder in predicting grandparent satisfaction above factors such as grandparent age, gender and behaviour. The reliability and generalisability of these findings however is questionable when the results are commonly based on studies using single item measures of satisfaction (Thiele and Whelan, 2006).

Very little is understood about the expectations and attitudes of grandparents. Grandparents have little control over many aspects of the role such as timing, how many grandchildren they will have, or how often they will see them. Nonetheless, both grandparents and parents still bring some expectations of the role. Generally, grandparents expect to see their grandchildren and feel valued, parents expect grandparents to support them, and grandchildren may expect grandparents to tell stories of the family history and provide gifts (Somary and Strieker, 1998;

Kemp, 2004). These expectations are negotiated within each family context (Finch and Mason, 1993; Mason *et al.*, 2007).

While this research has focussed on factors within the individual that may influence what grandparenthood is to individuals, the social norms, intergenerational relationships, and individual ecological contexts also need to be taken into account in explanations or theories of grandparenthood. Understanding grandparenting in contemporary society needs fuller exploration of the lived experiences of grandparents (both grandmothers and grandfathers), taking into account shifts in sociodemographic characteristics of grandparents and families such as increased divorce rates, geographical proximity and seeing grandchildren into adulthood (Thiele and Whelan, 2008; Muller and Litwin, 2011).

2.5 Narrative Literature Review of Grandparenting in the Context of Disability

This chapter so far has aimed to give an overview of the contexts within which grandparenting currently takes place and current theorising of grandparenthood. In this final section I present a more detailed review of grandparenthood specifically in the context of grandchild disability. In order to get a full understanding of the current literature in this context a more systematic search of the literature was conducted. Searches were carried out using Scopus, Web of Science and PsychInfo using the keywords ‘grandparent’, ‘grandmother’, ‘grandfather’, ‘disability’, ‘childhood disability’ and ‘special needs’. The references of identified articles and citations of those articles were also scanned for relevant articles. Papers that discussed the role of grandparents and the experience of grandparents in the context of grandchild disability were included. Quantitative studies were included if they were primarily research investigating the factors affecting grandparent involvement, outcomes for parents (e.g., stress, wellbeing), or measuring grandparent satisfaction. Qualitative studies that focussed on broader questions were included if experience of grandparenthood from either a parent or grandparent perspective was a clear focus of the analysis. I have also included details from three reviews and a book in this narrative review.

Children with a disability can require special care due to physical disabilities, medical conditions, intellectual disabilities, behavioural issues and emotional problems. As highlighted in Chapter 1, families of children with a disability are known to face additional caring responsibilities, increased financial demands, and higher levels of stress linked to the physical demands of the child, challenges with communication and psychological demands, alongside unmet resource need and a lack of support networks (Roberts and Lawton, 2001; Sloper and Beresford, 2006). Though welfare support and benefits are available to families, these can often be inadequate (Contact a Family, 2015). The extent of the needs of these families highlights the importance of their support networks, including grandparents. Supportive family networks can help families adjust to having a child with a disability and reduce levels of stress and anxiety (Plumb, 2011). The family is also important in contributing to the experiences of strength, adaptation, and positivity (Maul and Singer, 2009). The occurrence of having a disabled grandchild can bring families closer together and provide positive and rewarding experiences through overcoming challenges (Hastings *et al.*, 2002).

Despite the importance of grandparents in supporting families of children with a disability, the experience of grandparenthood in this context is still relatively under-researched. There have been three reviews of the experience of grandparenthood in the context of grandchild disability published over the last two decades all highlighting the vital role of grandparents in this context and the need to further understand both the support grandparents provide but also how the role is experienced by grandparents themselves and what their own support needs are (Hastings, 1997; Mitchell, 2007; Lee and Gardner, 2010). More recently Findler and Taubman–Ben-Ari (2016) published a book focussing on grandparenthood in the context of grandchild disability based on their work with parents and grandparents in Israel, describing how grandparents themselves react to and understand their role in the context of grandchild disability.

How the grandparenting role and identity is affected by the birth of a grandchild with a disability or diagnosis of a disability is still unclear. Much of the literature on grandparenting in this context has focussed on the role of grandparents in supporting parents at the time of diagnosis. When learning of their grandchild's diagnosis research indicates that grandparents, like parents, may experience a period of mourning as well as adjustment, as they come to terms with the loss of the grandchild they expected (Hastings, 1997; Noy and Taubman–Ben-Ari, 2016). At the same time, grandparents are also experiencing distress and pain for their own adult child (Vadasy, 1987; Findler, 2016). A qualitative study in Australia has explored the role and experiences of 22 grandparents of children with a range of disabilities and described grandparenting in this context as an "emotional rollercoaster" (Woodbridge *et al.*, 2009, p. 37). Grandparents described processes involving adjustment (transition from anger to acceptance), double grief (sadness about what might have been for both the grandchild and their child), and pride in family (Woodbridge *et al.*, 2009). Grandparent feelings of sorrow and pain mean some grandparents find it difficult to be there for their adult child (Seligman, 1991). In contrast, others report masking these feelings in order to provide support to their adult child (Miller *et al.*, 2012).

Studies with parents reporting on the involvement of grandparents have found that grandparents' acceptance and adjustment to their grandchild's diagnosis contributes to improvements in parental coping (Mirfin-Veitch *et al.*, 1997; Green, 2001), psychological wellbeing (Heller *et al.*, 2000), increased optimism (Ekas *et al.*, 2010) and overall adjustment (Seligman, 1991). On the other hand, a lack of understanding can lead to a lack of needed support and higher levels of stress for parents (Baranowski and Schilmoeller, 1999). Several studies with grandparents have reported how it can be hard for grandparents to acquire the appropriate understanding of their grandchild's diagnosis and prognosis due to lack of access to professional support (Margetts *et al.*, 2006; Anderson, 2010; Lee and Gardner, 2010). The information about the grandchild's disability and support needs may also not come easily from the child's parents, depending on the quality of the relationship with the parent or the parents' own understanding of the disability (Katz and Kessel, 2002). Having information about the grandchild's disability can help grandparents understand how best to support their adult child and grandchild (Gallagher *et al.*, 2010; Prendeville and Kinsella, 2019). Research focussing on mothers and grandmothers of children with autism spectrum disorder (ASD) in particular has found that understanding of the disability, positive communication with the parents and professionals, and inclusion in the care and discussions of the grandchild's disability encourages grandparent involvement with a grandchild, with the opposite discouraging engagement and involvement (Sullivan *et al.*, 2012; D'Astous *et al.*, 2013).

Engstrand *et al.* (2019) carried out a quantitative study of the needs of 120 grandparents of pre-school aged children with ASD in Sweden. Grandparents reported a number of needs to help them communicate with people involved in their grandchild's care including: help with discussing their concerns about the grandchild's ASD with their adult child, help with learning how to communicate with teachers and other professionals, and help with how to explain their grandchild's ASD to others. Grandparents also reported a number of needs in helping them support their grandchild and adult child, such as access to family counselling, learning strategies to help their grandchild develop skills, how to handle their behaviours, and help with learning how to provide adaptive play or recreation experiences for their grandchild. Whilst only focussed on one clinical group, this research has gone some way to fill the gap in knowledge about what support grandparents themselves need that has been missing from the literature thus far (Mitchell, 2007). Grandparents want to be involved but there needs to be an increasing recognition of the support and information they need to be there for their family in the context of childhood disability.

Consistent across nearly all the literature on grandparenting in the context of grandchild disability is the type of support grandparents provide to their adult child and grandchild. Grandparents are providing vast amounts of practical support and emotional support that is highly valued by parents (Hornby and Ashworth, 1994; Katz and Kessel, 2002; McNee and

Jackson, 2012; Yamashiro and Matsukura, 2014). Those providing instrumental support are involved in activities such as babysitting and financial support (Sandler *et al.*, 1995). Those providing emotional support act in the role of ‘being there’ for their adult child and grandchild, by giving advice, acting as a confidante and giving encouragement (Heller *et al.*, 2000; Moffatt *et al.*, 2019). As well as providing instrumental and emotional support, grandparents may also be called upon to act as an additional advocate for the child’s needs and asked to participate in treatment decisions (Anderson, 2010; Moffatt *et al.*, 2019). Involvement in appointments and diagnosis, has again been particularly prominent in the ASD literature, with descriptions of how grandparents are involved in first recognising a concern (Anderson, 2010; Gallagher *et al.*, 2010). Within their role grandparents are reported as actively seeking out assistance for their adult child and grandchild from various sectors (Moffatt *et al.*, 2019). Moffatt *et al.* (2019), in interviews with nine grandparents in the UK, described the efforts grandparents exerted to familiarise themselves the with complex and constantly changing health, social and education systems. Within the context of grandchild disability, grandparents have also described an important part of their role is supporting the wider family unit and making sure relationships within the immediate and wider family unit are maintained (Margetts *et al.*, 2006; Miller *et al.*, 2012).

In looking at grandparents’ experiences in the context of grandchild disability, grandparents report offering support to their adult children despite their own age and physical disabilities (Gardner *et al.*, 1994; Schilmoeller and Baranowski, 1998). The commitment to offering support to their adult children can come at a cost to their own plans for their later life (Woodbridge *et al.*, 2011) and at a cost to their own social support, with grandparents of children with a disability reporting lower perceived social support from friends than grandparents of children without a disability (Miller *et al.*, 2012; Findler, 2014).

From the literature and the recent publication by Findler and Taubman–Ben-Ari (2016) it is suggested that grandparenting in the context of disability has similar patterns and influences as grandparents of children without a disability. There is a similar hierarchy of support with maternal grandmothers providing the majority of support (Mitchell, 2007). Only two studies have directly compared support offered by grandparents of children with a disability and the support offered by grandparents of children without a disability. Both described no differences in mothers’ reports of the amount of support provided by grandparents using a support function scale (Findler, 2000; Pit-ten Cate *et al.*, 2007). When looking at the effect of lineage across both groups Findler (2000) found the highest level of support was provided by maternal grandmothers and the lowest by paternal grandfathers. In both groups mothers were more satisfied with the support they received from their own mothers compared to their mothers-in-law. Similarly Pit-ten Cate *et al.* (2007) found ratings of maternal grandparent support were reported as significantly higher than ratings of paternal grandparent support in both mothers of children with and without disability (Pit-ten Cate *et al.*, 2007). Both these studies focussed on the support provided to mothers therefore it may be that differences in support provided by grandparents of children with a disability would be seen more clearly when asking other family members, such as the grandchild's siblings. Using Neugarten and Weinstein's (1964) typologies of grandparenting Woodbridge *et al.* (2011) in Australia described the experience and enactment of the grandparenting role not differing due to the grandchild's disability. What differed was the context and nature of the grandparenting role. For example, with typically developing grandchildren the grandparenting role and style may be enacted by paying school fees or helping with homework, whereas for a grandchild with disability it was enacted by attending specialist appointments or learning alternative methods of communication.

An aspect of grandparenting in this context that grandparents have reported as finding difficult is managing the boundaries of their role. Grandparents of grandchildren with ASD in particular have reported struggling with the balance of being a source of support but not interfering, for example when it comes to disciplining the grandchild (Margetts *et al.*, 2006; D'Astous *et al.*, 2013). Quite often these boundaries are reported to have been put in place by the grandparent themselves, rather than by the parent. Grandparents recognise that their role is different to that of a parent and that parenting norms have changed since they were parents to young children (Margetts *et al.*, 2006; Moffatt *et al.*, 2019). Some grandparents struggle to know how much to intervene and in what way (Ariel and Naseef, 2005), and have described tension and role confusion over treatment decisions and appropriate methods of discipline for the grandchild (Hillman, 2007). Prendeville and Kinsella (2019) conducted interviews with parents and grandparents from nine families of children with ASD in Ireland. The interviews highlighted how the needs of the grandchild had changed family roles, particularly during times of stress. Families described themselves as being brought closer together, but also described how the traditionally defined roles of the grandparent became blurred with the grandparent being identified as a very close friend as well as a family member, making the boundaries of their role difficult to identify.

Another issue raised has been grandparents' concerns for the future. Grandparents of children with disability have raised concerns about what might happen when they can no longer provide emotional and instrumental support due to increasing frailty or death (Miller *et al.*, 2012; Moffatt *et al.*, 2019; Prendeville and Kinsella, 2019). Grandparents have also expressed concern about their adult child’s availability to care for them as they get older due to the pressures of bringing up a grandchild with a disability (Findler, 2016). In a similar vein, grandparents have expressed anxiety about who will care for the parent (their adult child) in the parent’s later life, given the parent is unlikely to be able to rely on the child with a disability for support (Scherman *et al.*, 1995).

There is a great deal more research required to understand the grandparent perspective of their role in the lives of grandchildren with disability, and to understand how taking on the role of a critical support person might impact on grandparents’ lives. The literature to date has tended to focus on how grandparents support parents and grandchildren. Very little research has focussed on the grandparents themselves and how they experience their role. These studies indicate that grandparents play a vital role in the lives of the parent and grandchild, but the studies have been limited to small sample sizes and have mostly focussed on families of young children rather than adolescent or adult grandchildren with a disability (Mitchell, 2007; Lee and Gardner, 2010). One area where there has been an increase in research is the role of grandparents in the care of children with ASD. This is perhaps due to the its increasing reported prevalence (Simonoff, 2012) and the particular set of stressors gaining a diagnosis, and the day to day challenges diagnosis comes with (behavioural problems, difficulties in communication, social isolation, additional medical problems and difficulties accessing support services following diagnosis) (Hastings and Brown, 2002; American Psychiatric Association, 2013). More research is needed to understand whether the issues raised within this ASD research are found in other disabilities.

There is still much to learn about grandparenthood in the context of grandchild disability, and with more grandparents potentially experiencing it due to medical advances, more research into influencing factors within and outside the family is needed.

2.6 Conclusion

Much of the social policy concern with the interrelationship between shifting demographics, changing family forms (extended families living further apart for example), and reducing availability of formal care via shrinking welfare services, has focussed on the care gap created for looking after older people (Pickard, 2015); little time has been spent considering how those same shifts may be affecting older people’s availability to be involved in caring for others, for example, grandchildren.

As the population is ageing, generations are spending longer in each other’s lives, increasing the importance of intergenerational ties. Research is beginning to explore how these relationships change with age, with some focussing on the change in the grandparent-parent-grandchild relationship over time. The changes in the experience of grandparenthood are reflected in the changing definitions of the grandparent role. We have moved away from Neugarten and Weinstein's (1964) definition which focused on the grandparent’s degree of involvement in their grandchild’s life, to contemporary definitions that aim to take a multidimensional examination of grandparenthood that takes into account features of the family system, characteristics of the individual, and the environment in which the family functions (Timonen and Arber, 2012; Timonen, 2019). Although research suggests that shifts in family relationships and roles, demographics, and broader contexts are placing greater emphasis on the importance of grandparents in the care of children with disability, the significance of grandparents’ roles and the effect of their support on various family members is under researched (Mitchell, 2007).

Grandparents can provide invaluable support to parents of children with disability, but with most research focussed on the parent’s perspective, much more research is needed to understand grandparents’ perspectives of their role and potentially what their support needs are. The research with parents has drawn attention to the types of support provided by grandparents, however, in order to further understand grandparenting in the context of grandchild disability, an intergenerational approach is needed to emphasise the nuances of grandparenting in this context and how support is managed within families.

Chapter 3. Methodology and Methods: Intergenerational Narratives Approach

3.1 Introduction

In this chapter, the study design and methods are explained and justified. The underlying methodology for the fieldwork is discussed, followed by the methods for recruitment, data generation and analysis. The chapter concludes with a reflexive account of the process of data collection. The previous chapters have highlighted the importance of grandparents in the lives of families of children with a disability, but also that little is known about the experience of grandparenthood in this context in the UK. One of the main aims of this research was to understand the current lived experiences of grandparenthood in the context of grandchild disability. I aimed to gain a greater depth of understanding of the topics raised by previous research and gain some understanding of what factors enable grandparents to enact types of support, the reasons behind the ways grandparents enact their role, and how these caring relationships change over time. It was important to collect data that would help inform the collaborators, Contact, and other organisations on how to support grandparents and their families, and also data that could inform policy related to grandparenting and families of children with a disability.

As with many research projects, there were some challenges in carrying out the research as it was outlined in the original proposal. There were two aspects of the methodology that did not go as expected and therefore resulted in some changes in the methods and analysis carried out. Firstly, I had planned to use purposive sampling in order to gain an as maximally heterogeneous sample as possible to explore the potential range of experiences of grandparenthood in the context of grandchild disability. This would have included interviewing grandparents of children with a wide range of disabilities, families of different structures, and a range of ages of grandparents and grandchildren. However, while there was initially a lot of interest in the research, expressions of interest tailed off quickly and, although efforts were made to gain further interest, in the end all participants who expressed an interest were interviewed preventing a purposive sampling approach.

Secondly, when writing the proposal for this research and when I first set out conducting the interviews, I had intended to include a sample of grandchildren. The grandchild voice is missing from the literature currently, especially in the context of disability. However, as is described in section 3.8.4 of this chapter, the grandchild interviews did not go to plan and the grandchild interviews were not included in the final analysis. Therefore, when discussing intergenerational methods within this chapter I refer to the inclusion of two generations (grandparents and their adult children) rather than three generations.

3.2 Methodological Approach

Much of the current knowledge about grandparenting in the context of grandchild disability has focused on the frequency of contact and types of support grandparents provide to their grandchildren and adult children. Research has investigated how factors such as gender, lineage, marital status, and geographical proximity influence these outcomes. However, particularly in the UK, there is still very limited knowledge about the role and experience of grandparents in the context of grandchild disability, which would make taking a hypothesis-driven approach challenging. Instead, I recognised there needed to be a qualitative exploration of experiences of grandparenthood and a greater understanding of the processes that had led to the current situation of participants. Therefore, I took an exploratory qualitative approach to the research topic to begin to understand some of the key issues for UK grandparents. Qualitative methods allowed a focus on the grandparents' and parents' everyday lives in detail, provided access to the individual's perspective, and meant the complexity of changing care dynamics and relationships could be explored (Silverman, 2005).

Within qualitative research it is important for the researcher to outline their epistemological and ontological approach, as these directly impact the methodology chosen and the approach to analysis taken by the researcher. There are three core epistemological approaches: objectivism, subjectivism and constructionism/interpretivism (Crotty, 1998). Objectivism is a stance most commonly aligned with quantitative research, where something that already exists is being unveiled and measured. On the other end of the spectrum is subjectivism, where there is a belief that objects make no contribution of their own to the generation of meaning. Instead meaning is imposed on objects by the subject. Perhaps in between these two epistemologies is social constructivism, which is the approach this research takes. Social constructivism refers to how interactions between subjects and objects construct meaning which can result in more than one valid interpretation (Krauss, 2005; Bryman, 2012). Bryman (2012) explains how social constructivism emphasises the ways in which humans construct their own realities through their interactions with, and their experience of the world (p.33). This reality creation, or the participants understanding of their reality, is shaped by their life experiences, and societal and cultural expectations, rules and norms. These experiences and expectations will bring particular aspects into view and give them meaning, acting as a lens through which individuals see and understand a phenomenon. In taking this approach I was able to understand each participant's own understanding of their reality and their lived experience and how their reality was shaped, without trying to find one truth.

Choosing the method that is best suited to the research questions is vital for obtaining the desired results. Interpretative Phenomenological Approaches (IPA; Smith and Sparkes, 2006) were considered in understanding the phenomena of being a grandparent in the context of grandchild disability. IPA is a popular method used for qualitative psychological research to understand a particular phenomenon and how participants make sense of that phenomena (Willig, 2013). If my research questions had just been focussed on understanding the phenomena of grandparenting in the context of grandchild disability, then this method may have been appropriate. However, IPA methods are generally focussed on understanding the essence of the phenomena, rather than participants' experience of the phenomena and how they make meaning out of their experience (Creswell, 2013). My research questions aimed to understand the contexts within which grandparenthood was taking place and how society, institutions and the context of family shaped those experiences, which may not be understood through IPA methods. Another popular method is Grounded Theory (Glaser, 1967; Charmaz, 2006) which has been used to understand both psychological and sociological processes. Rather than a focus on singular narratives, grounded theory work is often more concerned with substantive cross-case theory development (Padgett, 2012). Data collection and analysis occurs simultaneously, with the interview guide developing through themes emerging from the data analysis of previous interviews. The research questions of this thesis were not aiming to establish a theory or explanation of grandparenthood in the context of grandchild disability. Instead, the exploratory nature of the project was interested in hearing a range of stories, all of which were individual and uninfluenced by prior interviews or stories. With this mind, a narrative approach was seen as the most suited method as is described below in more detail.

3.2.1 Narrative approach

When deciding on an approach for this research, I wanted to ensure that the methods used allowed for the grandparents' and parents' own perspectives to be at the forefront of the research. With this in mind, I drew on narrative methods to collect data. The narrative interview setting gives prioritisation to the participants' perspectives and the meanings they assign to their stories, rather than imposing a more specific agenda, theory, or set of topics on the interview (Du Bois and Wright, 2002; Anderson and Kirkpatrick, 2016). The narrative approach is also well suited to broader research questions (Bailey-Rodriguez *et al.*, 2018), such as mine: what are the experiences of grandparenthood in the context of grandchild disability?

Since being recognised as a way of gaining a greater understanding of human experience, there has been growing interest in the use of narrative methods in psychological and sociological research over recent years. The term 'narrative' is often used synonymously with the term 'storytelling'. Within this research I wanted to be able to let the participants tell *their* stories.

Taking a narrative approach enabled access the participants' lived experiences and thereby I could attempt to understand the world from their point of view (Kvale, 1999). Narratives can be understood as stories that may order events across time, but they are more than just a list of events, as story-tellers make links in both time and meaning throughout their narratives (Anderson and Kirkpatrick, 2016). Within narratives, or stories, as well as the experiences being described or recollected, researchers can gain an understanding of how that experience was shaped, constrained or marked by society, culture and the resources available to the individuals in the narrator's social world (Kelly, 2005; Frost and Ouellette, 2011; Frost, 2013). The plot of the story provides the context in which we can understand the events, actors and relationships that make up the story. Being able to discuss in-depth their experiences of grandparenthood in the context of grandchild disability allowed for an understanding of the "richness, depth, nuance, context, multi-dimensionality and complexity" (Mason, 2002, p. 1) of the participants' lives.

Narratives allow for the collection of data beyond simple descriptions of what occurred and allows for information about causal explanatory frameworks and information about how and why the events happened as they did. Alongside this the narrative approach allows participants to provide reflective interpretations of events from a personal perspective that provides a subjective stance on what occurred (Peterson and McCabe, 1994; Fivush *et al.*, 2010). By asking grandparents and parents to tell their stories, I hoped to gain an understanding of each generation's understanding of grandparenthood in the context of grandchild child disability, what was important to them in shaping the grandparent role and intergenerational support within their families.

Another appealing aspect of the narrative approach is its ability to give a sense of the participants' identities. By analysing stories told by participants, researchers are able to gain an understanding of what and how aspects of social context meaningfully become a part of an individual's lived experiences. Added to this, in telling their story the individual makes sense of their experiences both during the construction and telling of the story (Fivush, 2008; McAdams, 2008). A narrative identity is formed through the stories we tell of ourselves and to others and through these narratives individuals can begin to define themselves and try to convey this to others (Smith and Sparkes, 2006). The sense of self reflected in stories reveals what is more or less important, valued, and self-defining for individuals (McAdams and Pals, 2006). Through narrative interviews and the accounts given by the grandparents and parents a sense of what it is to be grandparent or a family of a child with a disability to them could be identified.

Narrative approaches have become increasingly popular in ageing research, to the point where 'Narrative Gerontology' is now a recognised area of research (Kenyon *et al.*, 2001; Randall, 2007). Within the field of ageing, narrative methods have been used to examine social policy (Biggs, 2001), issues of masculinity (Smith *et al.*, 2007), interpersonal and intimate relationships (Jones, 2002), experiences of health and illness (Jolanki, 2004), care work (Twigg, 2000; Ribeiro *et al.*, 2007) and retirement (Smith and Dougherty, 2012). In particular, narrative is popular within ageing studies because of its ability to investigate both the similarities and differences in experiences of ageing over the lifecourse. For Jan-Erik and Kenyon (1996) narratives can reveal some of the complexities and contradictions in the experience of growing older, along with presenting different selves and identities over the lifecourse.

Narrative approaches have also been used regularly in family research to further understand family relationships and dynamics, such as parent narratives of childhood disability (Kelly, 2005), women caring for ageing parents (Ko *et al.*, 2019), and family ties and genetics (McLaughlin, 2015). The narratives embedded in the stories people tell about family do not just provide insight into a family's identity, but also the development of that identity (Mason, 2004; Kellas, 2005; Finch, 2007). Other common areas of research using a narrative approach include looking at the experience of caregivers (Ayres, 2000; Tasker and Stonebridge, 2016) and in understanding human experience of difficult times or disruptions, such as chronic illness, divorce, and infertility (Riessman, 2008; Papathomas *et al.*, 2015; Hartman *et al.*, 2016). Narratives are "inextricably emotionally-structured" (Kleres, 2011, p. 183); therefore, when disruptions or difficult times occur, story-telling can help individuals and the researcher make sense of the events and their emotions as they describe and evaluate the events (Becker, 1997; Dennis *et al.*, 2018). As has been described in other narrative research, in telling their story, participants also get the opportunity to further understand and share their experiences, actions, identities and relationships (Rees *et al.*, 2013).

Therefore, it follows that narrative methods are appropriate for in-depth study on the topic of grandparenthood in the context of grandchild disability. The interviews in this study were used to elicit rich data about the lived experiences of grandparenthood in the context of grandchild disability, the meaning and value participants give to the caring relationships, and changes over time discussed by participants. The narrative approach allowed for participants to describe their lived experience of grandparenthood in their own terms, describing events that they believe to be important aspects of their identity and experience.

There are a number of different approaches that can be taken to the narrative interview, for example the Life story interview (McAdams, 2008), the Biographic narrative interview method

(BNIM; Wengraf, 2001), or the Free association narrative interview (Hollway, 2000). Each approach has slight differences in how the interview is approached. In designing my interview format, I drew on the BNIM and free association methods to draw out narratives on experiences of grandparenthood. A narrative interview generally does not include a list of questions about the individual's experience but instead gives space for the interviewee to somewhat control and direct the interview (Anderson and Kirkpatrick, 2016; Bailey-Rodriguez *et al.*, 2018). To achieve this, an open question designed to elicit a narrative or story from the interviewee is asked at the beginning of the interview. Drawing on the BNIM method, during the main interview the researcher makes brief notes about the topics raised during the narration, using keywords used by the interviewee (Wengraf, 2001). In the phase following the main narration these notes are then used to encourage elaboration of the narrative. The follow-up questions are usually asked in the format of being narratively pointed, only referring to topics that were raised in the narrative and asked in the order in which they were raised in the narrative. The free association interview method builds on this by allowing for a number of open-ended and narrative-eliciting questions based on particular themes related to the research question that could be asked after the initial narrative (Hollway, 2000).

An important and challenging aspect of the narrative interview is active listening while the interviewee tells their story. The researcher must allow the interviewee the time and space to present their narrative. The usual rules of conversation of turn-taking and entrance and exit talk do not apply, with turns in talk for the interviewee lasting longer. However, during the active listening the researcher must be prepared to notice when the interviewee needs support and reassurance to continue with their narrative (Hollway, 2000; Wengraf, 2001). Interviews are very dependent on the interviewer building a good rapport with the interviewee so that they feel comfortable enough to discuss their experiences.

I aimed to get as wide a range of participants as possible in terms of the type of disability the grandchild had and the family circumstances (lineage, gender, relationship status and working status); therefore, the narrative approach allowed for these different circumstances to be explored and showed how they might shape the narrative given. By giving each participant the opportunity to tell their own story, counter-perspectives could be expressed, and unexplored areas and topics could be raised by the participants. This is discussed more in the following section.

3.2.2 Intergenerational approach

As highlighted in the literature review, much of the previous research on the topic of grandparenthood in the context of grandchild disability has focussed on the parent opinion.

Very few existing qualitative studies in this research context have included both the parent and the grandparent together from the same family. To truly understand the experience of grandparenthood and the dynamics of care across intergenerational relationships over and across time, it is necessary to try to include multiple generations (grandparent, adult child, and grandchild) in the research where possible. All the roles are inextricably linked as grandparents only become grandparents because of their adult children having children and becoming parents. The experience of grandparenthood can also be strongly influenced by the quality of the relationship between parents and grandparents (as described in Chapter 2, section 2.3). Trying to include the voices of multiple family members will help to provide a more nuanced picture of the multidimensional nature of the role. Interviewing multiple family members also allows for an understanding of family development and the family processes that form over time and may influence how the grandparenthood is experienced and enacted.

From a family theorist approach, a family is not necessarily a homogenous unit that will share a cohesive story, instead a family is a group of individuals coexisting in complex and changing relationships with each other (Scott, 1997; Warin *et al.*, 2007). Finch and Mason (1993) highlighted in their work on negotiations of family responsibilities that seeing the family from one member's perspective can give a distorted picture of that family. Within social sciences and family research, taking a multi-generational approach is being recognised as important in understanding family practices, 'doing' the family, and has important implications for social policy recognising families as a 'unit' rather than individuals. Family researchers are more often taking a comparative approach, for example, by focussing on gender or generational differences to understand how these factors affect individuals' experiences (McCarthy *et al.*, 2003; Warin *et al.*, 2007). For these reasons it is appropriate to select methods that allow for the observation of 'divergent realities'. Consequently, in this study I gained the perspective of two generations within families on the role and experience of grandparenthood.

An important decision to make was whether to interview family members separately or not. Given the potential for contrasting views, the raising of sensitive topics, and wanting the participants to see the importance of *their* story, it was decided to carry out the interviews separately. This meant that there would be no co-construction of stories and that each family member could expand fully on a topic without being interrupted. Taking this approach meant that the interview was less susceptible to participants holding back or altering information in the presence of another family member if that information could be taken the wrong way and negatively affect the relationship. This was seen throughout the interviews with many of the participants checking the confidentiality and expressing they were glad details would be kept confidential from their family. By interviewing the grandparents and parents separately, I was also able to compare accounts across the generations. Each individual family member had the opportunity to give their own accounts and meanings to roles, events or situations which may differ.

3.3 Recruitment and Sample

This section describes how the approaches described above were applied to the recruitment and selection processes in this research.

3.3.1 Recruitment strategy

The first step in data collection was the recruitment of grandparents. Recruitment for the study was conducted through Contact North East. An advert was placed in their monthly e-newsletter (Appendix A) and flyers were printed to be handed out at relevant events held by Contact and displayed at their office (Appendix B). Interested grandparents were able to contact me directly or could contact research partners at Contact if preferred in the first instance. I met with the local office for the UK charity Grandparents Plus, to try to increase advertisement for the research and reach more potential participants. However, the local office was working with custodial grandparents who would not meet the inclusion criteria. A poster advertising the research was also displayed at a hydrotherapy pool. However, no further expressions of interest were received.

For the initial recruitment of grandparents, a number of inclusion and exclusion criteria were agreed. The inclusion criteria were set as very open to encourage as many people as possible to come forward for the research. The inclusion criteria were:

1. A grandparent of a child of any age with a disability or special needs

In order to achieve the third aim of the study, assessing the impact of ageing, I wanted to be able to include grandparents and grandchildren of a range of ages. I also wanted to be able to include grandparents of children with a range of disabilities and special educational needs. Most of the previous research on grandparenthood in the context of grandchild disability has focussed on specific disabilities. By opening the recruitment up to all disabilities, I hoped to identify the general issues for grandparenting in this context.

2. A grandparent who provides any amount of informal care for their grandchild with a disability

I did not set an upper or lower limit on the amount of informal care grandparents provided to their grandchild with a disability. I wanted to encourage grandparents who were involved to any degree with their grandchild. This could include those who provided daily support to their grandchild to those who potentially had very little contact or involvement with their grandchild. This was to allow me to understand factors that both encourage or discourage the involvement of grandparents.

3. Able to speak and understand English language

Given the in-depth nature of the interviews and my own language abilities, having a good understanding of English and ability to speak English was necessary for taking part in the research. There was also no funding available to make use of an interpreter.

Despite trying to keep the inclusion criteria for recruitment as open as possible, there were two exclusion criteria that were set:

4. Not a grandparent of a child with a life-limiting condition

The decision was made to not include grandparents of children with life-limiting conditions (i.e., conditions where premature death is inevitable, and where there may be long periods of intensive treatment). While there is potentially some overlap in grandparents' experiences of having a grandchild with a life-limiting condition and a grandchild with a life-long disability (e.g., emotions at diagnosis, support to parents and other grandchildren), it was felt that the experiences could also be very different. The intensity and complex nature of the context in which grandparenting a child with a life-limiting condition takes place would warrant its own study rather than being included within this sample. Children with life-limiting conditions may have more long-term stays in hospital, need more specialist medical care, and palliative or hospice care (Donnelly *et al.*, 2005; Davies *et al.*, 2007). This would alter the care dynamics within families, including grandparent involvement that would potentially be very different to informal support provided by grandparents of children with a life-long disability.

5. Not a grandparent who has legal guardianship or custody of their grandchild with a disability

A decision was also made to exclude grandparents who had legal guardianship or custody of their grandchild. Again, while there may have been some overlap in experiences, it was felt this experience would raise issues different to providing informal care. There are a number of issues such as financial burdens (e.g., access to benefits and resources), legal issues around the adoption/guardianship process, impact on the grandparents' health and social life, and concerns for the future (Minkler and Fuller-Thomson, 1999; Hayslip and Kaminski, 2005; Hillman and Anderson, 2019) that are distinct to having legal guardianship or custody. Within these families parents may not be available to approach for interview and there could be very different relationship dynamics, which would also impact the aims of this study.

Grandparents who expressed an interest in the research were contacted by phone to go over the inclusion and exclusion criteria and to collect some information about themselves (age, working status, relationship status, and lineage) and their grandchild (disability and age). These details were initially collected in order to aid purposive sampling. However, as described at the beginning of this chapter this was not possible in the end. Although these details were used to make sure the initial grandparents interviewed had different characteristics (e.g., age of grandchild, paternal or maternal grandchild, type of disability) so that any initial differences could be highlighted and taken into account in the interviews that followed.

During the first phone call the research study was briefly explained and an information sheet (Appendix C) was sent via post or email. A follow-up phone call was conducted in which the grandparent had an opportunity to ask any questions about the research. If they wished to join the study an appointment was made for me to visit them at home to collect consent and conduct the interview. Details of the interview procedure are outlined in the next section.

The grandparents interviewed acted as gatekeepers to the recruitment of the parents. At the end of the grandparent interviews, grandparents were asked if they thought a parent or both parents of their grandchild with a disability would be interested in the study and if they would be happy to be contacted about this in the near future. When it came to begin the parent recruitment, grandparents were contacted by telephone or email (whichever was their preferred method of contact) and asked if they would be happy to pass on an information sheet (Appendix D). If parents were interested in taking part in the study, they were instructed to contact me by telephone or email. Following an expression of interest, a phone call was arranged for me to explain the research study and answer any questions they had about the research. If the parent was happy an appointment was made for me to visit them to collect consent and carry out the interview.

Sample

Grandparent Sample

Eighteen grandparents/grandparent couples expressed an interest in taking part in the research. One grandmother did not meet the inclusion criteria as she had legal guardianship of her grandchild. Two grandmothers were not recruited as I was unable to contact them following their expression of interest. Fifteen interviews (including two pilot interviews with grandparents from the advisory group) were carried out with 21 grandparents: nine interviews with grandmothers and six interviews with married grandmother-grandfather couples (who were happy to be interviewed together).

Table 3 gives a summary of the grandparent characteristics. The grandparents’ ages ranged from 52-85 years, the majority of whom were married and retired. Of the 15 interviews, 11 were with maternal grandparents and four were with parental grandparents. Only one grandparent (or grandparent couple) was interviewed from each family.

Two grandmothers interviewed had only one grandchild (the grandchild with a disability). The majority (n=9) had three grandchildren across all their adult children. The grandchildren with a disability ages ranged from 4-19 years of age at the time of the interview. Most of the grandparents had just one grandchild with a disability, however three grandparents interviewed had multiple grandchildren with a disability (2-4 grandchildren). Across all the grandparents recruited, there were 20 grandchildren with a disability: eleven had ASD (four of whom were non-verbal), three had cerebral palsy (two non-verbal, one used a communication aid with some speech), two had Down’s syndrome (one communicated using Makaton), three had congenital disorders (birth defects), and one had Rhett’s syndrome.

All the grandparents provided regular, weekly informal support to their adult child and grandchild. All lived in North East England. The majority lived in close geographical proximity to their adult child and grandchild, and one grandmother lived an hour drive from her adult child and grandchild (range: 0.5-52 miles). None of the grandparents lived in the same house as their grandchild.

Parent Sample

From the 15 grandparent interviews, all but two of the parents were approached about taking part in the research. One grandmother only agreed to participate if her daughter was not contacted due to her relationship with her daughter at the time. Another grandparent did not respond to communication following her interview about approaching the parent. Of the 13 parents who were approached, 10 agreed to participate. Three parents declined to take part due to: 1) not wanting to discuss the grandchild’s disability, 2) being too busy to take part, and 3) because of their own health problems.

Table 4 gives a summary of the parent characteristics. Nine of the interviews were with mothers and one with a mother and father couple. The majority of the parents were married/co-habiting and worked part-time. One mother was looking for paid employment after being a full-time caregiver of her child for several years. Seven of the parents had two children, three parents had one child.

Table 3: Interviewed Grandparent Characteristics

	N
Occupational Status	
Full time work	2
Part time work	2
Retired	17
Age retired (years)	50-69
Relationship Status	
Married	18
Widowed	2
Divorced	0
Single	1
Own Health Conditions	
Yes	13
No	8
Age (years)	52-85
Number of grandchildren	1-10
Number of grandchildren with a disability	1-4

Table 4: Interviewed Parent Characteristics

	N
Occupational Status	
Full time work	3
Part time work	5
Full time carer	2
Looking for work	1
Relationship Status	
Married	8
Divorced	2
Co-habiting	1
Age (years)	26-45
Number of children	1-2
Number of children with a disability	1-2

Table 5: Family Characteristics

Relationship to grandchild	**Pseudonym of parents**[1]	**Age range of adult**[2]	**Marital Status**	**Pseudonym of grandchildren with a disability**	**Age range of grandchild**[3]
Maternal grandparents	**Albert & Pearl**	70-74	Married	Harrison	10-14
Mother	**Diane**	40-44	Divorced		
Paternal grandparents	**Amanda** & Karl	60-64	Married	Samuel	0-4
Mother & Father	**Jamila** & Luke	25-30	Co-habiting		
Maternal grandparents	**Alice** & Eric	70-74	Married	Thomas	10-14
Mother and stepfather	Anna & Jason	-	Married		
Paternal grandmother and step-grandfather	**Audrey** & John	60-64	Married	Brian	5-9
Mother and Father	**Lauren** & Patrick	35-39	Married		
Maternal grandparents	**Joan & Andrew**	70-74, 65-69	Married	Ellie & Charlie	5-9
Mother	**Cathy** & Peter	45-59	Married		
Maternal grandmother	**Mary**	60-64	Single		
Mothers and Father	Rose & Carl	35-39	Co-habiting	Stephanie & Michael	10-14
Mother	Ruth	35-39	Separated	Lucy and Kayla	10-14, 5-9

Maternal grandparents	**Patricia & Terry**	65-69, 80-84	Married	Dylan	15-19
Mother	**Kelly**	35-39	Co-habiting		
Paternal grandparents	**Elsie** & Bruce	60-64	Married	Jacob	5-9
Mother	**Grace** & Mark	40-44	Married		
Paternal grandparents	**Henry & Shirley**	60-64, 70-74	Married	Malachi	5-9
Mother & Father	**Whitney & David**	35-39, 45-49	Married		
Maternal grandmother	**Paula**	70-74	Widowed	Jack	10-14
Mother	**Cheryl** & Paul	40-44	Married		
Maternal grandparents	**Annie** & Derek	60-64	Married	Aiden	5-9
Mother	**Melissa** & Ned	35-39	Married		
Maternal grandparents	**Hazel** & Gary	50-54	Married	Tyler and Tim	0-4, 5-9
Mother and Father	Ruby & Joshua	-	Married		
Maternal grandmother	**Clara**	65-69	Widowed	Miles	5-9
Mother and father	Tara & Daniel	-	Co-habiting		
Maternal grandparents	**Judy & Kevin**	60-64	Married	Jesse	5-9
Mother	**Sonia** & Glenn	35-39	Married		
Maternal grandparents	**Margaret & Perry**	60-64, 70-74	Married	Oscar	0-4
Mother and father	Molly & Shaun	-	Married		

[1] Names of interviewees in **bold.** [2] Only ages of adult participants interviewed available. [3] Age range given to maintain anonymity.

3.3.2 Ethics and ethical approval

This research was assessed by Newcastle University Faculty of Medical Sciences Ethics Committee and approval was given in July 2017 (reference: 1288/9395/2017). The ethics approval letter can be seen in Appendix F. Informed written consent was obtained from all participants. All participants were told the interview could be stopped at any time and they could withdraw from the study if they wished.

I was aware of the sensitive nature of the topics that could potentially be discussed during the interviews, and the thought and care that needed to be given to interviewing multiple members of a family. It was highlighted in the information sheets and at the beginning of the interviews that all information would be kept confidential and that anything said in the interview would not be discussed with other family members taking part in the research. Confidentiality would only be broken if any concern of risk or harm to an individual was raised.

In order to maintain confidentiality, all the participants have been given a pseudonym first name. Names of all other family members mentioned in interviews were also changed in the transcripts. As well as names, all other identifiable information, such as places, schools or hospitals were removed to maintain the anonymity of the families.

3.4 Interview Process and Schedules

All interviews were carried out face-to-face with participants. At the start of the meeting the aim of the research was explained to the participant and they were given another opportunity to ask any questions they had. Once participants confirmed that they understood the aim of the study and the nature of the interviews, written informed consent was completed. All interviews were audio-recorded using an Olympus Digital Voice Recorder, DS-2400.

Interviews took place in the location of participants' choosing. Most were conducted at the participants' home, but other locations (e.g., university, other family member's home) were used due to logistics. To open up the conversational space and help put the interviewees at ease, the interview started with a general question asking participants to tell the researcher some details about themselves, such as whether they worked and what their family unit consisted of. The narrative was then initiated with a single question, *"Can you tell me about your experience of being a grandparent to a child with a disability, describing events or experiences that are important to you?"* (re-worded for the parent interview). The participant was then allowed to give their narrative with no interruptions. Notes and keywords were written down in a sequential order of topics raised during the narrative. Participants were given encouragement to continue with their narrative when needed (e.g., nodding, reassuring noises of interest) and pauses were allowed to give the participant time to continue with their narrative.

Once the participant's initial narrative was complete, it was elaborated on with follow-up questions from the list of keywords and notes I had made while the participants were telling their story. This helped to follow-up, clarify and collect more details on the topics and issues raised in the participants' stories. I had an interview agenda which comprised of a list of pre-identified subject headings and topics that could be drawn on to aid focus and prompt discussion in areas of interest (Appendix G). This was especially useful when participants were struggling to tell their story in detail (e.g., saying they were not sure what to say) and needed more prompting. Some of the participants' struggled to give in-depth descriptions of the support they gave to the family in the initial narrative. They gave very basic descriptions in the first instance of their role, while others went into greater detail about how the experience of diagnosis, family relationships and how they felt about their role, without needing any prompting questions.

At the very end of the interview, if they had not been answered through the interview, a sociodemographic questionnaire was completed with questions including relationship status, employment status, hours of grandchild care provided, and number of [grand]children (full questionnaires in Appendix H). On average the interviews with grandparents lasted 1 hour 26 minutes (range 1 hour- 2 hours). Parent interviews lasted on average 1 hour 12 minutes, (range 52 minutes to 1 hour 42 minutes).

Participants were asked if there were any further details they would like to add, were offered the opportunity to ask any questions and then thanked for their participation. Each participant received a £10 shopping voucher as a thank you for their participation and time.

3.5 Data Analysis

My approach to analysis came from social constructivist position (Burr, 2004). From this position I viewed knowledge as both context and time dependent and language playing an important role as, for example, the same event could be described in different ways, leading to different perceptions or understandings of events (Crotty, 1998). This was very important in analysing each generations accounts of events. In some families different 'versions' of events were told by the different generations. In the analysis I was not looking for one 'correct' account, and throughout the analysis and write-up I kept in mind that each version was true to the participant giving their account. With this in mind as well, when analysing the interviews, I tried to keep aware of how each family member's own circumstances and experiences may shape their perception and their story. The goal was not to find one understanding of the experience of grandparenthood in the context of grandchild disability, but rather to understand the range of experiences and influencing factors on those experiences and perceptions.

In applying a social constructivist epistemology (Burr, 2004), it is important to recognise that the findings of the research are contextually specific to my interactions with the participants at that point in time and the meaning that I have drawn from those interactions. The findings were a consequence of the interaction between me and the participant. Therefore, it is possible that someone else replicating this research may not draw the same conclusions.

All the interviews were transcribed verbatim by me using Microsoft Word. All names were changed, and other identifiable details were removed and replaced with a simple description (e.g., [PLACE OF WORK], [SCHOOL], [HOSPITAL]). In the transcriptions I wanted to include as much detail as possible, therefore three dots (…) represent a pause, [ellipsis] with blank space represents when one or more words have been omitted due to being inaudible, and then square brackets [ ] were used to provide the reader with additional information pertinent to the conversation (e.g., expressions of emotions, interruptions to the interview). Doing the transcription process myself was a very important first step in understanding the data before the process of data analysis began (Lapadat and Lindsay, 1999).

Transcripts were imported into NVivo 11 for analysis. Grandparent transcripts were read and re-read to familiarise myself with the data. My initial stages of coding included line-by-line (or small section-by-small section) coding to aid understanding of what was being said. An inductive approach was used to identify key themes emerging from the data by noting the repetitions, categories, similarities, and differences (Ryan and Bernard, 2003). However, it is important to be aware that no study can be completely inductive. Strauss and Corbin (1998) recognise this as researchers have background knowledge and concepts they will use in confronting their data (Payne and Payne, 2004).

Constant comparison methods, as proposed by Strauss (1987), were used, with new data collected being compared to previous transcripts. In making these comparisons I aimed to establish analytic distinctions in the data and develop a way of explaining the data rather than simply describing it. An initial set of codes was established which were condensed into key codes detailing ideas and thoughts contained within the narratives. See Appendix J for a mind map of initial codes identified.

For the analysis of the parent transcripts a similar process of transcribing, reading and re-reading the transcripts was carried out while data collection continued. Line-by-line or section-by-section coding was conducted with constant comparison to the codes used for the grandparent interviews, highlighting similar topics of discussion. New codes were also added as they emerged from the parent data. Again, codes were condensed to key codes summarising the key issues and themes from the parent narratives. See Appendix K for a mind map of initial codes identified.

The codes from both the grandparent and parent interviews were compared and contrasted identifying similar narratives as well as identifying contrasting narratives and themes. Many themes were identified in the data and there were a number of ways I could have presented the data in this thesis. Through the analysis process and discussions with my supervisory team, I chose to present the data in three overarching themes from across the parent and grandparent interviews. These three themes reflected what I interpreted as the main story of the interviews, defining the experience of grandparenthood and the dynamics of intergenerational support within the families (Figure 1).

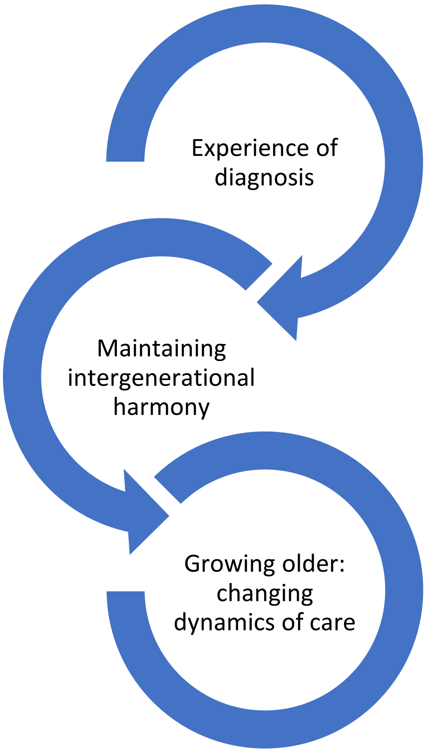


Figure 1: Overarching themes of analysis

3.6 Advisory Group Contribution

Early on in the PhD process, an Advisory Group was set up for this research. The Advisory Group included the Regional North East & Cumbria Manager and the Regional Information Officer at Contact North East to bring the perspective of the charity and their experience of working with families of children with a disability. Through an advert in the Contact e-newsletter, two grandparents (a grandmother and grandfather from different families) of grandchildren with a disability joined the group. The group was a helpful way to work effectively with the collaborators of the project (Contact North East) and to engage with grandparents to make sure the research was addressing topics that were important to them. Two academics working in the field of ageing and disability also joined the group. I attended each meeting along with one or two supervisors.

The Advisory Group meet three times over the course of the research. In the first meeting the proposed research questions and research methods were presented. I also shared the information sheets and interview agendas to receive feedback. Following the feedback, Contact North East's contact details were added to the information sheets. The grandparents also gave helpful feedback on how to prepare the participants for the structure of the interview. For example, the story-telling aspect of the interview was explained clearly in the telephone call arranging the interview, in order to give the grandparents and parents time to think about what they would want to share. A second meeting was conducted halfway through the grandparent recruitment and interviews. At the second meeting some initial anonymised data from the first ten interviews were presented to the group. The feedback at this point allowed for some credibility checking of my themes, that is, to explore if the themes resonated with the grandparents in the group (who had been interviewed). Having a mixed group of academics, the collaborators and the grandparents in the meetings led to helpful discussions of theory and how this was reflected in practice and in the lived experiences of the grandparents.

In the final meeting a summary of the findings was given to the Advisory Group. Presenting the findings to the group and taking on board their feedback and the discussions gave credibility to the main themes that emerged from the final analysis. The group also provided feedback on the content of a summary document I had drafted to be sent out to all the families who had taken part in the research. I initially had some concerns about sending a summary which included both the grandparent and parent perspectives due to the sensitive topics raised in the interviews; however, the grandparents felt it was important for both generations to see the overall summary.

3.7 Limitations of Sample

There are some important reflections to make on the sample that were recruited. As stated at the beginning of the chapter, in the initial research proposal, a method of purposeful sampling was intended with the aim of recruiting grandparents with a range of genders, lineage, age, and employment status. However, due to a limited number of expressions of interest being received I interviewed all the grandparents who expressed an interest. The sample still provided some variety in the family structures, types of disability and employment, however there are some of aspects of the sample that warrant some reflection.

The majority of grandparents and parents that were interviewed were grandmothers and mothers. Of the six grandfathers who participated, two were the grandparent who initially expressed an interest in the research and made the first contact. The other four grandfathers were present at interviews that had been arranged through their wives (the grandmothers). This gender bias seemed to reflect the care and support dynamics in these families, with it typically being the mother or grandmother taking responsibility for the majority of the support work. This gender ratio is in line with previous studies which have shown grandmothers and mothers taking on the majority of care work in families (Hank and Buber, 2008; Horsfall and Dempsey, 2015). In the cases where it was the grandfather who initially expressed an interest, the grandfather often described themselves as the grandparent who was most involved in the support of the grandchild, mainly because of the grandmother's declining health. Furthermore, 11 of the grandparents/couples that came forward for the research were maternal grandparents, with four being paternal, as is consistent again with previous research on the hierarchy of grandparent involvement (Wheelock and Jones, 2002). Therefore, how much findings may reflect contemporary grandfathers and paternal grandparents experiences need considering.

Another important factor to bear in mind when analysing and interpreting the findings from this sample is that there may be some effect of the self-selection process. It is possible that grandparents who are coping better with the amount of support they provide, who have better relationships with their grandchild's parents and who are more involved in general, are more likely to volunteer themselves for this type of research. For example, one grandparent only took part in the interview when I clarified I did not have to approach her daughter to participate as well, otherwise she would have refused to participate. Other grandparents in this position may have opted not to put themselves forward for the research to avoid a possible conflict with their adult child. Many of the grandparents saw the advert for recruitment by the parent passing on the information, therefore the quality of family relations may have impacted the number of grandparents seeing the advert for the study. These are all characteristics that have been found to influence grandparent involvement in grandchildren's lives (Lee and Gardner, 2010) and so may have influenced the experiences described by this sample. However, finding avenues to reach grandparents in this context without using parents as gatekeepers is not easy. Finally, all the families recruited had been or were currently in touch with the North East branch of Contact and therefore were in some contact with services. It is possible that families without any contact with other services may have different experiences.

The grandparents interviewed as part of this research were grandparents who were involved in their adult children's and grandchildren's lives. Therefore, the results reflect these grandparents and not all grandparents of children with a disability. It is important to acknowledge that there are grandparents not included in this research who may have different experiences. This includes grandparents more estranged from their family or grandchild, and grandparents who live further away from their family. Therefore, no clear conclusions can be drawn about why some grandparents may be more involved than others and what some of the barriers to grandparent involvement are, or how the dynamics of intergenerational relationships may be different in families with less involved grandparents. Likewise, with the parent interviews, despite both mothers and fathers being invited to be interviewed, it was always the mother (with the exception of one father) who participated in the interview. This may have been linked to other factors such as the fact that in these families the father usually worked full-time while the mother had reduced her working hours to take on the care work for the child. Therefore, practically it was easier for mothers to participate than fathers. These gendered differences in participation of both grandmothers and mothers more than likely reflects the gendered nature of involvement in care and family kin-keeping activities (Wiscott and Kopera-Frye, 2000; Dubas, 2001).

A final limitation was the recruitment of grandchildren to participate in interviews. There was a limitation on the number of grandchildren that could be approached due to the age limit placed on which grandchildren could be approached and being unable to meet some children's communication needs. With more time and resources, I would have trained in using communication systems such as Talking Mats or Picture Exchange Communication Systems that would have allowed for the participation of more grandchildren. Furthermore, the grandchildren discussed in this thesis were mostly school-aged, except one. I had initially aimed to recruit families with grandchildren of a range of ages. However, expressions of interest were not received from families of older children (other than one family), therefore some of the issues and challenges raised about the future were ones speculated by the families rather than descriptions of the actual challenges or experiences the families face as the generations aged.

3.8 Reflective Account

Below I give some of my reflections and thoughts collected while conducting the research and some retrospective thoughts since completing the data collection and analysis.

3.8.1 My experience entering this research

There are some relevant reflections that are worthwhile to consider ahead of the results of the analysis. Firstly, it is important to acknowledge my position and experience of grandparents and disability as the researcher. I have a good relationship with my maternal grandparents, speaking to them on the phone on a regular basis and visiting them as often as I can. They are both relatively healthy for their age and still live independently in their 80s and 90s. I lost my paternal grandparents before I was 10 years of age, with my paternal grandfather dying very suddenly and unexpectedly. I do not recall much about my paternal grandmother being ill before she died. Most of my memories of grandparents are in relation to my maternal grandparents. Every half term and school summer holidays involved spending a lot of time staying over at my grandparents' house, who lived one hour away, while my parents worked (in particular the days my mother worked). Christmases were spent with my maternal grandparents and they would often come on holiday with us. My maternal grandfather has also offered a lot of financial support to me, my siblings and my cousins, in particular to allow me to further my education at university. I have had and still have a very close relationship with my maternal grandparents. From this experience with my grandparents it has given me expectations of what grandparents 'should' be like. I have never entirely considered how differently grandparents could be considered or considered the circumstances that led to my relationship with my grandparents.

I have not had much experience of disability in my personal life: most of my experience and knowledge has come from my experience as a researcher and the families I have met through my research roles. However, one aspect of my family life was in the back of my mind during the process of designing and conducting this research and analysing the data. My uncle (on my father's side) had epilepsy and learning difficulties. He was cared for by my paternal grandparents until they died, at which point my father took over managing his care and finances. My grandparents arranged their working life around the care of my uncle with my grandfather working during the day and then my grandmother went to work overnight, meaning one parent was always home for my uncle. One story that stays in my mind that my father told me is that my paternal grandparents worked very hard throughout their working life, but both died in their sixties before they could enjoy retirement or access any kind of pension. My father talks about this as an injustice to them; they worked hard, saved, looked after their son well into his adult-life, then passed away before they could take or enjoy a break from their hard work. My father became my uncle's advocate/power of attorney when my grandfather died. He found my uncle some appropriate supported accommodation, managed his finances and supported his medical and social care, until my uncle passed away suddenly several years later when I was in my twenties. While I do not have a detailed understanding of what happened with my uncle's care, it gave me an understanding on how disability can be a part of family life, the impact disability can have on different family members, and also all the agencies involved with the family in this context.

More of my experience and knowledge of disability has come from my work as a research assistant, working with young people (aged 14 to 22 years) with ASD and mental health conditions, and young people with cerebral palsy. These young people were older than the majority of the children in this study. Through my previous work I have seen the struggles and joys families have with accessing support for young adults and how important family support was to them. However, in that research I was very focussed on the access and support from healthcare and social services, rather than focussing on the family support. I was focussed on the experiences of the young person as they were entering adolescence, rather than considering some of the challenges and experiences that had occurred before that point.

3.8.2 Lessons learnt from pilot interviews

When starting, I had relatively little experience in using qualitative research methods to collect data. I used the training opportunities available to me to prepare me as much as possible to collect the grandparents', parents' and grandchildren's stories. Two pilot interviews were carried out with grandparents from the Advisory Group. Pilot interviews were carried out to test the interview agenda and as a practice for myself being a novice qualitative researcher. In these pilot interviews the interview was started by going through a sociodemographic questionnaire. On review of the transcripts, it was decided that this order could encourage participants to then provide short answers to the open questions. Therefore, the interview was changed to start with a more open question asking participants to tell me a little bit about themselves and then more specific sociodemographic details were collected at the end of the interview. In some cases, these sociodemographic questions at the end of the interview, particularly around work and retirement prompted more narratives about these topics rather than just short answers.

The pilot interviews also highlighted the importance and difficulty of active listening and simultaneously note-taking so that appropriate and sequential follow-up questions could be answered. Following these interviews, I put in place a better method for notetaking. Previously I had been making notes on the interview agenda but following the pilot interviews I used a notepad that was just for notetaking during the interviews. This allowed me to make clear notes about what was being said without being distracted by what was on the interview agenda. I also used this notebook to record my own reflections on the interview and initial thoughts immediately following the interview which I was able to refer back to when starting the analysis. The process of notetaking and active listening became easier as I became more familiar with the interview agenda and the interview process.

Following the pilot interviews, I also asked the grandparents for feedback on how they felt the interview process went and how comfortable they felt providing their story. Both agreed it was helpful to reiterate at the beginning of the interview that I was not looking for right or wrong answers and was just interested in the story they had to tell me. Otherwise, they felt they had been able to cover all the topics they wished to cover and felt sensitive topics had been approached with thoughtful consideration.

3.8.3 Reflections on doing the research

The first reflection was on the presence of other family members, other than those taking part in the research. For the majority of interviews no one else was present other than me and the interviewee. In two cases the grandparents' adult-daughters were present but in another room. Whether this resulted in some grandparents holding back in their stories due to the potential of their daughters overhearing is not known. When interviewing couples, the narrative given was mostly a shared narrative with each of them describing events that had happened, the support they give, and providing their perspective on the same event. This did lead to a bit of interruption with one person's flow being interrupted by the partner adding their detail in. In one circumstance the couple had been separated for several years and had restarted their relationship a few years after their grandchildren had been born; therefore, where others were able to share narratives, this couple had quite different narratives when discussing the earlier years of their grandchildren's lives. As the interviewer I had to be very aware of making sure both grandparents' perspectives were covered on certain topics, asking the same question and directing it at each of the grandparents in turn.

Interviews were arranged around work and childcare schedules to minimise the chance of the interview being interrupted or affected by the presence of other family members. However, one interview was interrupted with a phone call from the grandmother's daughter who needed help with the grandchildren as her son at school needed collecting early. The daughter and grandmother returned to the house and the interview continued, but there was a very noticeable change in tone of the answers to questions when the daughter and grandchildren were sitting in the room next to us. I brought the interview to an end shortly after this as the grandmother was clearly distracted by and aware of her family sitting nearby.

On two occasions the interview had been arranged and began with one grandparent but then their partner joined the interview at a later point. In one case a grandfather was being interviewed with the grandmother around in the background, she later came in and joined the interview halfway through. In the second instance a grandmother was being interviewed and the grandfather returned to the home towards the end of the interview and was invited to join in by the grandmother. In both cases consent was gained at the end of the interview to include their contributions in the transcripts. However, these grandparents' full stories were not achieved in the interview and as the interviewer I tried to focus the interview on gaining more detail on the narrative provided by the first grandparent.

In the lead up to interviewing parents I had begun some analysis of the grandparent interviews and was becoming very familiar with the stories and themes coming out of these interviews. In the parent interviews it was explicitly stated that I would not discuss anything that was said in the grandparent interview. I did, however, find myself becoming very aware that I was very familiar with the narrative the grandparent(s) had provided and making sure this did not lead me to subconsciously guide the narrative in a particular direction. The set-up and process of the narrative helped with this, but I continuously made a considerable effort to make sure I was not asking potentially leading follow-up questions towards the end of the interview.

Another aspect of separate intergenerational interviews is handling conflicting stories from the parent and grandparent. While writing up the results I was keeping in mind the question "whose story am I telling?" Parents and grandparents were giving their own perspectives and I wanted to make sure I was not assuming one story was correct over the other. Throughout the results chapters I have tried to ensure I provide both perspectives and understand how each individual came to their own view.

Finally, in conducting the grandparent and parent interviews I was aware of how emotional the interviews could be. From the outset I knew topics of a very sensitive nature would come up and that I would be asking participants to describe and reflect on experiences that they may find very difficult to talk about. While transcribing some of the earlier interviews I tried to reflect on how I handled some of the emotions expressed in the interviews. It became very common for participants to cry during the interviews. I always offered participants a break from the interview and allowed them to change the topic of the question and move on if preferred. However, while transcribing I also became aware of how I was handling the showing of emotion. I questioned whether I was being over-protective of the participants by avoiding following up on topics that had caused upset. I believe I handled the situations appropriately and sensitively, using my past experience as a researcher, but mostly through human empathy. In some cases, it was necessary to stop and move on from the discussion that was causing the participant upset; however, more often than not, many participants were happy to continue the discussion following a short break or they themselves returned to the topic at a later stage of the interview. Some of the discussions had were topics the grandparents and parents seemed to have never openly discussed before, or the discussion was taking them back to a time they had moved on from or not reflected on for a long time. Therefore, sometimes just a moment of pause was needed for participants to be able to articulate their experiences and emotions. Many of the participants described how cathartic the experience of taking part in the interview had been. They were reflecting on and processing thoughts about the grandchild, the family and themselves that they had not always been able to openly discuss; therefore, sometimes unexpected emotions were released. These emotions were sometimes difficult to see and hear as the researcher and some of the experiences shared were extremely sad and upsetting. However, there were also so many happy and positive stories. More often than not the interviews ended on a positive note which I think helped me walking away from the interviews and processing what had been shared. The stories shared by these participants will likely stay with me forever, and I hope will have positive impact on me as a researcher in the future.

3.8.4 Experience of trying to include grandchildren in the research

As stated earlier in the chapter, my original intention had been to include a sample of grandchildren in this research project. The grandchild voice is largely absent in the current literature of grandparenthood in the context of grandchild disability. There is growing recognition of the importance of including children's voices in research and understanding their lived experiences (Wise, 2002; Balen *et al.*, 2006; Clavering and McLaughlin, 2010). Significant consideration was given to the inclusion of children in the research, including age limits for inclusion, assent and consent procedures, designing appropriate information sheets and designing a topic guide for the interviews (see Appendices E and I). I engaged with literature to understand useful methods of interviewing children, as well as seeking advice from fellow researchers who had carried out interviews with children and especially children with a disability. Following guidance from 'Ethical Research Involving Children' (Graham *et al.*, 2013), a recommended guidance by the ESRC, I took a reflexive approach to trying to involve children in the research, considering the relevant contextual issues (i.e. the topic of the research, methods of the research) and how the consent process could be tailored to meet the needs of the grandchildren in terms of their age and the disability (Morison *et al.*, 2000; Powell *et al.*, 2012). Specific information sheets were made for age groups 8-12 years and 13 years and above (Appendix E), adapted to describe the research in way understandable for those age groups. Extra care and time were taken to explain the research to the children at the visit and that there was no pressure put on the child to participate, despite how keen their parent may be for them to be involved. As is typically practiced in research involving children below 16 years, I gained written *assent* (affirmative agreement) from the child and then written *consent* from their parent. These practices and approaches were to make sure that the research maintained rigorous ethical practices, avoiding any potential harm to participants, as well as allowing for the meaningful involvement of children in this research.

I recruited three grandchildren (aged 8-13 years) to the study and interviewed them with their parents present. All the interviews were very different, and all did not go as expected. The content of the grandchild interviews was also coded (Appendix L). However, due to some of the difficulties I had in conducting the grandchild interviews, there was limited content that could be coded in relation to the research questions. In all the interviews the grandchildren gave very short answers to the questions (1-4 words) and often could or would not give more detail or explanation when prompted. Grandchildren stated how they spent time with their grandparents and what types of activities they did together (e.g., childcare, playing games, days out together). However, there was little description of their enjoyment or dislike of activities, or emotional aspects of their relationship with their grandparent. When reviewing the transcripts, it also become clear that a lot of the content had been guided by the mothers, who were all present at the interviews, rather than the content being raised by the grandchild. I was not satisfied that I had managed to gain the grandchild’s own perspective on the relationship. For these reasons, I made the decision to exclude the grandchild data from the main analysis of this thesis. However, I wanted to use this section to documents my efforts to include grandchildren and lessons learnt from the process that I will take forward with me in the future as a researcher.

Before this project I had not had much experience with interviewing younger children. My previous research assistant roles had given me experience in interviewing young people, aged 14 years and over, so I had some sense of how it would differ from interviewing an adult. I had sought advice from colleagues who had interviewed children and I engaged with literature around interviewing children to prepare as best I could. The three interviews that were conducted all went very differently and I had a number of reflections on what I believe influenced how the interviews went and ultimately resulted in me not including the grandchild data in the final analysis.

In two of the families where I interviewed the grandchild, the mothers had described how much the grandchild loved the grandparent(s) and how happy they would be to talk about them. This meant I then went into both interviews with a naïve sense that it would go smoothly, and I would have no problems encouraging the grandchild to discuss their relationship with their grandparent(s). In both cases, these interviews did not go as smoothly as expected. When I attended the first grandchild interview it became apparent very early on that the grandchild had had an argument with his mother that morning. The child’s language and behaviour during the interview gave the impression he was using the interview setting potentially as a way to retaliate at his mother by not fully complying with the research. He was swearing, moving around a lot and continually asking his mother for food or drinks which broke up the flow of the interview. He often said he did not want to answer questions or gave one-word answers to questions. I had told him at the beginning of the interview if there was anything he did not want to discuss he could say he did not want to answer, and I would move on to another question. I struggled to find the balance between respecting his right not to answer a question and also trying to find questions that he was willing to answer that would give me potential content for analysis. This interview was also difficult in that some of the comments the grandchild was making were giving very different perspective on his relationship with his grandparents to that which had been expressed by the parent and the grandparent. This threw me and my expectations of how the interview would go. This was also difficult because of the presence of his mother in the interview. They often disagreed with each other throughout the interview on comments he made about what he did with his grandparents, which potentially discouraged the grandchild to share his view.

In the second interview, the mother had forgotten to tell the grandchild I was coming so the grandchild had not had warning about my arrival or a reminder of why I was there. I tried to insist we re-arrange, knowing that the interview may not go as well if the grandchild was not expecting me and had been pulled away from an activity he was enjoying. The interview went ahead after the grandchild was encouraged to participate by his parents. I felt it was not a good way to start off the interview. I spent more time trying to make the grandchild feel at ease with me and comfortable in the interview setting but he was anxious to get back to his video that had been interrupted by my arrival. Again, this meant I felt I did not get his full engagement in the interview and he, again, was giving short answers to questions and shrugging his shoulders a lot in response to questions, limiting the content I could get out of the interview.

The final grandchild interview was with a slightly older child who communicated primarily through his communication aid. I had some previous experience of interacting with someone using a communication aid, but it was a different system to the one being used by this participant. The grandchild’s mother was also present to help interpret his gestures and help guide him to use his communication aid to answer the questions. This grandchild was really engaged in the interview process and the interview was interspersed with a lot of talk about himself and him asking lots of questions about me. This may have been due to him being a bit older or simply that he was more interested in the process than the other grandchildren.

In all the grandchild interviews the mothers were present. In one way this helped the grandchild feel more comfortable in the interview setting and also with me. It was also a reassurance for me having the mother present in the room. In all cases they helped with interpreting what the child was saying or clarifying comments the grandchild had made. However, as stated earlier, when I reviewed the transcripts it became clear that the mothers had guided a lot the grandchild's content in the interviews. For example, they often jumped in to answer questions for the grandchild when I was giving the grandchild time to think or would often prompt or guide the grandchild's answer. The original aim of including grandchildren in the research had been to gain *their* perspective and give them a voice in interpretations of their relationship with grandparents. However, given how the interviews had gone, reflecting on how much was actually their own perspective being given and how much was guided by the mother, I did not feel I had truly captured their perspective or voice.

Some of the issues in these interviews were beyond my control as a researcher; however, in Chapter 7 (section 7.5) I describe some ways in which the process of interviewing the grandchildren could have been improved on reflection and how I would approach the grandchild interviews differently in the future.

3.9 Summary

This chapter has outlined the justification for the methodology and methods used in this study to understand the experience of grandparenthood in the context of grandchild disability. The following chapters now turn attention to presenting the findings gained from the methods described here. The grandparent and parent perspectives are presented, highlighting their shared stories and their own individual accounts of their experience of grandparenting. The next three chapters outline the main findings from the analysis. Chapter 4 describes the family experience of diagnosis, Chapter 5 describes the approaches families take to maintain intergenerational harmony, and then finally Chapter 6 explores the changing roles within families as they age.

Chapter 4. Where the Story Began: Receiving a Diagnosis and Family Adaptation

4.1 Introduction

Becoming a grandparent is one of the most significant transitions in later adult life (Kaufman and Elder, 2003; Findler and Taubman–Ben-Ari, 2016) leading to changes in the individual, the family, and the family relations. Like other transitions in life, it comes with many challenges which can be experienced either positively or negatively. This transition may come with more challenges and opportunities when a child is born with or diagnosed with a disability. Across three results chapters, using both the grandparent and parent perspectives, I outline how the grandparents of this study experienced their transition to becoming a grandparent of a child with a disability, how this transition shaped family relationships, and how the experience of grandparenthood in the context of disability changed as the family members aged and each generation started to go through their own life transitions.

This first results chapter describes the experiences of diagnosis and the families' efforts to embed disability into family life. Nearly all the grandparents' responses to the initial open question- *"Can you tell me about your experience of being a grandparent to a child with a disability?"*- started with a description of the family receiving the diagnosis and the build-up of events preceding that diagnosis. Despite it having been several years since diagnosis for the majority of the families, the memories of this time were still vivid with grandparents and parents, giving rich accounts of this period and their experiences. Therefore, it seems fitting to present these experiences in the first results chapter of this thesis as a lens to view their changing and current perceptions of grandparenthood, and to understand the consequent experiences of grandparenthood in this context.

Theories and discussion of the impact of childhood disability on the family have seen a major shift. From a psychological viewpoint, where once it was discussed from a negative perspective, describing feelings of grief, caregiver burden and family dysfunction (Helff and Glidden, 1998; Baxter *et al.*, 2000; Heiman, 2002), more contemporary research highlights family strengths and resilience, and focuses on changing policy and practice to support families managing the care of their children in positive, respectful and empowering ways (Flaherty and Masters Glidden, 2000; Hastings and Taunt, 2002; Potter, 2016). Disability studies have also challenged the narrative of burden in families of children with a disability, positing that the burden is instead created by state responses to disability (Read, 1991; McKeever and Miller, 2004; Shakespeare, 2006; Thomas, 2007). Rather than focussing purely on personal and psychological variables, wider social and cultural factors need to be considered in understanding the family response to having a child with a disability.

There has been a substantial body of psychological research that has explored stress, coping and adaptations of families with children with disabilities, focussing mainly on the parents (Yau and Li-Tsang, 1999; Smith *et al.*, 2001) and more recently on siblings (Knecht *et al.*, 2015; Thomas *et al.*, 2016; Wofford and Carlson, 2017). Many studies describe how grandparents can help or hinder the parents during the time of receiving a diagnosis, rather than exploring grandparents' own experience (Hastings, 1997; Hastings *et al.*, 2002). This chapter aims to bring attention to the grandparents' experience of a grandchild being diagnosed with a disability and how it affects them in their transition to becoming a grandparent. The chapter focusses on the grandparents' accounts, with the parent accounts added as some additional context for the family experience of adapting. This chapter is presented in three sections: the *family experience of diagnosis*, *finding a new family norm*, and the *meaning of grandparenthood*.

4.2 Family Experience of Diagnosis

"It's a whole new world, and it's a big learning curve for everyone, for all of us" (Alice, Thomas's maternal grandmother)

The diagnosis or recognition of concerns about the grandchild was where most of the grandparent stories began. This was the starting point of their journey of being a grandparent of a grandchild with a disability. What came through the accounts very clearly was that it was not just the grandchild receiving a diagnosis. The diagnosis was something the whole family received and experienced, including the grandparents. There was variation across grandparents in how they came to learn of the grandchild's diagnosis, especially in terms of the timing of the diagnosis. Four grandparents described the diagnosis being given at birth or very close to birth. This was often described in terms of shock as they recalled having no concerns or suspicions that there would be any problems during the pregnancy;

> *"And erm, when they delivered the baby, well Malachi [grandchild], that's when they discovered he had Down's syndrome. For whatever reason, I mean we hadn't taken anything to suggest there was anything wrong or anything. But nobody really was aware that there was a particular problem of that nature with him until he was actually born and of course it was a bit shock for the parents as well."*
>
> *(Henry, Malachi's paternal grandfather)*

In most of these circumstances the grandchild required immediate medical attention and treatment, with parents making important decisions about their child's immediate treatment. Grandparents described themselves as being an important source of emotional support at this time as well as providing advice and acting as a sounding board for the parents. The parents' accounts also described how important the grandparent support had been for them and their coping in these initial stages. For example, in Wendy's (Malachi's mother) case both her children had needed surgery and medical treatment immediately after birth and she had greatly valued the support of grandparents on both occasions;

> *"And I think all this [support] just kept us buoyant. I remember through both situations with Malachi [grandchild] and Chloe [Malachi's sister], the erm hospital teams constantly almost commended us for our stability and our balance and our compliance, understanding where we were with both of them and what was feasibly the next step. And I think that was because of the whole support system that we have, you know. And so many people contributed to that but Henry and Shirley [paternal grandparents] greatly so, absolutely greatly so."*
>
> *(Wendy, Malachi's mother)*

Grandparents acted as a source of knowledge, using their own parental experience, and were an important source for parents to turn to while they were trying to process new information about their child's disability. At this point the grandparents were very much being 'parents' to their adult child, supporting them with decisions that needed to be made and helping parents have discussion with doctors about treatment options.

Five grandparents described symptoms beginning to occur very early on in the grandchild's life and a diagnosis was received after several months of back and forth visits to health professionals. These grandparents described this time as worrisome and sometimes frustrating as they could see there were problems, but they and their adult child could not get a clear diagnosis for the grandchild. Samuel's paternal grandmother, Amanda, described the family's frustrations when Samuel was losing weight, despite appearing to feed well. She described how she and her daughter-in-law had their concerns ignored and were being passed back and forth between professionals. It was not until they were eventually sent to hospital that they discovered the congenital disorder causing Samuel's failure to thrive;

> *"We would go to the clinic; they would weigh him. I've got to be very honest, they were, em, "oh you're obviously not producing enough milk", "You need to be.... He's not putting on weight, he's losing weight". So, he was back in hospital again. They then decided they thought he had a tongue tie. So that was snipped. "Oh, he'll feed much better now." Well he was feeding beautifully, but you could just see this baby sort of disappearing before your eyes, you know."*
>
> *(Amanda, Samuel's paternal grandmother)*

These early months were described as a traumatic time as the grandparents and parents could see the grandchild struggling but not knowing why. Amanda described to me how she had taken a lot of pictures of Samuel when he was a baby but had deleted a lot of them now because of how upsetting she found it looking back over them and being reminded of that time. Research on parents' experiences of diagnosis have described some parents being unable to get validation of their concerns (Ahern, 2000) and experiences of navigating a maze of professionals and services in order to get a confirmed diagnosis (Missiuna *et al.*, 2006). Some grandparents were very involved in the appointments and visits when trying to get a diagnosis and they were experiencing similar worries and frustration as the parent in trying to navigate systems and get a diagnosis for the child.

The grandparents described above had very little time to question the presence of problems before receiving the diagnosis. However, for the remaining six grandparents whose grandchildren were diagnosed with ASD, the diagnosis came several years after birth, when the grandchildren started missing milestones and not developing as was expected. This led to different accounts of the experience of diagnosis, with the lead up to the diagnosis being described and the experience of this period having implications for the reaction to the diagnosis. The grandparents often described themselves as having a greater part in recognising the problem and how they had raised concerns about the grandchild or had suspicions of a problem before the parent expressed any concerns. Grandparents described picking up on the fact the grandchild was not doing what they would expect such as responding to their name, being slow to start walking, losing skills they had previously developed, or not interacting with other children as expected. The process of raising concerns and recognising a problem added further complexity to the experience of diagnosis within these families. Grandparents reflected that their concerns were raised because the amount of time they were spending with the grandchild allowed them to notice differences and delays. Four of the grandparents described a heightened awareness of child development through their own experience of parenting a child with a disability;

> *Judy:* *Yeah because I think sometimes parents don't want to see things. And as a grandparent in some ways you don't want to see things, but I think with us having experience of a disability we're aware of things.*
>
> *Kevin:* *We were doing things different, you know what I mean, they weren't… Sonia [mother] would be like on her days off going out, so she wasn't like sitting all day with him and I think that was the difference."*
>
> *(Judy and Kevin, Jesse's maternal grandparents)*

Though for some grandparents their awareness and experience may be seen as an advantage in being able to identify behaviours indicating a concern for the child's development as early as possible, many described this as being a very difficult position to be in. They wanted the grandchild to receive help and support as quickly as possible, but also did not want to face the prospect of telling their adult child that they thought there was a problem with the grandchild's development;

> *"Very difficult. Very difficult. This is their precious child, you know, how can I burst their bubble? So difficult. And when you see them together, they are lovely together the pair of them. She [mother] absolutely loves him. He [grandchild] loves her. How could I spoil that?"*
>
> *(Margaret, Oscar's maternal grandmother)*

Grandparents, like Oscar's grandmother, did not want to cause their adult child pain or upset by raising the sensitive topic of there being a problem with the grandchild's development, but also felt it was important for the parent to be aware of a potential problem in order to give the grandchild the best chance. This experience was made more challenging when grandparents tried to raise their concerns, but parents did not agree with them. In most cases the parent would also eventually notice the problems and agree with the grandparent, yet there were some circumstances where the grandparent described the parent as continuing to be in denial about the struggles and challenges the grandchild was facing. Margaret (Oscar's maternal grandmother) provided a lot of childcare for her grandson and had raised some concerns with her daughter about his development particularly that he had not started talking. Her daughter, however, was described as not having concerns, being very adamant that her son was fine, and that the delays in speech were due to other reasons that could be easily sorted;

> *"But I just thought nah, there's more. There's more to it. And I had suggested autism to her, and she said no, definitely not. And after his third birthday he started nursery, and we explained to them that he didn't speak. And he went for a few weeks and when I would take him in, I just thought, the playgroup leader, I just thought, you know. You know what I know. And err, my daughter's just in complete denial. I didn't say anything, but I just thought, you [playgroup leader] and I both know what's going on here."*
>
> *(Margaret, Oscar's maternal grandmother)*

Margaret recounted being in a very difficult position of seeing her grandson struggle and wanting to get him support as soon as possible, but her daughter was adamant nothing was wrong. Even when Margaret tried to raise her concerns with her son-in-law he was described as having the same attitude that his son did not have a disability and was just developing slowly and would eventually catch up. Oscar (grandson) eventually got the diagnosis Margaret had suspected following the nursery staff suggesting an assessment was needed, however she then described still facing difficulties with her daughter's acceptance of the diagnosis and getting what she thought was the best support for her grandson, particularly around schooling. Neither Margaret's daughter nor son-in-law were approached to be interviewed at Margaret's request, therefore they may have a different perspective of that period. Other grandmothers recounted similar experiences to Margaret. Grandparents were trying to manage the parents' feelings as well as also trying to get the right help and support for the grandchild. These difficulties and the build-up to the diagnosis meant these grandparents experienced the diagnosis very differently to those who received a more instant diagnosis.

Previous studies of grandparenthood in the context of disability often describe how the parents are usually managing the work of trying to get grandparents to understand and accept a diagnosis (Seligman, 1991; Sandler *et al.*, 1995; D'Astous *et al.*, 2013). This situation was described less often in the families in this research, with only one description from a parent of a grandparent denying there being a problem. Lauren (Brian's mother) described the problems she had in getting her son's paternal grandmother and her own husband to recognise and support her concerns about her son's development. Lauren described this as a particularly difficult and upsetting time as she was concerned about her son but was not getting the emotional support and back-up she wanted or needed from her family;

> *"And that's when it got, erm, tensions were high because I was like saying to Patrick [Brian's father] "Read this, read that. Brian does this, Brian does that. Look at the signs Patrick." And I could see Patrick starting to like realise and see. And then he would go with his mam and he would talk to his mam and he would come back and have a total different mind-set. And then one day I was like, "So are you now saying Brian isn't autistic?" And he was like "Well yeah." And that's when it just erupted, and I was like, "We need to sit down and have it out." I says, "Because I'm having enough." I says, "I know for a fact when you go and see your mam with the kids" I says, "You come back in a total different mind-set and you start saying different things. And she starts giving you these books about the over-sensitive child and things like that." And I was like, stop listening to her Patrick. I says, "You know your son, you've seen it from the word off. You've seen the videos, you've seen the signs. And I was like, how much do I have to convince you that your son is autistic? And I felt like screaming from the rooftop."*
>
> *(Lauren, Brian's mother)*

By not having anyone to talk to and back up her concerns, Lauren delayed seeking out help, as she was not sure who or where to turn to. The lack of support added to her stress and upset. Lauren's mother-in-law was one of the grandparents interviewed. She did not discuss the same issues that Lauren did around diagnosis, however she did note how Lauren was the main family member with concerns, suggesting it was Lauren's motherly bond that meant she recognised the problems more than other family members;

> *"She started noticing that at about 11-month-old he would stare at things you know. But he still hit all of his milestones and he still looked in your eyes and all of the classic things he never used to do. But then at about the age of two or three he started getting worse, frightened with balloons, not wanting to go down alley ways, walking*

> *backwards. And it was his mum really, I mean, bless her, Lauren, she hit on it. She was more worried than most of the rest of the family. Obviously, she was with him all the time. He was part of her. And she knew that something wasn't right."*
>
> *(Audrey, Brian's paternal grandmother)*

The contrast in descriptions of this time between Lauren's account and Audrey's account were quite stark. Audrey's quotation above and descriptions throughout her interview suggested that she simply did not recognise some of the problems until the diagnosis or was not concerned by the behaviours, while Lauren's account described a complete denial of a disability and almost purposeful dismissal of any potential disability. Lauren also found Audrey's reaction difficult because Audrey had a background in child health and had another grandson with a similar diagnosis. Audrey did not mention this other grandchild in her interview and Lauren described Audrey's denial of his diagnosis as well. Lauren described how the other grandchild's diagnosis was something that was not openly discussed in the family, which added to her worry about raising her concerns about her son. The one person who Lauren expected to understand and help, because of Audrey's background in child health, was not a source of support at that point in time, making the period of diagnosis more challenging for Lauren and adding to her stress.

Lauren and Audrey were an exception to the rule in this sample, and in general grandparents were very emotionally supportive of parents at the time of diagnosis. Grandmothers described attending appointments with the parent and grandchild or taking an interest in what happened in appointments they did not attend. This type of involvement has been described in other studies which show that many grandparents of a child with a disability are actively involved in the diagnostic process from the beginning (Anderson, 2010; Gallagher *et al.*, 2010). Rather than learning of the diagnosis second-hand, grandparents were learning of the diagnosis alongside the parents. In the next section I explore in more detail the grandparents' reaction to and processing of the diagnosis.

4.2.1 Emotional processing

All the grandparents described the period around receiving the diagnosis as an emotional time, some more than others. While parents received information from medical professionals and busied themselves with the immediate needs of their child, grandparents described themselves as working hard in the background, being there for their adult child while also masking their own emotions. Receiving the diagnosis raised a number of emotions (shock, upset, relief, frustration) for the grandparents and parents as they dealt with the information they were receiving and processed what this would mean for the family's future. A few of the grandparents described experiencing very little upset and they just instantly accepted the grandchild's diagnosis and the grandchild for who they were. They loved them no matter what; there was nothing to come to terms with. Though they may still wish that their grandchild did not have a disability, they were accepting of it;

> *"Yes, it was you know you just think, well, in an ideal world you'd love every child to be normal. But Jesse is Jesse. And he's our grandson and we love him to bits. And it doesn't really matter to us as long as he's happy, he's healthy and everything's right in Jesse's world. We're happy."*
>
> *(Judy, Jesse's maternal grandmother)*

This type of reaction seemed to be more common in the grandparent interviews where they saw the disability as being relatively mild with fewer complex needs and a potentially better prognosis for the grandchild. For example, the grandchild was managing well on medication, able to attend mainstream school or was able to participate in most activities without additional support. Grandparents would always wish that their grandchild did not have a disability at all and be curious what the grandchild would be like without it, but they reported accepting the circumstances.

However, most grandparents did describe to me some of the pain and deep upset they experienced at the time of diagnosis. As was described in the literature review, parents have been described as going through a bereavement or experience of grief when their child is diagnosed due to the loss of their 'dream child' (Riesz, 2004; Whittingham *et al.*, 2013). Grandparents here also described an experience of grief and bereavement;

> *"Worried and upset, really quite devastated. But it's something you can't really say to them [parents]. Because I think we all felt the same. It is a little bit like a bereavement because what you thought you were going to have, like a little boy growing up, isn't going to happen. And just the worry really, it was, it was awful. Erm, just the whole thing, I couldn't sleep, you know, you couldn't, coz you kept waking… It's probably the worst thing that's happened to anyone in the family. And it's not that, it's, we mean it for Jacob [grandchild], not for us. I'm not selfish, oh god my life's ruined type of thing, it's not."*
>
> *(Elsie, Jacob's paternal grandmother)*

As Elsie says, the upset was not necessarily for themselves. It was directed to their adult child and to their grandchild. They had lost the grandchild they expected but were also grieving for their adult child and the inevitable change to the adult child's life as well. Grandparents' grief has been described as three-fold as they grieve for themselves, their adult child and their grandchild (Woodbridge *et al.*, 2009; Moules *et al.*, 2012). Grandparents did not express to me a grief for themselves, often making it very clear the upset they were describing was not for them but for their child and grandchild. Within this grief process there was a time of re-adjustment while the shock of the diagnosis wore off and they began to process how family life may or may not change. However, the sadness did not go away, with many grandparents still showing a great deal of pain and upset during the interview, despite it having been several years for some since the diagnosis. Joan (Charlie and Ellie's maternal grandmother), in particular, described and showed her upset and how receiving the diagnosis had affected her. Joan had spoken about how wanted the grandchildren had been following the difficulties her daughter had experienced trying to conceive;

> *"For me initially, because Andrew [grandfather] wasn't here when they [grandchildren] were born, erm, I think most nights I came home from the hospital and cried. Erm. And I don't think it was for myself, I think I just thought, the children had been so wanted and for things to turn out the way they did, I just thought life was so unfair. Emm, to the point that I no longer believe in God. It's completely, it has completely smashed any faith that I did have. And I think I was, you know, quite, I did have quite a lot of faith, but I'm sorry, I just think when those children were so wanted what sort of a God would do this to those parents. I, I no longer have a faith."*
>
> *(Joan, Charlie and Ellie's maternal grandmother)*

Joan really struggled with what she saw as the unfairness and injustice of her grandchildren's disability. Other grandparents described a similar kind of frustration of 'why them?'. Why their family? Grandparents were in search of a reason or cause as to why this happened to them. Were they to blame? Could something have been done to result in a different outcome?

> *"And you just think why. You know, it's always, always in the back of your mind. Why Aiden? Why Melissa [mother]? Because [DISABILITY] is one of these where both the, erm, both the parents have to have the faulty gene and it's literally one of those one in a million things"*
>
> *(Annie, Aiden's maternal grandmother)*

As a way of dealing with the diagnosis some of the grandparents described a search for an answer to 'why them?', but often not being able to find a meaningful and satisfying answer. Five of the families were told about genetic causes of the disability. Most did not discuss the genetic link in detail in the interview, seeming to place no blame on specific family members or expressing feelings of guilt. One grandmother had wanted to explore the genetic link more and find its origin purely out of interest, especially given the family history of her daughter-in-law was unknown (due to adoption). However, her son had asked her not to, stating that it is what it is and finding out the genetic history would not change anything. One mother, Lauren (Brian's mother), spoke in quite a lot of depth about the gene that she had passed on to her son that was linked to his disability;

> *"Erm, but yeah, I just felt ashamed, I was angry. I was like, what have I done wrong? I breastfed me first son, I ate salads for 9 months. I stopped eating chocolate, I exercised. I did everything possibly right to try and have like the most perfect, healthy boy. What*

> *did I do wrong? And that's how I felt at the time and I felt like I had failed. And even now like, I think, ahh well I've given Brian the autism because he's got my dodgy gene, do you know what I mean? But then I can't think like that."*
>
> *(Lauren, Brian's mother)*

Lauren described feeling guilty that she had passed a gene on to her son, but then also reflected that she could not think like that as she had had the gene passed on to her and so on. In most cases there was no definitive reason or cause that could be given as to what had caused the disability. The thoughts about genetic links to the grandchild's disability were not explored deeply in the interviews, but many of the comments reflected findings of other research in terms of finding a biological responsibility for the grandchild's disability, its link to decisions about having more children, and expressions of 'bad luck' rather than culpability (McLaughlin and Clavering, 2011).

Grandparents described receiving the grandchild's diagnosis as upsetting, no matter how 'prepared' they were for hearing it. For example, despite Margaret's strong suspicions that her grandson Oscar had ASD, this did not dampen the shock when the official diagnosis was received;

> *"But even, doesn't matter how much you prepare for it, once you get the diagnosis it's like you're being told for the first time, you know. And one of the things the paediatrician said which I found quite shocking, she said erm, I asked a specific question, I said "Will he ever talk?" And she said, "Well he might say words, but he'll never have a conversation."*
>
> *(Margaret, Oscar's maternal grandmother)*

The realisation and details of the prognosis were upsetting for the families. However, the grandparents often described suppressing or masking their own emotions about the diagnosis in order to be a support system for their adult child. Even though they were also feeling similar emotions to their adult child, they tried to keep those emotions to themselves when in the company of their adult child;

> *"Yeah I think so. I think, because we've got to, em, I think at first, (..) it was horrendous when they rang and said you need to bring him back in [to hospital] because I'm thinking, oh my, you do, you think the worst don't you, you know. And, the trauma of being a new parent, and I couldn't imagine what they must have been going through. And, you have doctors coming, and I mean they were in and out all night, taking bloods and all of this. So, what I tried to do is, yes, I was very anxious for them and for the baby but try to sort of mask that in a sense of sort of calmness."*
>
> *(Amanda, Samuel's paternal grandmother)*

At the time of the diagnosis in particular, grandparents perceived themselves as needing to be parents to their adult children, which meant suppressing some of their own feelings to be completely there for their adult child. This has been described in other research with accounts of grandparents hiding their pain and anxiety in order to support their adult child (Margetts *et al.*, 2006; Miller *et al.*, 2012). This hiding and masking of their pain seems to be a notable source of emotional work for grandparents. They were working to try to protect their family from the potential upset they were feeling and help the family move forward while also trying to privately process their own emotions.

4.2.2 Bringing disability into family life

Part of how the family reacted to and adapted to having a child with a disability was the way disability was viewed within family life: was it part of their world or a separate world? In Alice's (Thomas's maternal grandmother) interview she referred to the "*world of disabilities*" and wanting her daughter and grandchild to avoid becoming a part of that world. One of Alice's motivations for the support she gave was to keep her daughter's life as 'normal' as possible and separate from disability. By the 'world of disability' she was referring to support groups, her daughter becoming a full-time caregiver, and constantly visiting hospitals. She did not want her grandchild's disability to define their family, especially when there were other grandchildren without a disability;

> *"We've got Thomas [grandchild] in the mix, three kids. But she's [mother] now in a different, she's moved away from that world of disabilities. She does everything she possibly can for Thomas, we all do. We really really do. Couldn't do any more. But she's moved away from this lot, this [Support Group]. Which is great, I'm not, honestly, I'm not criticising, I'm not knocking it at all. But these mums and what have you, some of them were, I don't know. She was drawn into a world of disabilities and I'm thinking, Anna, you know, I couldn't, you can't, that's not the norm. This is it what's going on here with all these other kids. And now she's got kids that, one at school, one a playgroup. And it's mayhem but it's the right sort of mayhem."*
>
> *(Alice, Thomas's maternal grandmother)*

For families where the grandchild with a disability was an only child it was possibly easier for the families to completely centre family life on that grandchild than when other siblings without disability were present. For example, while Alice had multiple grandchildren and was focussed on giving them 'ordinary' family time, Elsie (Jacob's paternal grandmother) only had one grandchild. In Elsie's family all the routines and family activities revolved around Jacob and his needs. They all got involved in support groups, they all adapted their homes, and all tried to incorporate aspects of his speech and language therapy into play, embedding disability into family life;

> *"And, when Jacob [grandchild] was younger, it's not so important now, but if they were going to do anything everybody would go. Erm, anything to do with, like Centre Parcs we've been a few times, and we all went. Brian and Joan [maternal grandparents] and*

> *Bruce [step-grandfather] and I, and Jacob with his mam and dad. We tended to do a lot of things, because if he was anxious, the more people that he was comfortable with, made life easy. Because somebody else could help him instead, because everything would be so hard, I think if you didn't have other support to help you."*
>
> *(Elsie, Jacob's paternal grandmother)*

In Jacob's family, everything was focussed on what made life easier for him and helped support his needs. This was also reflected in the interviews of other grandparents with only one grandchild. They were able to focus all their attention and resources on their grandchild with a disability and adapt family activities to suit the grandchild and their needs. The grandchild was the centre of family life. The families with more than one grandchild were able to embed disability into family life but it could not be the centre of family life. There were other competing needs of other grandchildren that also needed to be accommodated and attended to.

Part of how well families were able to adapt family life to accommodate needs arising from the grandchild's disability appeared to depend on their past experience of disability and how much disability had been a 'part of their world' beforehand. Grandparents described how their previous experience of disability had potentially helped them be more at ease with the diagnosis. Some of the grandparents had their own children or other family members who also had a disability. This meant that disability was not seen as something new or unknown or as a different world. Disability was already part of their world. These families had some familiarity with the process of working with health professionals and other services that seemed to help them accept and adjust quicker to the diagnosis. For example, Hazel (Tyler's maternal grandmother) had her own children with ASD and mental health problems, as well as now grandchildren with disabilities;

> *"Massively, massively. And I think it [having children with a disability] was preparation for that [having a grandchild with a disability]. And I think because my two daughters have grown up having siblings with [DISABILITY], they've been aware of some of the strategies and I think it took the fear out of having a child with a disability as well. Because they'd always been to support groups and when we've had Christmas parties for children with disabilities, they'd been there and seen the children with different disabilities. I was quite grateful for that really."*
>
> *(Hazel, Tyler's maternal grandmother)*

For Hazel, and other grandparents in the study, having some experience of disability meant it was not something that was feared as much or as unknown. Even when other more distant family members had a disability, it gave the grandparents some kind of reference point and some source of information when their grandchild was diagnosed. As the quotation at the beginning of section 4.2 suggested, for some families having a child with a disability and the experiences around this were new, and it put some families on a sharp learning curve.

Six of the grandparents spoke about having experience of childhood disability from their paid employment, whether that was working as a nurse or in schools or nurseries. This experience was not as personal as having a child or family member with a disability, but it meant they had some knowledge of what particular disabilities were like. Just having some knowledge, if not a lot, about disability appeared to help grandparents with their adjustment. In Woodbridge *et al's.* (2011) study they acknowledged that all the grandparents had experience of disability from their occupations, which they believed helped them cope with and support their families when it was their grandchild being diagnosed. Some knowledge and some experience of disability within their 'world' seemed to be beneficial for grandparents in processing the information they were receiving about their grandchild. Being in the workplace or having previously worked in related areas also meant grandparents had their own sources of information to turn to or had easier access to useful information.

However, this prior knowledge came with some disadvantages as well as advantages. For example, Mary (Kayla's maternal grandmother) had an adult daughter with a disability and had worked as a nurse and in social care, as well as being involved in advocacy work and charities. This meant Mary was well acquainted with the challenges of having a child with a disability and the difficulties of getting support;

> *"And I can't believe that 30 years down the line I'm fighting the same type of battles that I had 30 years ago. You know, you think there is so much known now about autism it would be a bit easier to get support put in place and that but it's not. I find that very upsetting."*
>
> *(Mary, Kayla's maternal grandmother)*

Disability had become a significant part of Mary's world and she spent much of her adult life working to support her own family and other families with children with a disability. Experiencing the same struggles now with the availability and suitability of support services as she had with her own children was a source of significant frustration for Mary. She was watching and helping her daughters fight the same battles she had fought for them. Diane (Harrison's mother), who worked with children with a disability and their families in a school, described having prior knowledge and experience as a "*double-edged sword*". This experience meant they knew a great deal, particularly about the challenges of raising a child with a disability and the generally poor levels of statutory support available. They were aware of the services they needed to try and be in touch with, the challenges in getting support, and how complicated the needs of the child could become. On the other hand, they were prepared for these challenges and also saw how well some children were able to thrive and enjoy life.

Another way of adjusting to disability in family life was to see some of the positives in this change in family life. Whether that was new opportunities available to the family (e.g., becoming part of a new community) or seeing some of the strengths of the grandchild. Parents' and grandparents' interviews gave details on the grandchild's disability and their needs; however, there were also lots of descriptions about the strengths and achievements of the grandchild and the grandparents taking great enjoyment and satisfaction from these;

> *"He's got a wicked sense of humour. Which pleases me when, even just having the imaginary friend that's naughty. It pleased me a lot that he had the mental capacity to invent an imaginary friend and now he's learning wit and sarcasm and playing tricks and things like this. It's pleasing to see that he's got that ability."*
>
> *(Paula, Jack's maternal grandmother)*

All the grandparents acknowledged more energy (both physically and mentally) was invested in having a grandchild with a disability, but this investment also reaped rewards, especially when the grandchild reached milestones and achievements. Enjoying the positives and making the most of events and occasions with their grandchild provided a great source of resilience against some of the harder aspects of having a grandchild with a disability.

Where, in the initial time after diagnosis, the parents and grandparents were concerned about what the grandchild's abilities would be, with time they were able to see them develop different skills and make, sometimes unexpected, achievements. Seeing their grandchild coping with their disability and taking part in activities helped with the acceptance of the disability and showed that the impairments were not holding the grandchild back;

> *"He doesn't let his disability get in the way of anything. He does frame football. They're all in their walking frames playing football and that's with the [FOUNDATION]."*
>
> *(Annie, Aiden's maternal grandmother)*

Seeing their grandchild still taking part in the types of activities they were expecting before diagnosis and seeing the new opportunities available to the grandchild and family through the experience of disability helped with accepting the diagnosis. Within the stories, I also noticed that many grandparents used language to describe some aspects of the grandchild's disability as simply 'being different' or as traits of the grandchild's personality rather than as a need or symptom;

> *"I'm just getting to know the little traits he has. It's like at the minute he likes to be first in the queue at the traffic lights. Like you come to traffic lights you'd be annoyed if you*

> *just missed it and you get caught on the red, so you stop. Jesse [grandchild] thinks that brilliant because we're first in the queue."*
>
> *(Kevin, Jesse's maternal grandfather)*

Throughout Kevin's interview he repeatedly stated he had no problem or difficulty with his grandson's diagnosis. Kevin saw Jesse's need for routines and behaviours as just part of Jesse's personality and was fascinated by them rather than being frustrated or concerned about them. For some of the families there were aspects of the grandchild's disability that were difficult and hard work, but being able to take a different perspective on some other aspects of their behaviour and see them more as differences rather than disabilities seemed to be a source of resilience for families in coping and adjusting to disability in family life.

Another factor the families used in coping with the diagnosis was recognising what could have been and comparing their situation to other families who they saw as being in a more challenging position than themselves;

> *"He's lovely, he's a beautiful little boy. He's lovely, he's cuddly, he's affectionate. He's not violent, he's not aggressive, the way you hear so many autistic children are. He's not like that. He's lovely."*
>
> *(Margaret, Oscar's maternal grandmother)*

Grandparents described their grandchild as 'getting off lightly' or being 'not that bad' in comparison to other children with the same disability. Positioning themselves on the lower end of a continuum of severity allowed some grandparents to take a more positive perspective on their situation, as has been seen for parents (Wang *et al.*, 2004; Davis and Gavidia-Payne, 2009). This was not something all the grandparents were able to do, with some of them positioning the grandchild at the other end of the continuum and expressing a desire of what could have been if the grandchild was less affected by their disability. However, even for these grandparents there was a recognition that it was not helpful to think that way and instead they needed to accept what was and make the most of the positives;

> *"I think sometimes you just think life isn't always what you want it to be but you've just got to make the most of it, you know, put things in perspective and that, and I think just stay positive and cope with it. And you know, celebrate all the good things and a different way of looking at things really."*
>
> *(Hazel, Tyler's maternal grandmother)*

Taking a change in perspective on the disability and the impact it may have on family life appeared to be important for the families' coping and acceptance and how they embedded disability into family life. Experiences reported in other research have shown how grandparents move from initial feelings of sadness and worry to more positive feelings of acceptance and involvement (Schilmoeller and Baranowski, 1998). There was not a simple process of moving from grief to acceptance. Families took the positives when they could and dealt with the challenges and lows as they came. These positive experiences are potentially an important buffer and coping strategy for grandparents during stressful periods, as they are for parents (Folkman and Moskowitz, 2000; Folkman, 2008). No matter what the experience and reaction to diagnosis had been for grandparents interviewed, all gave accounts of how the family adapted over time following diagnosis and had embedded disability into family life in a way that suited their wider family.

4.2.3 Becoming an 'expert' grandparent

Following the diagnosis one reaction of many of the grandparents was to become an expert in their grandchild's disability and become an expert caregiver to their grandchild. On learning their grandchild's diagnosis many of the grandparents made a concerted effort to gain as much knowledge as they could about the disability;

> *"Yeah, I like to know as much as I can about things, so yes, I read as much as I can about it and research, emm, stuff like that. So yeah, I've tried to keep up with the situation really."*
>
> *(Paula, Jack's maternal grandmother)*

As described earlier, some grandparents had not experienced disability prior to their experience with their grandchild, so they made an effort to do their own research to understand what is known about the disability and keep up to date with progress and knowledge around the disability. Nearly all grandparents were able to describe in great detail the disability the grandchild had, how it affected the grandchild and treatment options.

Part of becoming an 'expert' grandparent also involved having to learn very specific skills in relation to their grandchild's disability in order to be able to take care of them. This included going on first aid courses, getting specialist training in how to use medical equipment (e.g., suction machines, oxygen tanks), and learning how to draw dosages of and administer medication;

> *"He has his suction equipment so when secretions pool, you've got to get that in and get it out. So yeah, but that's only here and at our house. They're the only places where you have to learn. And you have to be taught how to use the oxygen on him because you could have the oxygen turned up too high and that would hurt. And all of that. It's just all the things you have to learn. The dosage for his medication. Exactly when his medication is due, and things like that."*
>
> *(Annie, Aiden's maternal grandmother)*

Grandparents gained these skills so that they could be fully involved in the care of their grandchild and described attending support groups with their adult children in order to learn techniques to manage the child's behaviours and needs;

> *"And me and my daughter went to the Early Bird sessions before Christmas. Erm, so we've learnt how to like communicate with him, get the best out of him. And that's where my husband is now. He's going now with Oscar's dad, but Oscar's dad's not getting the time off work, so he's gone this morning but that's what they're doing. But when I was coming back from the Early Bird and I was saying to me husband this is the way we've got to interact with him [grandchild], how we communicate with him."*
>
> *(Margaret, Oscar's maternal grandmother)*

Gaining knowledge was not just about being able to help with the medial care needs of the grandchild, it was also to be able to communicate and interact with their grandchild to be able to build a relationship with their grandchild. Grandparents needed to learn certain skills to be able to provide practical support, but they did not want to just be 'expert carers', they wanted to be grandparents who had a loving relationship with their grandchild. Understanding the grandchild's disability and learning how to interact with them helped build that relationship as well. Seven of the grandchildren were described as being non-verbal or having limited use of spoken language, therefore learning how to use the communication tools the grandchild used (e.g., Makaton sign system, Talking Mats) was important in being able to communicate and interact more personally with their grandchild. This was not an easy task for grandparents. Although some had been on courses, grandparents did not always feel confident using the augmentative and alternative communication systems. Whitney and David described how Malachi's grandparents had heavily relied on their other granddaughter for interpretation of the grandchild's communication;

> ***Father:*** *It frustrates them simply because they want to communicate with him more, they want to understand him. They want to meet his needs.*
>
> ***Mother:*** *Erm but they have been scared about that, when, I know when he [grandchild] first started coming over by himself, they asked if Chloe [sister] could come as well. Because they were scared that if he needed something that they wouldn't understand. So, before that, before Chloe was in the position to actually help them, before that they just had you know, the fear without any support as well unless we were there. So erm, and obviously as he's getting better with communication, they're getting older so it's probably just, just passing the prime time of actually you know developing that sort of level. But that's the biggest issue with everybody though, even, it's his communication.*
>
> ***Father:*** *Probably subconsciously, well I don't know, but I would imagine if I was in their shoes [..], that difficulty with communication would subconsciously put me off spending more time with the child.*

(Whitney and David, Malachi's parents)

Grandparents did not have all the exposure parents had in learning the communication needs of the grandchild, thus their confidence in their ability to understand their grandchild's communication, and therefore potential needs, could hold them back from spending time alone with their grandchild and in turn could be a challenge in building a relationship with their grandchild.

This desire to seek out information about the grandchild's disability has been found in other research on grandparenting in the context of disability (Hillman, 2007; Hillman *et al.*, 2017; Prendeville and Kinsella, 2019). Grandparents may not have the same resources or access to health professionals or education service staff as parents do to obtain first-hand information about the grandchild's disability (Hastings, 1997; Schilmoeller and Baranowski, 1998); therefore they seek it out themselves. By gaining more knowledge about the disability it gave the grandparents more confidence in providing support to the grandchild and in supporting their adult child. Learning more about the grandchild's disability helped the grandparents to understand it, build a relationship with their grandchild, and embed disability into family life.

4.3 Finding a New Family Norm

"I just thought we, grandparenting would be helping, I don't know…" (Patricia, Dylan's maternal grandmother)

Following diagnosis, parents and grandparents needed to adapt to their new situation as a family caregiver to a child with a disability. The families were learning about their child's disability, getting to know health professionals, finding available support and finding a new family routine that supported the child's care needs. Alongside this, grandparents were figuring out what their role was within the family. This often meant discarding previous expectations of grandparenthood and family life, adjusting to a new form of family life, and re-examining their values and priorities. In this section I detail how the grandparents and parents described forming a new family norm. This included *re-adjusting expectations, family adaptations,* and then *pride in family* for how well they had adjusted.

4.3.1 Re-adjusting grandparent expectations

Nearly all the grandparents expected to become grandparents at some point in their later life and in general described looking forward to this role. Grandparents' accounts described how they expected to be involved and have a big role in their grandchild's life. Once the grandchild was born or once the diagnosis was received, grandparents indicated there was a shift in their expectations of grandparenthood as they began to realise and understand the grandchild's disability and what needs they would have;

> *"So yes, from that point of, you just sort of change your… what am I thinking, I said something like you have to change your dreams really for the child. You know, when they're [mother] pregnant you think oh just as long as everything's alright and everything. Then when it's not what you anticipated you've just got to change how you go about things."*
>
> *(Paula, Jack's maternal grandmother)*

Grandparents described a difference in how their role was playing out and would continue to play out differently than they had expected. When I asked Joan (Charlie and Ellie's maternal grandmother) the opening question about her experience of grandparenthood her first statement was;

> *"Emm, well basically (..) It's not what we expected. Emm, we, in some ways we feel helpless because Charlie [grandchild] has a tracheostomy and because of that we, we've never had, we've never been able to have the children stay with us as normal grandparents would do because of the complexities of the problems."*
>
> *(Joan, Charlie and Ellie's maternal grandmother)*

For Joan, her account described a huge difference in her expectations of grandparenthood and the reality of her experience, often making comparisons between her experience and what 'normal grandparents' experience. One aspect of adjusting to a new form of family life was acknowledging and adjusting to some of the perceived restrictions to roles and activities when having a grandchild with a disability. The grandparents described barriers or restrictions to the types of activities they could do with their grandchild. They could not always have their grandchild over for the night because of equipment needs, or they could not take their grandchild to soft play [an indoor type of play area common in the UK] or the park because of the sensory and safety needs of the grandchild;

> *"And also, because he doesn't respond to his name, if you take him swimming and he climbs out the pool, he'll just run off and he'll be excited and flapping and loving it, but he won't come back. So, you know, it can be quite difficult, places to go, things to do."*
>
> *(Hazel, Tyler's maternal grandmother)*

Visiting places took much more thought and consideration as to whether it would be suitable and safe for the grandchild. Even times like Christmas were described as restricted, with families only being able to host events at certain homes to allow for the grandchild's equipment needs, some families not decorating their house for Christmas because of sensory needs of the grandchild, and some grandparents describing difficulties in tasks like buying presents for their grandchild;

> *"I mean even at like Christmas and birthdays we usually end up just buying them clothes because they've got so many toys because people have very kindly bought them toys and things but obviously, most of the toys they can't physically play with and it's kind of*

> *difficult to get any sort of interaction with them because they, you know, with them being…"*
>
> *(Joan, Charlie and Ellie's maternal grandmother)*

More thought was having to be put into what may have previously been expected to be simple tasks or parts of what they saw as being a grandparent. When describing what they did with their grandchild, outside of providing childcare, there was a theme of restriction in the grandparents' interviews in terms of the kinds of interaction they could have with their grandchild. As discussed in section 4.2.3, about communication being important for relationship building, doing these types of activities were also important for building a relationship with grandchildren. Therefore, not being able to do them as easily (or at all) meant grandparents had to seek other activities and ways of building a relationship with their grandchildren, which for most was through providing care and support. Grandparents did not discuss how they thought their access to activities with their grandchild could be improved. They described these restrictions as part of their family life, rather than discussing how environments could improve access for them (e.g., appropriate changing facilities for older children with a disability). Grandparents were adjusting their expectations downwards rather than thinking how more could be done to help their expectations be met.

Alongside some of the restrictions and differences in what activities their grandparent role involved, some grandparents described how their role differed from their expectations due to the intensity of the role;

> *"This isn't what we had planned. I mean we said we'd look after him [Oscar] while she [Oscar's mother] went to work four days a week but we didn't realise what we were getting into really."*
>
> *(Margaret, Oscar's maternal grandmother)*

In Margaret's account, her expectations of grandparenthood and offering to provide childcare while her two daughters worked did not meet the reality of the day-to-day care work she was providing in taking care of her grandchildren, one of whom had a disability. The task was much more demanding and more intense than she had ever expected. This was partly because of the needs of the grandchild, but also because of the time spent providing support because of other options of childcare not being available to the parents. Parents also acknowledged that the role of grandparents was more intense than they would have expected it to be;

> *"Yeah, I always thought they [grandparents] would be involved, definitely, I knew they would be involved, and I thought they [grandchild] would maybe have the nights with the grandmas and go out to play with them and things like that. But nothing to probably the extent of what we've got now."*

> *(Grace, Jacob's mother)*

As Grace describes above, many of the parents had expected some support from grandparents but had not expected the extent of support they received on an almost daily basis, both in terms of emotional support and practical support.

Although grandparenthood did not always match what they had expected it to be, some of the grandparents also recognised that they knew no different. Five grandparents had no other grandchildren so they did not know if some aspects of their experience of grandparenthood would be different with a grandchild without a disability. For those who did have other grandchildren without a disability, many commented how having other grandchildren sometimes highlighted the developmental delays or differences with their grandchild with a disability;

> *"Yeah. And he's erm, I mean me granddaughter, as we say they're [grandchildren] quite close to each other, they're 4 months difference and the height difference between the two of them just from that point of view. Erm, and she's like, she's a bright little kid. I'm not saying that because she's my granddaughter, but she is bright. She can hold a conversation. She's like having a conversation with an 80 or 90-year-old. She's quite tuned in and all that. Whereas he can barely, his speech is improving all the time and, but he can stand here, and he can talk to you for two or three minutes and you'd only be able to… we do Makaton [sign language system] and all that to help. But he, he's telling you a story, but you can't always understand."*
>
> *(Henry, Malachi's paternal grandfather)*

For Henry, his relationship with his granddaughter without a disability was very different to his relationship with his grandson with a disability. There were differences in the ways grandparents could communicate with their grandchild with a disability, how the grandchild communicated with them, and the activities they could do together. In particular seeing their other grandchildren growing up highlighted the differences in development;

> *"It's got harder though, because as Thomas's [grandchild] got older, he's got more and more disabled and you start, that awful realisation comes, when you think, you know, this child, whatever we do he's, he doesn't really, he doesn't fit in. And it's obvious, it's getting more and more obvious as they get older."*
>
> *(Alice, Thomas's maternal grandmother)*

There was a realisation that no matter how hard the family tried, the grandchild's needs could not be easily accommodated in family life without significant adjustments and adaptations being made. Expectations of grandparenthood and of the grandchild continued to be reframed and re-examined over time and compared to other grandchildren as the grandchild developed.

In the context of grandchild disability, grandparents had to cast away some of their previous expectations of 'ideal grandparenthood' and revise their plans and expectations of grandparenthood (Katz and Kessel, 2002; Woodbridge *et al.*, 2011). Not only were some of the types of activities different, but the intensity of the role was also different. Childcare and medical treatments were a dominant aspect of their role, and parents had a great need for this intense support.

4.3.2 Family adaptations

No matter what the reactions and level of acceptance were following the diagnosis, family-life needed to continue. Families would begin to find new routines and organise their schedule and their support around the grandchild's needs (Crowe and Florez, 2006; Brandon, 2007). Families described making adjustments in their lives and making adaptations to family life and their homes to accommodate and support the grandchild's needs. For some families this involved making physical adjustments, such as having medical equipment in the home or having supports added to their home (e.g., hoists, ramps). For others it was adjustments in approaches to daily activities that were described;

> *"You've got to learn to manage. You manage what you're going to do. You plan for what you're going to do. And you plan in advance. Doesn't stop you worrying about what's going to happen but… you plan."*
>
> *(Judy, Jesse's maternal grandmother)*

Both the parents and the grandparents described learning different processes and actions that helped in managing the child's behaviours and needs. Like Judy (Jesse's maternal grandmother) above, the parents and grandparents talked about planning ahead constantly and keeping in mind how their grandchild would be interpreting tasks and seeing situations. Families also described having to learn to go with the flow, and sometimes activities that were planned would have to be abandoned depending on how the grandchild was feeling;

> *"Because you do things what you have to do for Jacob [grandchild] at the time, you know. Sometimes you can do things and he's great, other times you think, better not do that. Or you make plans to go somewhere then you ring and say you're not going to come because you know you're on to a hiding to nothing really if you do it. Sometimes there's just things you can't do depending on how he is."*
>
> *(Elsie, Jacob's paternal grandmother)*

Grandparents and parents learned to recognise what the grandchild was and was not able to cope with or how their mood would affect how they reacted in different situations. Part of the family adaptation process was learning to be flexible and learning to take each day at a time.

Processes that made tasks easier for the grandchild became habit and some of the grandchild's needs or behaviours became the norm to the family;

> *"Yeah, I think as a family, all of us, all of these kids, they're all aware that Thomas [grandchild] is different, in loads of ways he's so different. But he's just Thomas and you know when you're out and about with Thomas, he's in his, you've got to have him in his wheelchair when he's out and about and he doesn't speak but he makes this noise which is like an "uhhh uhhh" constantly. And when you're out, in the supermarket people stop and stare. There'll be me with Thomas maybe and a couple of the others and oh this is Thomas. All of a sudden you have to stop and think, yeah but for everybody else this isn't the norm. In the early days I think my attitude was "What you staring at? What you staring at!?" you know… Now it's like, "Oh hi, yeah this is Thomas, this is happy noise", because people don't understand. Why should they? If you've never had a kid like that why would you?*
>
> *(Alice, Thomas's maternal grandmother)*

Behaviours or traits that were once seen as different and obvious had become the norm within the family. Parents and grandparents talked about no longer being fazed by events such as seizures or severe tantrums. This was just how family life was for them now and it had become a standard part of the family routine. Similarly, the support that the grandparents provided for the grandchild and their adult child became a part of their lives. Despite the masses of support grandparents provided and some of the challenges this support came with, as is described in the following two chapters, some grandparents described their support as something that was not exceptional or a hardship. Instead they had made it a part of their daily routine;

> *"It's become a part of our lives. You know it, it isn't a hardship, you know, because we just pitch in, anything they want we just pitch in and do it and sort of get on with it really. The same way that they have to."*
>
> *(Joan, Charlie and Ellie's grandmother)*

In the same way that parents had no choice but to make adjustments to care for their child with a disability and make it a part of their family life, grandparents also embedded the care work into their routines. Throughout their accounts, grandparents described adjustments they had made to their lives, including to work (described in more detail in section 5.5.1). Some had made what I interpreted as huge changes, such as deciding to move to a new country to be closer to the family. The grandparents however appeared to not see these as extensive changes and adjustments they had made. Instead they described it as being what they needed to do as a grandparent and parent and doing what a good grandparent would do. The changes were conveyed as part of becoming a grandparent that they did not mind, rather than major changes they had made to their lives. However, throughout the stories there were comments about some self-sacrifice grandparents had made, such as hobbies they did not participate in, or friends they did not see as often anymore. One grandmother, who had several grandchildren with a disability, commented on how isolated she had felt at one stage;

> *"Yeah. But the social side of it. The one time, a few years back, I felt very isolated from anybody. And I realised that you know, that I wasn't doing anything for myself."*
>
> *(Mary, Kayla's maternal grandmother)*

The time Mary was giving to support her adult children and grandchildren meant the time she was spending on herself or seeing her friends had significantly reduced. It may have been that even if the grandchildren had not had disabilities grandparents would have stepped back from their own interest and social lives to be involved in grandchild care. However, grandchild disability and the intensity of the support some grandparents provided meant a decision was made to put their family role first and sacrifice their own time, interests and social connections.

Adaptation is a constant process, and many of the families discussed changes in circumstances such as starting school or receiving additional diagnoses that meant routines needed to be constantly re-examined and adjusted. Whichever changes the families had made, they had made adaptations that suited their family life and accommodations for the grandchild's needs that were conducive to healthy development.

4.3.3 Pride in family

All the grandparents expressed their pride in and praise of the parents at how they were coping and adjusting. Within the literature on childhood disability and family adaptation, it is often stated how well families cope with and adapt to circumstances, even in the face of considerable stress levels (Van Riper *et al.*, 1992; King *et al.*, 2006). Many of the grandparents commented on how strong they thought their grandchild's parents were in dealing with some of the challenges of having a child with a disability;

> *"Unless you're actually doing it you just can't imagine how difficult and how much effort is needed to do what they do. It's frightening. How they manage to get through week to week just amazes me."*
>
> *(Joan, Charlie and Ellie's maternal grandmother)*

Grandparents praised the strength they saw in their adult children, often saying their adult child showed great resilience and coped better than they had themselves at some points in time when different events had occurred. In particular, single mothers or mothers where their partner had not coped as well at the time of diagnosis were praised for the strength they showed, sometimes carrying the load of two parents.

Grandparents also praised their adult children in how they had encouraged the best out of the grandchild and gave the grandchild the best opportunities to thrive, fighting for the best they could get for the child;

> *"She's excellent. I would say that, but she is really. And brings out the best in Jack. Well they [parents] both do, fight for the best for him."*
>
> *(Paula, Jack's maternal grandmother)*

All the parents 'fought' to have the best for their child, whether that be encouraging them to try new experiences or getting the right education placements for their child. Grandparents were proud of the efforts parents put into advocating for the grandchild. While grandparents were proud of the strength the parent had shown, many of the parents recognised the grandparents' roles in their coping and ability to support their child with a disability. As is described in the following chapter, the support grandparents provided (both practical and emotional) gave parents both physical and mental space to provide the best care they could for their child.

These feelings of pride were also reflected in grandparents' descriptions of the grandchild. Grandparents praised the strength and progress of the grandchild, how well they coped with appointments and treatments, and celebrated the achievements of the grandchild;

> *"He's achieved a lot of things, very much so. And I'm proud of him because he puts up with all sorts of awful things and he has no choice in anything… He has absolutely no choice in anything that happens to him. So yeah, full of admiration for Thomas."*
>
> *(Alice, Thomas's maternal grandmother)*

Grandparents were very proud of the milestones the grandchild had reached and, in some cases, how they had achieved more than was expected of them when they were diagnosed;

> *"And he has come on so much that he's, I mean at the time when they got the diagnosis he wasn't talking. He's talking and can talk the hind legs off a donkey. And he's doing so much. And he's, he's reaching far more and doing far more than we thought he would from things he'd done in the past."*
>
> *(Judy, Jesse's maternal grandmother)*

Grandparents of children without disability will express joy in watching their grandchildren reach milestones (Mansson, 2016), however this joy and pride was heightened in the families in this study. Both grandparents and parents described how moments others may take for granted, they see as immense highs and try to appreciate every achievement and progress the child makes. These feelings of pride in the family and celebrating the successes have been reported in current literature on grandparent experience of grandchild disability (Woodbridge *et al.*, 2009; Hillman *et al.*, 2017). As was seen in the accounts here, many studies report both the positive experiences of raising a child with a disability alongside negative experiences

(Hastings and Taunt, 2002; Trute *et al.*, 2007; Luijkx *et al.*, 2019). These positive experiences and focussing on the pride they had in their adult children and grandchildren helped grandparents to develop some resilience against some of the challenges of supporting a grandchild with a disability and helped the families embed disability into family life.

4.4 Meaning of Grandparenthood

"But I do love being a grandparent. You know they talk about biological clocks ticking but I found my granny one was ticking a lot harder than any of my children's biological clocks were ticking." (Paula, Jack's maternal grandmother)

There were several different accounts of what being a grandparent meant to the grandparents and how the context of disability had affected their view of grandparenthood. All the grandparents described the meaning of grandparenthood as 'being there' for their family, in particular their adult child. In one sense, being a grandparent was a continuation of their parent role to their adult child;

> *"Well I think as a parent, even though your family's grown up, you're always attached to them. You're always trying to work towards them having a better life than you or be able to get through life without having the hard struggle. So, and it continues with the grandchildren."*
>
> *(Pearl, Harrison's maternal grandmother)*

Many of the grandparents made comparisons between their experience of grandparenthood and parenthood, often making the comparison Mary gives below;

> *"In a sense its parenting without the responsibilities but I can't even say that coz I do have the responsibilities"*
>
> *(Mary, Kayla's maternal grandmother)*

As Mary says, while grandparents may have initially expected to have less responsibility, in the context of disability they described having a feeling of greater responsibility, to the grandchild and to their adult child. Grandparents did not just take the grandchild for a couple of hours on an outing or a visit and then hand the child back to the parents. Instead they were involved in intense (both emotionally and physically demanding) and sometimes long hours of care as a key support person. The grandparents expressed a great sense of duty to step in and support their family. These included roles of great responsibility such as attending school panel meetings and fighting for appropriate support for the grandchild. Being a key support person to their adult child and grandchild became a part of what it meant to be a grandparent to them.

Though some of the grandparents described grandparenthood as linked to supporting their family and being there for them, others felt more uncertainty about what it meant to be a grandparent in this context. This uncertainty came from how they thought the grandchild perceived them. Some of the grandmothers in particular described the grandchild as not seeing them as a grandmother but as an extension of the mother;

> *"But erm, he, I think, you don't know, but I think he sees me as an extension of his mother. I don't think he understands I'm a grandmother. I'm a caregiver in the same way that his mother is. And he'll be sitting, if he has his iPad, I'll be sitting, and he'll come, and he'll just move whatever, and he'll put himself on me knee, back against, watching the TV or whatever. Or he'll be playing, and he runs over, and he'll do that to me [touch cheek] and he'll run away again… but the face squeeze thing, I said "Does he do that a lot?" And Jennifer [sister] said, "Yeah but mostly only with mammy or you." So, he, there are things that he does, that he only does with his mam or with me."*
>
> *(Clara, Miles's maternal grandmother)*

Grandmothers noticed similarities in how the grandchild interacted with them and the mother, giving them the impression that the grandchild did not see them differently from their mother. This may be because their role involved similar care tasks such as changing, feeding, bathing, and providing therapy/medication. Even though other family members and professionals still view them as a grandparent, they perceived the grandchild as seeing them as a mother figure. Some of the grandparents were not sure the term 'grandparent' had any meaning to their grandchild. Whether grandma or grandad meant the same to the grandchild with a disability compared to a grandchild without a disability was uncertain, a thought that was upsetting for some of the grandmothers;

> *"So, from a grandparent's perspective. It's sad in way because in your mind you always think. Well Thomas knows he's alright here, he's safe and its lovely and all these. But he doesn't know, Thomas doesn't really know, he doesn't know. As long as he's got a hand to hold and somebody's feeding him, because he can't feed himself. He's 100% dependent… So as long as he gets those things. Thomas doesn't know I'm his grandparent. You know, I wish he did but he doesn't."*
>
> *(Alice, Thomas's maternal grandmother)*

There was a sense that part of a desired grandparent-grandchild bond was lost with the lack of recognition from the grandchild. Were they still a grandparent if the grandchild did not see them as one? Woodbridge *et al.* (2011) reported a similar experience in their research with grandparents, such that the grandchild's disability sometimes meant grandparents did not have the in-depth relationship they expected or hoped to have with their grandchild. This was then suggested to impact their identity as a grandparent.

However, the families also spoke of how much joy they felt when they perceived that they were really connecting with the grandchild, and the enjoyment they got out of seeing their grandchild enjoy their company;

> *"Yeah, I mean like even just putting Tyler in the bath, he absolutely loves the bath. And when he's in the bath and he just looks at you and smiles, you just think, that is so nice because you don't really get that. And my daughter was looking after him on Sunday morning when I went out to church and when I came back, and when I walked back in, he looked at me and smiled. And you wouldn't normally even notice that but because he doesn't normally give you that eye contact, so he knows who we are and things like that." (Hazel, Tyler's maternal grandmother)*

There were aspects of the role that grandparents found challenging, but moments such as those described by Hazel were treasured by the grandparents. The parents spoke of the reciprocation in the grandparent-grandchild relationship and the enjoyment the grandchildren got from spending time with their grandparents;

> *"I think it's [relationship with grandparents] really good. They [grandchildren] look forward to seeing them. Erm, they probably don't see my dad that much, as much as they see their other grandad... Erm, Ellie loves both of her grandmothers. She's non-verbal, she's got no words at all, but she squeals with delight when she sees them. Erm, Charlie calls them, what does he call them, 'galla' because he can't say grandma... But he has a good relationship with Peter's dad because Peter's dad will be quite silly with him. He'll sort of put stuff on the floor and play on the floor with him. Is quite daft with him and that's what they need, they need that kind of silliness."*
>
> *(Cathy, Charlie and Ellie's mother)*

Despite the fact that grandparenthood may not be what they expected, and it was sometimes challenging, there was abundant love evident in the accounts of both the parents and grandparents. As would be seen in grandparents of children without disability, having a connection and an enjoyable relationship with the grandchild is important for the grandparents' satisfaction in their role and their role identity as a grandparent (Thiele and Whelan, 2008). Despite some of the struggles grandparents had in doing expected activities or communicating with their grandchildren, they were building connections with their grandchildren in any way they could. However, this was not always easy, and the challenges did leave some grandparents questioning their identity and meaning of grandparenthood.

4.5 Conclusions

Many of the grandparents' and parents' accounts started with descriptions of the diagnosis and the experiences surrounding the recognition of the grandchild's difficulties and the diagnosis. Receiving a diagnosis was the point where the expectations of grandparenthood changed and the process of building a new vision for the future began. The introduction of disability into family life was an unexpected change in the families' lives. As Findler (2016) described it, becoming a grandparent of a child with a disability was a journey. The time of diagnosis was described in terms of a tragedy or trauma, as grandparents recalled feelings of bereavement as they let go of idealised expectations of grandparenthood. However, alongside this, grandparents constantly re-examined and readjusted their expectations of grandparenthood. Activities and adaptations to support the grandchild had become a part of family life and the families took a flexible approach, constantly adapting to the needs of the grandchild when necessary along their journey of being the family of a child with a disability.

However, adapting to a new family norm was not always easy. Families described moving on from the initial feelings of shock and upset following the diagnosis, but they also described some aspects they still found difficult. It was not the diagnosis, which is a label, that they continued to find difficult but the consequences of the diagnosis, such as time spent at hospital, fitting in appointments, some of the care needs of the child or some of the child's more challenging behaviours. Nevertheless, there were many descriptions of positive aspects of raising a grandchild with a disability that seemed to help build the grandparents' resilience against some of the harder aspects. The grandparents described taking a strengths-based approach to helping their adult child, making the most of the grandchild's achievements and their abilities. More and more literature in the field of childhood disability has taken a focus on looking at positive experiences and the co-existence of both positive and negative emotions (Hastings and Taunt, 2002; Trute *et al.*, 2007; Luijkx *et al.*, 2019), which were also reflected in these interviews. This strengths-based approach and acknowledging the positive experiences was important for grandparents' coping and adjustment to being a grandparent of a disabled grandchild.

It was interesting to see some of the differences in descriptions of reaction to and adaptation to the introduction of disability into family life. To some degree, the nature and extent of the disability (e.g., complexity of care needs and dependency for care) appeared to result in differing reactions to diagnosis and ability to adapt. The different types and severity of disability placed different restrictions on the grandparent roles and extent to which their expectations of grandparenthood had to change. For example, Joan (Charlie and Ellie's maternal grandmother) was a grandparent to grandchildren who had very complex needs and needed 24-hour care, whereas Amanda (Samuel's paternal grandmother) had a grandchild whose disability was being managed successfully with medication. Amanda had been able to maintain most of her expectations of grandparenthood in terms of her involvement with her grandson and the activities they could do together, whereas Joan had to completely re-adjust her expectations and find new ways to interact with and be a part of her grandchildren's lives.

All the families, irrespective of the grandchild's disability, had found a new family norm that was currently working for them. Grandparents were a part of this process through adapting their own lives to be a key support person for their adult child. Grandparents all described having embedded disability into their own life as well as family life. There has been very little research that has looked at grandparents' adjustment to having a grandchild with a disability. Many of the grandparents described masking their own feelings of sorrow and upset in order to be a source of support for their adult child. The findings of this chapter point to the importance of focussing on the needs of grandparents as well when a child is diagnosed with a disability, especially given the double grief they may be experiencing and the help and advice they may need in being a key source of support to their adult chid.

It is recognised that when adults become grandparents they may need to acquire new skills, take on new roles, and modify previous roles (Taubman-Ben-Ari, 2012; Noy and Taubman–Ben-Ari, 2016). The grandparent's sense of self may require some re-structuring in order to add this new role of grandparent to their self-description (Moore and Rosenthal, 2016). However, for these grandparents it was a more complex label they were adding to their self-description, and it required more cognitive restructuring, as well as making practical changes, as they tried to add a role that they had not expected to add: being a grandparent to a grandchild with a disability. The adjustment of each family was interwoven with experiences of their past and current family relationships. In the next chapters these complexities are discussed, as well as the continued process of adaptation and negotiation.

Chapter 5. Maintaining Intergenerational Harmony: Solidarity, Conflict and Negotiation

5.1 Introduction

Chapter 4 described how the birth of a grandchild with a disability or later diagnosis can evoke a range of emotional adjustments and a change in the way roles are perceived. The experience of having a child with a disability within a family can also evoke a change in family relations. In this chapter I present the types of support provided by grandparents, and present the complex experiences recited by the grandparents and parents in their stories of intergenerational relationships; *strengthening family bonds, expressions of family tension/conflict,* and *negotiation*.

One of the most notable studies of understanding intergenerational relationships is Bengtson and Silverstein's work on the Longitudinal Studies of Generations (Silverstein and Bengtson, 2019). Research has looked at intergenerational relationships in terms of adult children caring for ageing parents (Silverstein *et al.*, 2006; Merz *et al.*, 2009; Fingerman *et al.*, 2010), grandparents caring for grandchildren, and intergenerational support to multiple generations (Margolis and Wright, 2017; Zelezná, 2018). However, there is still relatively limited research within the context of grandchild disability (Seligman, 1991; Mirfin-Veitch *et al.*, 1997; Mitchell, 2007). Intergenerational support is of great value to families with children with a disability as they can face additional caring responsibilities and emotional demands in their everyday life arising from the a lack of formal support (Beresford, 1994; Roberts and Lawton, 2001; Neely-Barnes and Dia, 2008). Previous research in the context of grandchild disability has highlighted the important role grandparents play in providing practical, emotional and financial support to the parents and to the grandchild (Hornby and Ashworth, 1994; Hastings, 1997; Katz and Kessel, 2002; Hillman, 2007). In this chapter I aim to build on this by describing the types of intergenerational support provided by the grandparents I interviewed, but also draw out some of the factors that shape the support given and how this support may affect the quality of intergenerational relationships.

In the literature review I described several proposed theories that highlight the complexity and variability of familial relationships, with the co-existence of both closeness and conflict within family relationships, such as the intergenerational solidarity hypothesis (Bengtson and Roberts, 1991) and intergenerational ambivalence (Connidis, 2015). There are several factors that have been described as influencing intergenerational relationships and the level of intergenerational support, including geographical proximity and the movement of families (Kivett, 1991), age (Ben Shlomo and Taubman – Ben-Ari, 2016) and health (Dellmann-Jenkins *et al.*, 2000). There has also been growing research attention paid to the interaction between levels of intergenerational support and welfare support systems. For example, countries with increased funding for formal childcare (e.g., Sweden and Denmark) see lower levels of grandparent childcare than countries such as the United States, where there are very low levels of formal childcare and therefore high levels of grandparent childcare (Meyer and Kandic, 2017). Throughout this chapter I demonstrate how the current welfare state in England was part of the grandparents' and parents' descriptions of intergenerational support.

5.2 Types of Grandparent Support

"It's hard to put into words really what we do for Harrison because we're just there, you know." (Albert, Harrison's maternal grandfather)

All the grandparents interviewed in this study spent regular time with their grandchildren and supporting their adult children each week. When recounting their experiences of being a grandparent, the grandparents gave in-depth descriptions of how their role was enacted. Many described their role as a grandparent as being there for their family and to help their family in any way they could. Grandparents recounted the different types of practical support they provided to their families in terms of childcare and helping with school runs;

> *"Sometimes it's [childcare] for a few hours, sometimes it's for a whole day. And now with them [grandsons] both being at school, I'll pick them up from school so that they're here until about, it's really just about three hours now as oppose to like days."*
>
> *(Audrey, Brian's paternal grandmother)*

Grandchildren spent evenings or weekends with their grandparents, or grandparents provided more support during school holidays, on school inset/staff training days, or when the grandchild needed to be absent from school due to illness. These kinds of supports are also reported by many grandparents of children without disability (Glaser *et al.*, 2013; Moore and Rosenthal, 2016). However, for grandparents of children with a disability this type of practical support was enacted differently, with the extent of help needed being greater. For example, help with getting ready for school would mean help with dressing the grandchild and getting them into a wheelchair and onto school transport. Some grandparents, such as Joan, were helping by covering for formal carers;

> *"If there's no carer, some mornings I'm there at quarter to seven in the morning to help her [mother] get the children. If Peter's [father] at work and she's on her own with the children, because both children need eyes on the whole time. Sometimes I'm there, as I say, at quarter to seven in the morning to get them up, washed, dressed, fed and out by 8 o'clock in the morning for school."*
>
> *(Joan, Charlie and Ellie's maternal grandmother)*

Due to the severity of the grandchildren's disability and their level of need, two families had formal carers as part of a care package (a combination of services put together to meet the child's assessed needs) they received from social services. However, there were occasions when grandparents needed to step in when the formal carers were off sick, on holiday or needed elsewhere. In their absence it was not a simple task for parents to find another formal carer (if available). Parents spoke about the importance of formal carers being someone the grandchild was comfortable with; therefore, grandparents were seen as the best people to step in when needed to cover for formal carers. The rest of the families interviewed did not have a care package and therefore did not have formal carers for support, meaning grandparents provided huge amounts of hands-on support. All the grandparents provided this support without expectation or desire for payment, despite sometimes acknowledging the extra costs to them of providing such support, both in terms of financial costs (e.g., days out, food) and in terms of personal costs to their social life (as described in Chapter 4, section 4.3). Many grandparents mentioned small tokens of appreciation given such as a meal out at a restaurant or small gifts of thanks from the parents. Joan was the only grandparent who was paid, but this was only for the hours when she was covering for paid formal carers who had called in sick or were on annual leave. This was to make sure the family did not lose those care hours when their care package was reviewed.

A motivation for the amounts of practical support provided by grandparents was to give their adult child some respite from the demands of caring for a child with a disability. This was particularly present in families where the grandchild had needs that required constant care and for those whose parents would often have to stay awake or give night-time support to their child. Where grandparents had the capacity to do so, they would have the grandchild stay over for a night to give the parent(s) a night off;

Annie: *So yeah, it is, it is, she [mother] does have a good support network at home, but she needs it. Because coping with a baby like that, it's so, so hard. Because at any given time at that point, Aiden [grandchild] could stop breathing. And it was even worse before we knew what the diagnosis was, because you thought, oh has he got a bug or something like that, but it wasn't. So even now, Aiden is monitored. So, when he goes to bed at night the monitor's on. So, you listen for his breathing all night long.*

Researcher: *You can never really switch off then. It's a constant…*

Annie: *Not at all. Not at all. And that's why Aiden comes to our house and he'll come sort of on a Saturday or whatever to give Melissa a break. So that's like one night where I don't get any sleep, but Melissa for 6 nights doesn't get any sleep. And, and she's worn out. Absolutely worn out.*

(Annie, Aiden's maternal grandmother)

Though staying overnight at a grandparent's house may be a common activity in general, for these grandparents the activity was much more intense. As Annie describes above, having a grandchild to stay overnight could involve constant care and always had the risk of rapidly escalating to an emergency. As well as being more physically demanding, this activity was very emotionally demanding, with grandparents having an almost constant fear and worry of something happening to the grandchild.

Only two of the families described access to formal respite care services (such as occasional overnight stays away from home), a service which many parents of children with a disability appreciate and need; therefore, grandparents were filling this gap and providing it themselves. The additional demands of looking after a child with a disability are well-known in the literature, and family members are an important source of support for parents of children with a disability, especially when more formal sources of support are not available or accessible for families (Wallander and Varni, 1998; Roberts and Lawton, 2001). Parents really valued this aspect of support from the grandparents. It gave them space to have time for themselves and a break, but also gave them time to process some of the information they were receiving about their child's disability;

> *"Sometimes when, especially when we've had, like we've just been away this weekend. And obviously it was only last week we got dropped the dyspraxia bombshell [new additional diagnosis] on us and so now trying to cope with that. So, it was nice for us to be able to have two days away where we could just sort of try to process it without having to think, right what's he up to? What's he up to? And sometimes we just need that time together because, even like, even our weekends are planned to the nth degree, so they are full on. Glenn [Jesse's father] says going back to work on Monday is for a rest [laugh]."*
>
> *(Sonia, Jesse's mother)*

Like Sonia, many of the parents commented on how the grandparent support gave them time to spend focussing on their relationship with their partner as well and spend time together away from their child. The respite support grandparents provided had multiple functions by giving parents a break, giving them time for themselves, time for their relationship or other children, and time for other tasks such as getting food shopping done.

Another form of support the grandparents provided was lifts to and from medical appointments and support during these appointments. There were three main practical reasons given for this: 1) to help remember information provided, or remember information to tell professionals, 2) to make sure they were up to date with the needs of the grandchild in order to feel confident looking after the grandchild, and 3) to help when the grandchild was feeling anxious about appointments or tests;

> *"But he [grandson] has to go for regular check-ups and we see the same consultant, or we try to, every time we go. And [doctor]'s absolutely wonderful. Samuel [grandchild] has a really good rapport with him. And he's just really really lovely with them. Praises Jamila [mother], which is great, which is what she wants. And, I have to laugh coz, occasionally they suggest things and then he'll look at me. Because I go to every visit with her. I go all the time. And he'll look at me and he'll say, "What does grandma think?" I'll say, well. Sometimes he has to alter the meds and he'll say, "oh well we need to have such and such or we need to have blood tests done." And I'll say to him, well his meds had been up last week, so you'll not get a true reading. "That's true, so we'll not do it this week shall we not Amanda [grandmother]. But the reason I go is, because obviously when I have him [grandson], I have to make sure the medication he's having is correct. And, his mummy's great, like I say she's fabulous, but I suppose people do things differently don't they."*
>
> *(Amanda, Samuel's paternal grandmother)*

All the grandparents who described attending appointments also described being welcomed in those appointments and listened to by health professionals, as described by Amanda above. Given the amount of time the grandparents were spending with their grandchildren on their own it was important for them to know what the grandchild's needs were and how to manage their medications or behaviours. This allowed them to become the 'expert grandparent' as described in section 4.2.3. Another aspect of the support during appointments was emotional support for the parent, especially if a parent was needing to attend an appointment on their own. While Amanda discussed more practical reasons for attending hospital appointments with her grandson, her daughter-in-law discussed the value she got from having someone to talk to about the appointment and issues raised in the appointment;

> *"Yeah, like til this day she does [attend appointments]. I wouldn't have it any other way though. Because I think, we used to, like if we go to the hospital appointments it's nice to have somebody else there so then, when you do hear stuff you're not just, like I would just pick up the negatives, but she'll listen for other things as well. So, when after we've been to the hospital, we talk about it and it's oh yeah, he did say that, oh yeah. So, it's nice to have somebody there."*
>
> *(Jamila, Samuel's mother)*

Grandparents helped parents in processing the information they received in appointments about the grandchild and helped parents focus on the positive information. In contrast to the detailed descriptions of practical support, this type of emotional support grandparents gave to parents was described in less detail by grandparents, possibly because it was harder to define or categorise than the types of practical support. Grandparents were there for the parent whenever they were needed, and sometimes this was by being someone for the parent to lean on and talk to. Many of the processes the families went through were very emotional and parents needed someone to turn to;

> *"I think most of it is practical, but you know, there are times I think when Cathy's [mother] needed a bit of emotional support and she's maybes had a rant or two, you know. I'm there to listen."*
>
> *(Joan, Charlie and Ellie's maternal grandmother)*

As well as dealing with the experience of diagnosis, the families faced many ups and downs with the grandchild's health, responses to medications and interventions, challenges with school and attempts to gain more formal support. All this took its toll on the parents and they needed someone to turn to who understood what they were going through and who would listen. Though some of the parents discussed friends they could turn to, many turned to the grandparents;

> *"She [grandmother] helps me with my, this sounds awful, with my mental health [crying]. She helps me with my mental health because I need somebody to talk to. [Crying] Sorry. So that side of it, the mental health, I need somebody to talk to about Jacob [grandchild]. And as much as I love my friends there are some things, I just don't want to talk to them about, do you know what I mean? I can tell them most things but there are things that I don't want to discuss. I want to go out and enjoy myself [giggle]. Don't want to be sat there in a pub like [crying noise]. Who's that odd girl?"*
>
> *(Grace, Jacob's mother)*

As grandparents were so involved in their adult children's lives, it was expressed that grandparents knew what they were going through and therefore parents could talk to them about how they were feeling or coping. An important aspect of emotional support from the grandparents as well was that it came without judgement. Whitney (Malachi's mother) spoke about how valuable her father's support was when she was struggling with her son's diagnosis;

> *"And my dad actually, it was really good because when we found out about Malachi [grandchild] he says, how you doing pet? And I just told him everything I was feeling. I didn't hold anything back and he just respected that. And some of the feelings I felt quite ashamed of because I was in shock, you know, it took me a while to just sort of settle down. Erm, and my dad just let me do that, and I will never, he'll never know how much I appreciated that… Erm but just to, just to talk to my dad without any judgement on the shock I was dealing with was fantastic, you know."*
>
> *(Whitney, Malachi's mother)*

Grandparents provided an opportunity to have a safe place for parents to discuss how they were feeling and how they were coping with some of the challenges they faced. This was not always the case though, and, as will be described in the following sections, the level of affectional solidarity or closeness and the level of conflict or tension in the grandparent-parent relationship influenced the level of emotional and practical support given by grandparents. A close bond and good quality relationship between the grandparent and parent resulted in higher levels of emotional support. However, an interesting aspect of this was also a sense of wanting to protect each other. While many parents spoke about leaning on and sharing their feelings about the grandchild with grandparents, each generation gave descriptions of controlling what they did and did not disclose to each other. Parents sometimes held information back, either about the grandchild or about themselves, in order to prevent the grandparent from worrying. Grandparents also showed this effort of protecting their adult child and grandchild by putting their own emotions to one side to be able to be there for their adult child;

> *"Oh my god. In front of Melissa* [mother]*, erm, I was her mum so I'm the person there, and her dad. We, we're the people there to, to be the ones for her to turn to. And then you would walk away and just crumble, absolutely crumble…*
>
> *But yeah, no I'm definitely definitely not as strong as Melissa and err, most definitely. When need be yes, I am a natural organiser, but when need be, I'm there. But then, erm, and her dad is the same, you walk away, and you crumble."*
>
> *(Annie, Aiden's maternal grandmother)*

Grandparents were, and wanted to be, a strong and stable source of support to the parent and grandchild, putting their own feelings and concerns to one side to be there for them. By masking their own emotions grandparents were carrying out considerable amounts of emotional work as well as practical support. The emotional and practical support from grandparents was greatly valued and appreciated by the parents, and all the parents were aware they were lucky to have such involved grandparents. However, not all parents have equal access to grandparent support, with numerous factors influencing grandparent involvement. Even though all these grandparents were heavily involved in their adult children's and grandchildren's lives, the accounts still reflected the complexity of grandparent involvement in families of children with a disability (Sullivan *et al.*, 2012), as is described in the rest of this chapter.

5.3 Strengthening Family Bonds

"My husband and I are very much involved with our daughters, and obviously with our grandson as well, with Aiden. Very much, very close family. Yeah really good family set up." (Annie, Aiden's maternal grandmother)

Within the literature on grandparenthood a consistent finding is that emotionally close relationships between grandparents and their adult child are conducive to close grandparent-grandchild relationships (Birditt *et al.*, 2012). Whereas a more emotionally distant relationship can make it difficult for a close grandparent-grandchild relationship to be formed. Bengtson and Roberts (1991) refer to this closeness as affectional solidarity in their model of intergenerational relationships. Reviews of intergenerational relationships in the context of grandchild disability have highlighted the importance of affectional solidarity in influencing grandparent involvement in a grandchild's life (Mitchell, 2007; Lee and Gardner, 2010).

Most of the grandparents presented their families as being 'close-knit' and that this had been a longstanding characteristic of their family life. Some attributed this to the mother-daughter bond, some to their religion and beliefs on the importance of family, and some to 'just being that sort of family'. This closeness was expressed as meaning there was no question about how involved they would be in their adult children's and their grandchildren's lives. The grandchild being diagnosed with a disability did not change this. Amanda was one grandmother who particularly expressed how close her family was;

> *"Like I say, we're very close-knit family so we're obviously very heavily involved."*
>
> *(Amanda, Samuel's paternal grandmother)*

Amanda was very involved in all her grandchildren's lives and described the particularly close bond she had with her grandson, Samuel, who had a disability. Across both the grandparent and parent interviews, close relationships and regular contact between the grandparent and their adult child (or son/daughter-in-law) appeared to facilitate regular contact and time with their grandchildren, and a close bond between grandparent and grandchild.

The grandparents and parents spoke about whether they thought the presence of a disability had brought them closer together as a family or not. The pre-existing close bond, like the one described by Amanda above, led some to perceive the experience as having no impact on how close they were now. However, others suggested that the experiences surrounding having a grandchild with a disability may have brought them closer, particularly the relationships between mothers and paternal grandparents. For example, while Grace (Jacob's mother) spoke about how close she and her mother-in-law (Elsie) are now, and had been for a long time, she also reflected on how close they would have been had her son not had a disability;

> *"So, I know she [grandmother] always wanted to have that relationship but how close maybe her and me would have been. I mean I've always liked her, always like Elsie. Always got on with her and maybe we would have been friends. But I don't know, I think this has probably made us very very close. Like a mate. She's me mate basically."*
>
> *(Grace, Jacob's mother)*

In the grandchild's early years, Grace and her husband had lived in another city away from the grandparents, but once they received a diagnosis, they chose to move closer to the grandparents, wanting to be near family. Having a grandchild with a disability had brought the family both geographically and emotionally closer. As well as the parent-grandparent relationship being stronger and closer, the same was reflected in the grandparents' accounts of their relationship with the grandchild. They expressed a special bond or greater enjoyment of their relationship with their grandchild with a disability;

> *"But he's gorgeous. He really is, he is so gorgeous. Well let's put it this way, I have three grandchildren, but my screensaver only has one of them."*
>
> *(Clara, Miles's maternal grandmother)*

This close bond between the grandparent and grandchild was also portrayed in the parents' descriptions of the relationship. The grandchildren were perceived to be getting a lot of joy and pleasure from grandparents, as expressed by Cheryl when talking about the relationship between her mother, Paula, and her son, Jack;

> *"She [grandmother], she's got a lovely bond with Jack [grandchild]. He was her first grandchild and they're really close. Jack's life revolves around his granny really. Who's his favourite person in the world? Granny. First thing he says when he gets up is, "Will I be seeing Granny today? Can I ring Granny? Can I go to Granny's house?"*
>
> *(Cheryl, Jack's mother)*

While previous research has suggested disability has no impact on the quality of intergenerational relationships (Mirfin-Veitch *et al.*, 1996; Mirfin-Veitch *et al.*, 1997), in this study the context of grandchild disability in some cases appeared to bring parents and grandparents closer and made for a special bond between the grandparent and grandchild. Affectional solidarity had possibly taken on a unique significance as the parents contend with the isolation and loneliness that has been associated with raising a child with a disability (Walker *et al.*, 2016; Byrne *et al.*, 2018). The grandchild disability served to bring already close families even closer as they spent greater amounts of time together, leant on each other for emotional support, and wanted to be involved in each other's lives.

Stories of how the family had come together as a whole to support the parent and the grandchild also helped facilitate this closeness in intergenerational relationships. In particular, there were stories about the 'other grandparent(s)' (those who had not taken part in the research). The grandparents interviewed were the grandparents who were described as more involved in the support of the grandchild. In some circumstances the other grandparents had died (n= 2 families), so their previous involvement came up in stories, or the other grandparents lived much further away (n= 5 families), therefore they could not be involved in the more day-to-day support. Two grandparents did not discuss the other grandparents as they were not and had never been involved in the grandchild's life. In three families the other grandparents were present but were described as not being involved due to their difficulty in understanding or coming to terms with the grandchild's disability. Conversely, in four of the families interviewed, the other set of grandparents were described as living nearby and described by the parent and grandparent interviewed as being involved in the grandchild's life. Within these families, both the parents and the grandparents expressed the family as being united, all working together and supporting each other to the same goal of giving the grandchild the best life they can, as described by Grace (Jacob's mother);

> *"I think because of what's happened with Jacob [grandchild], that's changed it all. Because everybody's Jacob [grandchild]. We're all together for one purpose here. There's no sort of, I want to do this, I want to that, or I think you should do this. It's all one purpose, so we're very much bonded because of Jacob... We're all quite good at coming together and having a chat about what's happened. And it'll take you like, we've had things where I've not slept for 3 nights and the same for Mark [father], and she's [Elsie] the same as well. Something's happened at school where we've been really upset about something. And then we're very good at sort of, you know like taking a deep breath and starting again. You know, that's what we do. Everyone's miserable for a few days then we talk it all through and then right, what are we going to do?"*
>
> *(Grace, Jacob's mother)*

The fact they were all going through the experience together and understood the needs of the grandchild meant they were united in working together to do what was best for the parents and the grandchild. Sets of grandparents who worked together sharing childcare duties were presented as offering social support to each other, for example swapping childcare 'shifts' if needed. Dealing with the possible complications of raising a grandchild with a disability, coping with some of the challenges they faced, and supporting each other in the face of a lack of other options were described as bringing these families closer together, both geographically and emotionally.

5.3.1 Support to the wider family

Within the interviews it was not just the grandparent-parent-grandchild relationship and support that was discussed. The wider family was also part of the stories both the parents and grandparents told, including aunts, uncles, siblings, and cousins. One aspect of support parents spoke about as being particularly valuable was the support grandparents gave to the other grandchildren. Of the 15 grandmothers/grandparent couples interviewed, 12 had other grandchildren without a disability. Some grandparents spoke about the limited involvement they felt they could have with their grandchild with a disability when the grandchild's needs were more complex and functioning more severely affected, as was described in Chapter 4. In these cases, these grandparents spoke more about the involvement they had with their other grandchildren. Grandparents spoke about an awareness that their adult child needed to dedicate more time and attention to the grandchild with a disability, so they described themselves as stepping in to make sure siblings did not miss out on activities or time spent with them;

> *"But because my oldest grandson is so severely autistic, he gets respite care for a couple of hours on a Saturday, but we often have the younger one, Tim, most weekends, just to give him some fun things to do. We tend to take him on holiday because obviously with Tyler being so disabled, they don't get away on holiday."*
>
> *(Hazel, Tyler's maternal grandmother)*

By providing support to other grandchildren, grandparents were making sure the other grandchildren were getting the attention they needed or wanted and were freeing up parents to focus on the child with a disability. This expression of supporting the wider family or 'keeping the family intact' has been described in other research of grandparenthood in the context of grandchild disability (Margetts *et al.*, 2006; Miller *et al.*, 2012). This can sometimes involve managing the different needs of multiple family members, as was raised by Margaret (Oscar's maternal grandmother) when discussing her role with her two daughters;

> *"But you try and be as supportive as you can. But another fly in the ointment is my other daughter. So, when the two of them [grandchildren] are playing together, and we've got, I mean we have Sunday lunch here every week. And to be quite honest the children are easier to look after when their parents aren't here. Because I'm not only balancing the needs of the children, it's these two mothers. You know, these two tiger mothers. Who are like so protective of their babies and when the little one is spoiling the jigsaw and what have you. And me other daughter Cassie, will say "But that's what you [mother] wanted. You wanted him to interact with other children." I said, you know, but not his jigsaw, not his favourite jigsaw. And I've just got to back off... It's balancing the needs of these two mothers and their precious offspring."*
>
> *(Margaret, Oscar's maternal grandmother)*

Grandmothers gave the impression that a key part of their role was to keep the family together and happy, considering the needs of all family members. As Margaret discussed above, her other daughter did not seem to be as understanding about some of the compromises and adjustments that were being made for the grandchild with a disability. There is a wealth of literature that has associated women (i.e. grandmothers and mothers) with kin-keeping activities, whether that be maintaining contact between family members, mediating family disputes, or caring for family members who need more support (Wiscott and Kopera-Frye, 2000; Dubas, 2001). These activities were reflected in the grandmothers' accounts, with descriptions of maintaining intergenerational harmony and trying to ensure all family members, not just the grandchild with a disability and their parent, received the support they needed. All these kin-keeping activities involved a lot of emotional work for grandmothers. They were managing the feelings and needs of multiple family members, as well as masking their own emotions.

Nearly all the parents had siblings (aunts and uncles to the grandchild) who lived nearby, however neither the grandparents nor parents mentioned any significant amount of support, practical or emotional, they received from them. When asked about other sources of support adult siblings were largely absent from the accounts, or when they were discussed parents and grandparents described the adult siblings as not being as involved because they were working full time, had their own children, or had their own health problems that limited the amount of practical support they could give;

> *"Yeah, well I think that was with her as well because she [sister] doesn't see him [grandchild] very often, because like, obviously she works full time. So, it was like when she did see him, she wasn't really like kind of au fait with what she should be doing with him, coz when he was a baby you had to be dead careful because he was quite floppy and things. Erm, so she was a bit nervous with him."*
>
> *(Melissa, Aiden's mother)*

Despite aunts and uncles not being able to provide practical support, most were described as being understanding of the extra support needs of the parents. There was very little discussion in the interviews of animosity or feelings of unfairness in the amounts of grandparent support between adult children. One reason for this may be the kin-keeping work grandparents were putting in to try to keep things equal across grandchildren. When there were multiple grandchildren, grandparents spoke about the efforts they went to make sure the time they spent with grandchildren was equal;

> *"Then you have to have them one at a time, so that they have special private time, so it takes twice as long so… [giggle] It was lovely yesterday, I'd had Jack [grandchild with a disability] on Saturday erm, and Leah [grandchild without a disability] has the hours written down like a time sheet. Got to have the same as Jack. And so, she came yesterday just as the snow was starting."*
>
> *(Paula, Jack's maternal grandmother)*

Like Paula, many grandmothers spoke about making sure they spent individual time with each grandchild, doing activities that each grandchild enjoyed, and parents recognised these efforts in their interviews as well. This was another form of kin-keeping and emotional work grandmothers were carrying out in their role to maintain the family bonds. Some literature has spoken about tension because of the extra attention a child with a disability may receive (Howlin, 1988; Randall and Parker, 1999). There was one example of this in this research, where one mother described a difference in the relationship between grandparents and her son with a disability and that with her son without a disability. Kelly described how her parents had been heavily involved in Dylan's (grandchild with a disability) life but did not have a close relationship with her younger son, Elliott;

> *"It has caused problems over the years, even now it does. They just haven't got that relationship with Elliott at all. And erm, you know he only lives across the road, but they might only see him for 5 minutes once a week, you know. Whereas with Dylan it's "Come over", and it has caused problems."*
>
> *(Kelly, Dylan's mother)*

Kelly described how the needs of Dylan seemed to have built a strong bond between him and his grandparents, whereas that same bond was not there with Dylan's younger brother, who was not as "*needy*". In contrast, one parent spoke about the opposite, with her feeling her son with a disability, Malachi, missed out on some activities compared to his sister and cousins. Chloe (sister) and Jessica (cousin), had sleepovers at the grandparents' house, whereas Malachi had not for a long time;

> *"Erm so there have been occasions where I think Malachi has missed out on a lot of time with his nanny and grandad because you know, Chloe will get it and Jessica will get it and Malachi doesn't. And that has sort of saddened me at times but at the same time because Malachi hasn't been aware of it it's not been him saddened, it's more me because I know he loves coming."*
>
> *(Whitney, Malachi's mother)*

Whitney felt that sometimes her son missed out on the time alone with his grandparents that his sister and cousin received, such as sleepovers at the grandparents' house. However, they were understanding of this given some of Malachi's additional needs and the grandparents' lower confidence in having him on his own overnight. Generally, grandparents did their best to keep things as equal as possible across adult children and grandchildren, however this task was not always easy or possible in the context of the needs and care demands of the grandchild with a disability, with some grandparents not having the confidence or appropriate environment to keep things equal.

Close family bonds in advance of the birth of the grandchild appeared to facilitate close bonds after the birth, and an almost automatic response from the grandparent to support the parent and grandchild in any way they could. Linking back to the Intergenerational Solidarity model, there were expressions of high levels of affectual solidarity, structural solidarity, and functional solidarity within these families. However, this intergenerational solidarity was not without its challenges, particularly when the wider family members were considered. The grandparent interviews highlighted the importance of not just the grandparent-parent-grandchild relationship, but the significant amount of emotional and practical work they did within the entire family to consolidate and strengthen bonds.

5.4 Expressions of Family Conflict/Tension

“So, the [grand]parents don’t get on which is always fun when we have barbeques and things, you have to have two of everything. But yeah, his [husband’s] parents, [tut], waste of space.” (Melissa, Aiden’s mother)

Exploring the accounts about the wider family context demonstrated grandparents’ and parents’ stories of a strengthening of the family system in response to grandchild disability. However, grandparent involvement in a family with a child with a disability was not without nuances and complexities. Grandparent support can be a negative factor when the type or amount of support is perceived as inappropriate by the parent (Gardner *et al.*, 1994; Lavers and Sonuga-Barke, 1997). It is also important to recognise that not all grandparents will want to, or be able to, provide the support needed, desired or expected by parents. The sense of obligation to provide support can be a heavy burden for some grandparents, with financial and personal costs to themselves. In this section I present some experiences of family conflict or tension raised in the interviews by the grandparents and the parents.

A main source of tension described was the level of dependence of parents on grandparents specifically for family care. As discussed in the last section, very few families described support from aunts, uncles or other members of the family unit; grandparents were the main source of family support. Some grandparents felt that the role of support to the parents and grandchildren had been left to them by other members of the family, particularly the other grandparents. There were a range of reasons given for this, including the other grandparents living further away, parental divorce, ill-health or disability, or a difference in approaches to grandparenthood. There was a sense for some of the grandparents interviewed that they were the only ones left and had no choice but to step in and support the adult child and grandchild, as exemplified by Albert (Harrison’s maternal grandfather) below. Albert and his wife had provided a lot of support to their daughter who separated from her husband when the grandchild was young. The paternal grandmother had died when the grandchild was very young and following this the paternal grandfather had moved away from the area with a new partner. Albert expressed a sense that the paternal grandfather had moved on without considering the needs of the grandchild, while he was left becoming one of the main sources of support;

> *“It wasn’t until after Harrison [grandchild] was born that, although I think there was a strain before that, it got worse after they realised what was the matter with Harrison, and I think, father and the other grandfather really, because he’s moved away,* erm *cannot really accept it… So, at the end of the day he [paternal grandfather] went off looking for love and he found a lady, and he’s down to [PLACE], been down there nearly 3 year now. So, we are sort of left holding the baby, you might say at this end you know.”*
>
> *(Albert, Harrison’s maternal grandfather)*

This sense of obligation or duty to provide care could be a source of ambivalence for grandparents of a grandchild with a disability. They wanted to have a relationship with their grandchildren but the obligation to provide larger amounts of childcare and the sense of 'no choice' in the matter was expressed as a negative aspect of their role, especially given some of the extra responsibilities of providing support for a child with additional needs. As has been found elsewhere with grandparents of children without a disability, grandparents faced an ambivalence of wanting to be there for their adult child and grandchild but also wanting some time for themselves (May *et al.*, 2012). For example, the weekend before I interviewed Hazel (Tyler's maternal grandmother), she had been looking after her two disabled grandsons from Friday morning until late Sunday evening;

> *"That was quite a long, intense weekend. I mean I love my grandchildren to bits, but it gets to the Sunday and I'm counting the hours waiting for them to go, just because it is such hard work, physically, particularly when they don't sleep at night."*
>
> *(Hazel, Tyler's maternal grandmother)*

For Hazel, despite the intensity of the support, she continued to offer it because she knew her daughter and son-in-law had no one else to turn to or ask for support. Hazel later commented that quite often her expected 'weekends off' from providing childcare and paid employment were taken up with more childcare support. The greater need for, and intensity of support may conflict with the plans grandparents have for their later life and retirement;

> *"And our Adam [grandson] even said "Grandma, you are retired, you're retired." Because I said I want to do, I want to sit down and have a read or do what I want, I cannot get, do anything what I want to do for myself. And it was like that, and Adam couldn't understand that. I says, I've been retired but I've been working for yous."*
>
> *(Pearl, Harrison's maternal grandmother)*

For all the grandparents, whether they were in paid employment or not, or had multiple caring roles or not, their 'free time' was limited and often taken over with the care and support needs of their grandchild and adult child. Many made efforts to maintain some time for themselves, whether that be a regular evening with friends once a week or keeping certain days as their 'day-off'. Efforts and activities like these helped to prevent feelings of frustration or resentment for the time and effort they spent caring for and supporting their family.

With the dependence of parents on grandparents for support and the desire for grandparents to be involved in their grandchild's life, there were expressions of efforts to maintain a level of intergenerational harmony. This meant tensions/conflicts were often put to one side in the interest of keeping the peace, and each generation continually negotiated their time and role. Grandparents also recognised that the dependence of parents on them to provide so much support was because they could not or were not receiving support from anywhere/anyone else. Therefore, much of the frustration and difficulty grandparents experienced was a result of a lack of formal services. Only two of the families had formal carers on a regular basis, two families had access to respite care services, and four families had access to occasional formal support (e.g., personal assistants once a month, support worker for a morning/afternoon out in the school holidays). The rest of the families had been assessed as not needing additional support, however, suitable facilities for after school activities or childcare were not available to them, creating this dependence on grandparents.

There were stories of specific events that caused tension and conflict within families that threatened to or had altered the quality of the relationship between grandparents and parents. This, in turn, resulted in different perceptions of the relationship between sets of grandparents and the grandchild. Both Annie (Aiden's maternal grandmother) and Melissa (Aiden's mother) told a story of an event that they reported as impacting the involvement of, and the relationship with, the paternal grandparents. When Aiden was younger and being diagnosed there were events where he stopped breathing and his mother had to perform resuscitation while waiting for ambulances to arrive. On one occasion this occurred when all the grandparents were at the parents' house. This was already a traumatic and scary experience for Melissa, however the reaction of her mother-in-law created even more upset and had a lasting effect on Melissa's relationship with the paternal grandparents;

> *"I was sat in the back in the car resuscitating Aiden [grandchild]… And erm, she [paternal grandmother] came over and she was, she's like "We're losing him, we're losing him. She's going to lose him here." And like when I was resuscitating him, I was like really? I'll never forgive her for it, and she knows I won't. It's just kind of like we don't talk about it now. And just things like that, I think, my mam and dad would never say that. Even if you think it you don't say it. Erm, so that's always kind of been in the back of my mind. I think he was about a year old when this happened. And then kind of ever since, I'm like well I don't particularly like them, I just kind of put up with them because they're the in-laws."*
>
> *(Melissa, Aiden's mother)*

The paternal grandmother's reaction to the situation Melissa recounted, and the lack of support she felt in that moment, was still having an effect on her relationship with the paternal grandparents several years later. The reactions to and acceptance of the grandchild's disability and events such as this appeared to result in different descriptions of the role and relationship grandparents had with their grandchildren, and the relationship between parents and grandparents. As has been found previously, the grandparents' acceptance and understanding of disability can have a negative impact on their involvement in the grandchild's life, the relationship with the parent, and the wellbeing of the parent (Seligman, 1991; Heller *et al.*, 2000; Green, 2001).

The grandparents' understanding or misunderstanding of the disability could also result in some tension in the grandparent-parent relationship. For example, Diane (Harrison's mother), discussed how it could be frustrating when her mother did not understand some of the long-term implications of the grandchild's disability. While she was trying to process information herself, she was having to explain things repeatedly to the grandparents;

> *"And I think they find, (.) um, I don't know about my dad. I think my dad does a bit as well, but my mum [giggle], very verbal, in the fact that like Harrison has difficulty with speech and a lot of it is to do with his breath control. Umm, [giggle] and sometimes he can say something really clearly because he's really relaxed. And she goes "Why don't you talk like that all the time." [giggle]. And I'll say, "But that's the point mum he can't." And things like that, and she'll say things like "Well I'm sure if he just got his legs going, he could walk."*
>
> *(Diane, Harrison's mother)*

Processing the diagnosis and then additional complexities that arose was a difficult task for parents and they would often turn to grandparents for emotional support at this time, as described in the previous chapter. But when the grandparent did not understand the information being given or did not fully comprehend the extent of the grandchild's difficulties, parents then had the extra work of helping the grandparent to understand. Grandparents' understanding of the grandchild's needs and difficulties was important for facilitating intergenerational solidarity, and therefore intergenerational support. The experience of these grandparents was similar to research on grandparents of children with ASD that has shown the importance of the grandparents' understanding of the grandchild's disability for positive and helpful involvement and relationship quality with the grandchild and the adult child (Hillman, 2007; Sullivan *et al.*, 2012; D'Astous *et al.*, 2013).

Expressions of conflict and tension mostly occurred in discussions around boundaries of roles that had been put in place within each family. There were delicate boundaries of the role that grandparents felt they had to manage and be aware of in order to avoid conflict. Paula (Jack's maternal grandmother) described clear boundaries in what she thought was a parent role and what was a grandparent role. These boundaries were created so that she was not seen to be interfering;

> *"You've just got to learn to shut up, I think basically. You just have to realise it's not your place to have an opinion or if you have got an opinion you keep it to yourself... But yeah, it's not a grandparent's job to, erm, to sort of put forward an opinion about things. It's their life and their children. Erm, so, as it should be."*

> *(Paula, Jack's maternal grandmother)*

As you would see in grandparent-parent relationships with children without a disability, there were differences described in parenting practice between parents and grandparents in terms of discipline, what the grandchild should be eating or what they should be wearing. Parents recognised and valued the grandparents' opinion and experience as a parent, but the grandchild was *their* child, and ultimately their responsibility; therefore, they were the final say in decisions about the grandchild. Parents spoke about the delicate balance of taking well-meaning advice from the grandparents, but also trying to assert their authority as the parent in making decisions about *their* child;

> *"And then on the downside to give a bit of a balance I guess, you've umm, I think this point about, because having a disabled kid is new for everyone it's like, (..) It's getting that balance between we're the parents and they're the grandparents. But because you're discovering stuff together, sometimes they've [grandparents] been a bit more assertive I think or forceful with their opinions on how to handle him… You know, do this with them, do that with them. I think it's all good suggestions, you never knock a suggestion back, but I think we've had to kind of reinforce our parenthood."*
>
> *(David, Malachi's father)*

As David states above, grandparents feel a strong connection to the grandchild and want to help, potentially drawing on their own experience of being a parent. However, parents spoke about the importance of keeping a parent-grandparent boundary. There were certain issues that parents wanted to deal with on their own and others where they welcomed grandparent involvement;

> *"I like to keep that [school] to me, because, I know what happens in school. And she [paternal grandmother] gets a bit emotional. She's very emotional. You kind of have to say let me deal with this. Not that she's not good, she would just get really emotional and annoyed about something. It's not the way, it's not going to help Jacob [grandchild]. So erm, I do the meetings. With Mark [father], Mark does them as well."*
>
> *(Grace, Jacob's mother)*

Grace had openly spoken to her mother-in-law about where and when she wanted her to step in and help. However, in most cases it seemed these boundaries were never explicitly discussed within families. It was more of a learning experience, seeing where and when the boundaries could be pushed or what was stepping over the line;

> *"But we'll, we'll get involved as much as we want to, to the point where we think, well I think, we've gone to that stage now, going a bit further might be a little bit pushy, do you know what I mean?"*
>
> *(Henry, Malachi's paternal grandfather)*

In the interest of maintaining intergenerational harmony it was better to stay behind the *"invisible line"* (Henry, paternal grandfather) and keep opinions to themselves. The balance of 'being there' but 'not interfering' (Mason *et al.*, 2007) may become harder as the desire to help and support becomes stronger during periods of stress and crisis. Families discussed disagreements between parents and grandparents about how to handle some of the grandchild's behaviours and needs;

> *"I mean, yeah sometimes they are in denial and their ways isn't our ways. Like they do tell Brian off for doing things and then Blake [brother] will say, "They told Brian off for doing this." Or "They told Brian off for doing that, but he couldn't really help it mam, it's just because he's different." And that's like a 6-year-old, you know saying that. So, they're still in their little ways, still sort of see past the autism. Not that I'm saying that Brian shouldn't be told off. If he's being naughty, fair enough, but it's like, sometimes it's that line of is he being naughty or is that the autism or whatever, you know what I mean?"*
>
> *(Lauren, Brian's mother)*

As Lauren describes above, there were sometimes differences in how much grandparents and parents made allowances for the child's disability in terms of what was perceived as behaviour requiring discipline. In some cases, this was just down to a different style of parenting, such as Clara (Miles's maternal grandmother) who described her approach as, *"I don't give him that extra, he still has to behave himself."* Whereas for others, it was the grandparents' understanding of which behaviours were a symptom of the grandchild's disability and which were bad behaviours that resulted in different practices and feelings of tension. These differences were not discussed and in order to maintain harmony there were more unspoken understandings of, for example, *"well, Granny's house, Granny's rules" (Paula, maternal grandmother)*. This seemed to be a satisfactory outcome for all parties and maintained the family harmony.

Grandparents' expressions of tension or conflict were not always described as coming from within the family, sometimes it was how they perceived their position in the family that resulted in descriptions of conflict. Grandparents often perceived themselves as being more than a grandparent;

> *"We are not just like ordinary grandparents. We do play a bigger part."*
>
> *(Elsie, Jacob's grandmother)*

However, outside of the family this is not always how grandparents felt. Grandparents spoke about the frustration that sometimes came from 'just being the grandparent' and not being able to step in as they would if they were a parent. Some grandparents used statements such as, *"I'm* *just the grandparent. I've got no say" (Margaret, maternal grandmother)*. In section 5.2 I described how some grandparents were welcomed into appointments and recognised by health professionals. However, for others, despite their greater involvement, this was described as not being reflected in their interactions with (or attempts at interaction with) health professionals or school staff. For example, Mary (Kayla's maternal grandmother) found it difficult to know when to step in or not when trying to get support for her grandchildren, but when she did try to step in her attempts to help were refused by her grandchildren's schools. Mary has multiple grandchildren with disability, as well as a daughter with a similar disability. This meant she was experienced in dealing with many of the issues her daughters were facing in getting support for the grandchildren at school;

> *"The part with schools. Some schools are very good with accepting me as parental sort of responsibilities type thing and communicating with me and that. But the two girls, the 12-year-old and 13-year-old who are both autistic, both got a diagnosis, go to the local comp and there's been lots of problems with that. That has been, because at one time they [the school] were telling me it wasn't my duty to talk to them about it. I wasn't the parent and things, but I think we've got over that now. My friend Susan, trying to get the autistic issues sorted out at the school. She is very good at meetings and things so she's going into the schools at the minute while the autism problems are getting sorted. Which is brilliant, you know. Because it's too emotional for me, I find it very difficult because I get so angry that they're not providing the support that they should be."*
>
> *(Mary, Kayla's maternal grandmother)*

In Mary's case the barriers and frustration then meant she relied on a friend and ex-colleague (Susan), who was a support worker to step in and help with the concerns Mary had about her grandchildren's education and support at school. I was not able to interview either of Mary's daughters to explore how they felt about this involvement, but Mary did not describe any rejection or upset from her daughters about this involvement. Other grandparents also described frustrations they had with schools and other professionals involved in the care of their grandchild, in terms of feeling like their opinion was not wanted or valued. Grandparents expressed a tension between seeing their adult child and grandchild struggling and wanting to do what they could to help but feeling powerless to intervene. The boundaries of care and family roles were different for each family and were being continuously renegotiated within the family and with outside agencies.

5.4.1 The grandparent-parent relationship

Earlier, the close bonds between parents and grandparents were described, but for some this relationship was expressed as one source of tension or upset. The mothers spoke of a change or loss in their relationship with their mother (the grandmother). When a mother's daughter also becomes a mother, this can bring a desire for greater closeness (Barnett *et al.*, 2010), but it also brings a change in the status of their relationship, from adult-child to adult-adult, with them now being ‘role colleagues’ (Fingerman, 2000). However, the birth or diagnosis of a grandchild with a disability means the norms that guide the parent-adult child relationship may not apply. Bojczyk *et al.* (2011) suggest this can affect how parents and their adult child understand one another, communicate with each other, and negotiate their relationship. For the majority of the families, the adult child was the first in the immediate family to have a child with a disability; therefore grandparents, or grandmothers, could share their experience of parenthood but could not relate these to the experience of raising a child with a disability. While many grandparents could share their experiences with their daughters, this was sometimes not relevant/possible in the context of grandchild disability, potentially altering this transition in the mother-adult daughter relationship. In the mothers’ accounts there was a sense that the mother-daughter relationships had been changed due to their dependency on the grandparent for more intense support. For example, Cheryl (Jack’s mother) spoke about how her relationship with her mother now revolved around the grandchildren;

> *“Yeah, I sometimes think that when Granny comes around the children are all wanting her attention, and I’ve always just stepped back. Erm, and I think, I’ve been very aware that I’ve done that because Granny wants to see them, and they want to see Granny and they’re fighting for attention anyway. And sometimes I feel like I don’t really have a close relationship with her because they kind of take that time and that space if you like. Now and then we do get to have a coffee together and that’s really nice but it’s all about the kids.”*
>
> *(Cheryl, Jack’s mother)*

This left Cheryl with a sense of loss in her relationship with her mother in order to make space for the grandchild-grandparent relationship. Mothers spoke about the efforts they went to in order to maintain relationships with the grandmothers outside of childcare. However, this was difficult while also managing work, time for themselves and their own time with their children. Parents were aware of how reliant they were on grandparents for childcare to allow them to work, socialise or have time for themselves. Parents spoke about not wanting to be a burden on the grandparents, and knowing that many of the grandparents would not have expected to spend their retirement providing the level of support that was being asked;

> *“I’ve always, I’ve always said to her [grandmother], I don’t know how much she believes me. I know it kind of, this wouldn’t be the answer, but I’ve always said we can manage, you know, so I never wanted her to feel like it was a burden or a chore. And I know she loves them, and I know she loves having them, but you know, it’s her retirement and I don’t want her to feel too tied.”*
>
> *(Cheryl, Jack’s mother)*

Parents recognised they were often asking a lot of the grandparents, and worried they were a burden on the grandparent, as described above by Cheryl who relied on her mother for regular childcare after school through the week as her husband frequently worked away. Those parents who relied heavily on grandparents for childcare often used the word 'guilty' when discussing the support they received from grandparents. There was a sense that the parents wanted to make sure the relationship between grandparents and grandchildren was more than acting as carer/babysitter;

> *"And obviously I'll go visit her [paternal grandmother], like if Patrick's [husband] at work, like Sunday he was at golf. Always golf. So, I was like well I'm going to go down to your mam's with the kids and go visit her. Because like, I wouldn't want her to feel like she's getting used because I think she has said that in the past. I said to Patrick, "Are you not going to go see your mam." And he's like "[mumble] Why?" And I'm like "It's your mam. Go ring her, go see her, go tell her that you care. Go and show that you appreciate that she looks after your kids pretty much half of the week." And erm, so I often go down and visit her and take cakes and things like that, and we sit and have a cuppa and things like that."*
>
> *(Lauren, Brian's mother)*

Parents, mostly the mothers, were putting in a lot of emotional work to maintain harmony in the family and make sure no-one was feeling exploited or unappreciated. Mothers seemed particularly aware of thanking the grandparents for the support they gave, sometimes giving up the limited free time they had to visit grandparents or take them out on more enjoyable, fun-centred activities, rather than just seeing them for childcare.

There was also a sense in the interviews that while the parents were very grateful for the support they received from grandparents, they did not feel they themselves, as the adult child, got the support or recognition they wanted from their parent. As was described in the previous chapter, grandparents expressed to me their pride in their adult child, but the parent accounts suggested that this was not always explicitly said to them;

> *"I don't ever feel like, I said about this the other day. It was something my dad said to us and I thought, "You're very, in fact you hardly ever say to us, you do a really good job." Lots of other people do… Lots of other people will say I don't know how you manage. Don't know how you cope. Don't know how you keep going and how you hold down a job and all that type of thing. Umm, but I never feel like I get that from them [grandparents]. And I don't think it's intentional. I don't think it's a mean thing or anything like that. I think they just don't even realise that they don't do it. Don't think they even realise that they don't ever say it… I hear them say to other people. I do hear, or they'll say something that they've said to someone else and I think, eee you never say that to me actually. I don't feel like you feel like that. Erm I think my relationship with them is very different. I think when I had Adam [child without a disability] I got much closer to me mam and I think that's quite often with women and their mum, going*

> *through that experience. But I don't feel like I have that close a relationship with them as I did then."*
>
> *(Diane, Harrison's mother)*

In these circumstances the high dependence of parents, particularly those like Diane who were single parents, on grandparents for childcare support meant the closeness that could develop between mother and daughter over the shared experience of motherhood was affected. So much of the support received was 'grandparent support', while the mothers felt the 'parent support' was missing from the relationship now. Everything revolved around the grandchild and time spent together was nearly always in relation to the grandchild, therefore there was no room for the maintenance of the grandmother and mother relationship. Each generation was perhaps finding it difficult in this new situation to determine what their role, and perception of their role to the other party, was as mother and daughter. Added to this was the complexity of the grandparent and parent lives. All the participants had busy lives juggling paid employment, care work (for multiple generations) and having a social life. This could leave little time or space for the grandmothers and mothers to have 'quality' time together. Negotiations of time were constantly being made.

5.5 Negotiation

"I do me best, within reason and thinking you've got to have a life of your own as well." (Paula, Jack's maternal grandmother)

An element of conflict or tension exists in most family relationships and this chapter so far has demonstrated how this can play out in the context of childhood disability and the additional circumstances that potentially increase levels of tension and conflict within these families. Even when tension did exist, the stories told by both the grandparents and the parents were about efforts that had been made to maintain a level of intergenerational harmony which prevented any conflict or tension significantly affecting the intergenerational relationships and therein the levels of intergenerational support (particularly grandparent support). These stories consisted of negotiations each generation made of their time and role in order to support each other and avoid conflict. The negotiations parents and grandparents recounted fell into three categories: availability, paid employment and childcare, and multiple care roles.

5.5.1 Grandparent availability

All the grandparents did their best to make themselves as available as possible to provide support to their adult child, grandchild and the wider family unit. There were stories of changing plans at very short notice when called upon by their adult child. For example, during one interview a grandmother had to leave the interview halfway through to help her daughter as one of the grandchildren had been ill at school. There were many stories about an almost 'on call' type of service grandparents provided for their adult child and grandchild;

> *"It works reasonably you know. And so, you just get a phone call saying "Mam, Lauren's at work, can you go pick the [children] from school." Or "I'm going to be behind today can you make sure you go pick them up." And so it's been like that all the time, right through their life."*
>
> *(Audrey, Brian's paternal grandmother)*

If the parents called saying they needed something, whether that be an emergency with the grandchild or simply needing help picking the grandchildren up from school, the grandparents were there and available for them. For grandparents who were working, there were also stories about leaving work early or changing schedules when they were needed for an emergency with the grandchild;

> *"And err, any support she [mother] wants, she knows it's there. She knows, it doesn't matter which time of day or night. Erm, I've been at work when I've received the call, "I'm coming." And pick her dad up at work and straight to the hospital. And we're the first ones that she calls for anything. Absolutely anything, yeah."*
>
> *(Annie, Aiden's maternal grandmother)*

Grandparents were usually the first port of call for support for parents, which meant they tried to be available as much as they could, even when working. The grandparents tailored their lives around the support they gave. This ranged from rearranging appointments or plans at the last minute to only booking holidays at certain times that suited the parents best for childcare purposes. The grandparents described constantly trying to think ahead and make sure any plans made would not interfere with the regular support they offered to their adult child;

> *"We just make sure that when we go on holiday, em that it's not when Peter [son-in-law] and Cathy [daughter] want to go on holiday. Or usually when the children are at school so that if we can't help that it's not too much of a burden for them without us here."*
>
> *(Joan, Charlie and Ellie's maternal grandmother)*

When plans could not be changed there was sometimes a level of guilt expressed by the grandparents. They were aware of how reliant the parents were on them for support and the limited alternative options they had. Parents did not have access to many (if any) childcare facilities such as after school groups or local babysitters, or these options were not able to support the grandchild's needs. When talking about their role, grandparents used phrases such as *"it was our duty to help"* (Patricia, Dylan's maternal grandmother) or *"It's just what you do as a grandparent"* (Joan, Charlie and Ellie's maternal grandmother). The support grandparents gave regardless of other commitments, such as work, could be explained by strong normative pressures to perform the grandparent role by 'being there' for their adult child and helping to look after young grandchildren. In the previous section I referred to the delicate balance grandparents experienced in 'not interfering' with their adult child and grandchild's life. On the other side of this, grandparents were also managing the balance of 'being there' when needed (May *et al.*, 2012). This normative pressure to be there for their family may be even stronger in families of children with a disability, where the needs of the family are greater, leading grandparents to make themselves as available as possible to provide support, for example by limiting their own leisure time to meet the requirements of the role (Lakomý and Kreidl, 2015).

Grandparents felt that they needed to make themselves available or felt obliged to make themselves as available as possible, because the parents did not have anyone else to turn to. In particular, the parents discussed the main issue being finding appropriate childcare for their child. Many could not afford the costs of formal childcare, others could not find suitable childcare that they felt comfortable leaving their child with, and others who were able to find formal carers often needed help to cover when carers were not able to attend. Grandparents became the main source of childcare and cover for formal carers. Grandparents also provided the flexibility needed to fit around the parents' shift patterns and to be able to be 'on call'. Some grandparents were able to make themselves available to the parent, whereas others had other commitments and roles that meant their availability had to be negotiated.

5.5.2 *Paid employment and childcare*

One of the main negotiations discussed was that around the parents' paid employment and finding childcare. When asked to tell me about their experiences of grandparenthood, nearly all the grandparents gave descriptions of their role in childcare for the grandchild with a disability. The majority of the grandparents gave details of their childcare schedule and 'shifts';

> *"You're asking how it affects us as grandparents. We've got a timetable.*
>
> [Brings in paper with a full year, week by week, colour coded for when they need to look after each grandchild]
>
> *The purple days are our days off. Weekends we obviously don't have them but there aren't many purple days."*
>
> *(Margaret, Oscar's maternal grandmother)*

Margaret, like many of the grandmothers, provided childcare daily to her three grandchildren for her two daughters. This included childcare before and after school for several hours, and childcare for full days for her youngest grandchild, sometimes from 7am until 6.30pm. Both her daughters worked shift patterns which changed regularly, so a schedule was regularly drawn up of which days she would have the grandchildren while her daughters and sons-in-law worked. The need to call upon grandparents for childcare was greater in these families of a grandchild with a disability when parents were unable to access, find or afford formal childcare.

There is some evidence that becoming a grandparent can have an effect on grandparents' decisions to leave the workforce, particularly for grandmothers, such as speeding up their retirement (Van Bavel and De Winter, 2013). Seventeen grandparents in the study were retired, with many of their stories discussing how being retired meant they were available to provide childcare if needed;

> *"Having worked in nurseries I know how much childcare costs and it's an absolute fortune. So, what we said, when we retired, if they had to go to work, we would pick up so they didn't end up having to pay for fees for nursery or anything like that."*
>
> *(Amanda, Samuel's paternal grandmother)*

Grandparents and the parents shared stories of discussions that had previously taken place about the grandparent helping with childcare in advance of the grandchild's birth. For the grandparents that had not retired, some discussed how they had reduced their working hours when the opportunity arose, for example flexi-retirement or part time hours, in order to be available to provide support if needed. In addition to financial reasons, the reliance on family care is even higher in families of children with disability, where a lack of access to, lack of trust in and lack of appropriate staff training has been found in formal childcare options (Russell, 2003; Contact a Family, 2015; Rutter, 2015). This issue was raised by parents in their discussions about the lack of options when it came to childcare;

> *"Umm, I think because of Jack's [grandchild], especially when he was little it wasn't necessarily that easy for him to access other childcare if you like, or like babysitters. There wasn't really any babysitters that I felt I could necessarily leave with the two of them. Other than her [grandmother], and at the time I had Paul's [father] mum as well, who was also quite involved."*
>
> *(Cheryl, Jack's mother)*

The 'usual' options, for example babysitters, breakfast and after-school clubs, were not an option for children with a disability and their parents. It was difficult, if not impossible, for parents to find available trained babysitters or to find suitable places their child could attend after school. Therefore, grandparents are playing an essential role and one that may become even more vital with cuts to the limited existing services. There was also the sense of parents wanting to leave their child with a 'trusted person'. Each of the children had their own needs and special requirements for care, whether that be medication, therapy, or understanding their behaviours. The parents and grandparents spoke of the expert knowledge grandparents had in caring for the grandchild, making them one of very few 'trusted persons'.

Being this ‘trusted person’ added to the feelings of obligation to support the family, or grandparents seeing it as their ‘duty’ to help, which in turn could potentially lead to decisions to reduce working hours or take retirement. The needs of the parents certainly seemed to be a part of the grandparents’ decisions to reduce working hours or to retire. The decision between the parent working and the grandparent working will likely become a larger issue with the increasing State Pension age in the UK, particularly its impact on women (Gray, 2005; Glaser *et al.*, 2010). Margaret, who was described earlier as providing daily childcare for her grandchildren since taking early retirement, expressed her anger about the situation;

> *“Margaret: Ahh, well really I’m not retired. I’m err, not old enough. You need to get something in your research about raising of the state pension age for women because err, I should still be at work.*
>
> *Researcher: Oh okay, have you not reached pension age yet then?*
>
> *Margaret: No.*
>
> *Researcher: That must have been quite a tough decision then, choosing to leave work.*
>
> *Margaret: Yes, I’m quite angry about it.*
>
> *Researcher: So, when will you reach pension age now?*
>
> *Margaret: 66, another 5 years. This is why there is all the trouble with the care system, because all the women who should be at home looking after their elderly parents are at work.*
>
> *(Margaret, Oscar’s maternal grandmother)*

Grandparents, in particular grandmothers, faced difficult decisions between feelings of obligation to care, decisions about their continued participation in the workforce, and their own financial stability in later life. While most of the grandparents in this study described having the financial resources to be able to make a choice between remaining in paid employment or leaving to help with childcare, for many grandparents in the UK there is no choice. They need to stay working for financial security, despite any desire or need to leave work for care work. There were four grandparents who still worked full time or part time, as shown in

Table *3 gives a summary of the grandparent characteristics. The grandparents’ ages ranged from 52-85 years, the majority of whom were married and retired. Of the 15 interviews, 11 were with maternal grandparents and four were with parental grandparents. Only one grandparent (or grandparent couple) was interviewed from each family.*

Two grandmothers *interviewed had only one grandchild (the grandchild with a disability). The majority (n=9) had three grandchildren across all their adult children. The grandchildren with a disability ages ranged from 4-19 years of age at the time of the interview. Most of the grandparents had just one grandchild with a disability, however three grandparents interviewed had multiple grandchildren with a disability (2-4 grandchildren). Across all the grandparents recruited, there were 20 grandchildren with a disability: eleven had ASD (four of whom were non-verbal), three had cerebral palsy (two non-verbal, one used* *a communication aid with some speech), two had Down's syndrome (one communicated using Makaton), three had congenital disorders (birth defects), and one had Rhett's syndrome.*

All the grandparents provided regular, weekly informal support to their adult child and grandchild. All lived in North East England. The majority lived in close geographical proximity to their adult child and grandchild, and one grandmother lived an hour drive from her adult child and grandchild (range: 0.5-52 miles). None of the grandparents lived in the same house as their grandchild.

Parent Sample

From the 15 grandparent interviews, all but two of the parents were approached about taking part in the research. One grandmother only agreed to participate if her daughter was not contacted due to her relationship with her daughter at the time. Another grandparent did not respond to communication following her interview about approaching the parent. Of the 13 parents who were approached, 10 agreed to participate. Three parents declined to take part due to: 1) not wanting to discuss the grandchild's disability, 2) being too busy to take part, and 3) because of their own health problems.

Table 4 gives a summary of the parent characteristics. Nine of the interviews were with mothers and one with a mother and father couple. The majority of the parents were married/co-habiting and worked part-time. One mother was looking for paid employment after being a full-time caregiver of her child for several years. Seven of the parents had two children, three parents had one child.

Table 3 (Chapter 3, section 0). This was usually because they had not reached retirement age and because they needed to be in paid employment for financial reasons. Work also provided other functions including structure, enjoyment and social engagement, and formed part of grandparents' identity;

> *"Well I think, erm, I'll work for a bit longer. Because I do like to go to work. We've worked as a group for a long time together. But just recently there's a couple of people that I've worked with who've retired and I have noticed… I've found, I've struggled a little bit recently. With this last little bit of a, a down spiral, with school and that for Jacob [grandson]. I did feel, I took it to heart a bit more than I normally would and it took me until I saw the doctor…and she was asking about anxiety and depression for me… When I was talking to the doctor it was only then I realised that really the people I talk to about everything would be the girls at work. And this year two of them have left. The people that I would normally sit and talk with. And erm, there's people there*

> *now like who've replaced, who are nice, but you just don't have that history. Because we'd worked together for 27 years and we'd been through, you know, marriages, divorces, bereavements. You name it. And everybody's really comfortable and it's nice to have people that you can be honest with and say, "I'm worried about this that and the other," which you wouldn't dream of saying to Mark [son] and Grace [daughter-in-law], in case they hadn't thought of that worry. Do you know what I mean?... All of us would be talking about something that you wouldn't dream about talking about with your family. And you knew that's where it stayed with the people, and they understood you so that was really good."*
>
> *(Elsie, Jacob's paternal grandmother)*

As Elsie demonstrates, strong friendships and relationships can be built up through work, which provides a great source of social support. As individuals retire or leave workplaces these relationships and support systems can change or be lost; therefore, a support system for the grandparent can be lost as well. Where Elsie felt she could not or did not want to talk to the parents, she was able to speak to her friends at work about concerns she had, thereby receiving emotional support. Decisions around giving up work are therefore complex in terms of the support the grandparents receive from the workplace alongside the financial factors and need from parents.

These negotiations grandparents were making about work were all expressed in relation to allowing the parent to return to the workforce. Grandparents providing childcare allowed the parent (specifically the mother) to return to paid employment. More frequently grandparents are being called upon to help with grandchildren so that their sons or daughters can pursue a career (Kulik, 2007; Settles *et al.*, 2009). Grandparents recounted how the parent working was important to them;

> *"And she [mother] continues to work, which is what we [grandparents] want. I want her to stay working. And so, it's just, you know, err. We all lend a hand but me more I suppose, from day one, really when we first knew there was something not right about Thomas [grandchild]."*
>
> *(Alice, Thomas's maternal grandmother)*

Similar to the grandparents, parents (especially single parents) spoke about the need to work for financial reasons, but also the need to work to have an identity away from being a full-time caregiver to their child. Just as the grandparent support helped give parents some respite, parents described work as a way to step away from their role as caregiver;

> *"Erm Peter [father] went back to work. He had taken a career break from his job, so he went back to work part time. So, we both work part time which we try and fit around the children. Erm, because the children are both so severely disabled we could get away without working but I think when, when you're a 24-hour carer you need an identity*

> *outside of that so, we both wanted to sort of keep a hand in as it were. Erm so yeah, that's what I do."*
>
> *(Cathy, Charlie and Ellie's mother)*

Cathy and her husband had both taken career breaks since having their children, and she had changed jobs to fit around the care needs of their children, but as Cathy says, they were both keen to stay in work in some way. The care package they received, and the support of grandparents allowed them to do this and add another aspect to their identity.

Parents also spoke about negotiations they had made of their working hours, when they could, to try and take some of the load off the grandparents. For example, Sonia (Jesse's mother) and her husband made changes to their work patterns when they realised the grandparents were struggling with the amount of childcare they were providing;

> *"The kids said, look, they rang us and said, are you coping? And we said, if you want the truth, no. Because it's hard to say no and they've got to work, you know what I mean?... Glenn [father] doesn't work on a Wednesday now. He has Wednesday off. So, Sonia [mother] is off Monday, Tuesday, and Glenn off Wednesday. So, it should only be Thursday, Friday."*
>
> *(Kevin, Jesse's maternal grandfather)*

Sonia and her husband (Jesse's parents) recognised that the grandparents were struggling with the amount of childcare they were providing, especially as they provided childcare for another one of their grandchildren two days a week as well. The strong solidarity in this family led to the negotiation of the parents' working hours to support the grandparents. Sonia was already working part-time following having children, and they worked out that they would be financially better off if she remained at work and her husband reduced his working hours to part time as well. This meant there was one less day a week where the grandparents needed to provide childcare. These parents were in a position where they were able to successfully negotiate a change in working days with their employers and had employers understanding of their situation.

Four of the mothers interviewed and one father had taken the decision to work part-time to balance the support their child needed and to cover childcare. Currently, UK government policies encourage mothers to return to work and simultaneously encourage grandparents to remain in the workforce (Gray, 2005). This is likely to mean that negotiations of work, family and childcare will become even more challenging for families of children with a disability. With no other appropriate formal services to access for childcare, intergenerational support will become an even more vital and necessary source of support.

5.5.3 Multiple care roles

Another aspect of contemporary grandparenting and the changing demographics of grandparents is the emergence of the ‘sandwich’ generation, where a generation are caring for the generation above and below them (Grundy and Henretta, 2006). The term ‘sandwich generation’ is often referred to when discussing family care for ageing parents in their later life and caring for children. Another term developed from this is the ‘club-sandwich’ generation (Abramson, 2015). These are parents who are caring for three generations: their parents, their children and their grandchildren. Extending life expectancies and medical advances have meant grandparents are providing long-term care and support to their own ageing parents (Keck and Saraceno, 2010). Six of the grandparents discussed the role they played in supporting their own parents who had health problems or needed support with daily living tasks such as shopping or housework. One grandparent described the extra work this involved and the burden they felt supporting effectively three generations;

> *“Andrew’s [grandfather] mum is 93 and she’s got raging Alzheimer’s. And up to a year ago she was living on her own, so we were…It was tiring because believe it or not, Andrew’s mum took more time than the kids. You know, it was, it was just an uphill battle with her the whole time because she didn’t think anything was wrong with her.”*
>
> *(Joan, Charlie and Ellie’s maternal grandmother)*

In these cases, grandparents were providing support to their own parents, whether that was helping parents to remain living in their own home or dealing with the process of moving their parent(s) into a nursing home or other form of supported accommodation. As well as the intergenerational solidarity shown to the downward generations, grandparents had high levels of intergenerational solidarity towards their ageing parents, increasing their involvement in supporting them when needed. There was a lot of effort and time that went into managing and organising this care and support for ageing parents, especially when it was being managed around the support and care they provided to their grandchild and adult child.

As another layer to this, there were two grandparents who also still needed to provide a lot of support to their own children (i.e. the siblings of the parent of a child with a disability), some of whom had their own health problems that required support. These grandmothers had to negotiate their parental and grandparental roles;

> *“To an extent, to an extent. I mean they’re [adult and adolescent children] functioning independently, but Haley [daughter] suffers quite a lot with anxiety because of her autism so that’s why she’s not in school today. And Ivan’s [son] at university, he’s doing really well but he still lives at home, he can’t, you know, can’t be independent and still needs that support and safe environment. And sometimes it’s quite difficult when we do have the grandkids round because Haley particularly struggles with a busy family and*

she doesn't like mess. The boys [grandchildren] can be very messy so that upsets her, so it has implications, knock-on effects for the rest of the family."

(Hazel, Tyler's maternal grandmother)

Some grandparents were performing a number of roles; that of a mother, grandmother and a daughter. Balancing all these roles and the needs of all the generations was a difficult task, particularly if they directly conflicted with each other. Grandparents were negotiating their time across all the support needs, usually at the expense of time to themselves to manage all their caring roles;

> *"It's just because, Sunday afternoon I like to meet friends and once I think I had Jack [grandson] at the park. I was just at the park with Jack on Sunday and I got a call from my friends saying "We're going to have a picnic on the beach. Come down." And I said, "Oh well I've got Jack at the minute." And then I thought, you know, I do want to go for a picnic on the beach, so I took Jack home."*
>
> *(Paula, Jack's maternal grandmother)*

Grandparents faced the potential for role overload as well as role conflict as they negotiated the support needs of the entire family, especially if they were also juggling other commitments such as work or maintaining friendships and later-life activities.

5.6 Conclusions

The types of support grandparents provided to their family, including practical and emotional support, are consistent with the existing literature from North America (McNee and Jackson, 2012; D'Astous *et al.*, 2013; Hillman *et al.*, 2017), Israel (Findler, 2016) and Australia (Woodbridge *et al.*, 2011; Miller *et al.*, 2012). In this research, having two generations' accounts added great value in understanding the many facets of family relationships in the context of grandchild disability. The two generation's accounts highlighted the masses of negotiation within families to provide a support network for the grandchild and their parent, the amount of emotional work carried out by mothers and grandmothers, and the varying sources of tension and conflict within families.

The uniqueness of each family was demonstrated in the interviews, however there were consistent expressions of types of intergenerational support, including practical (mostly childcare provision) and emotional support. All the families described close family bonds and a positive and supportive relationship between generations. However, alongside this there were also descriptions of tension and sometimes conflict within these same relationships. Across the interviews there was a sense of trying to maintain a form of intergenerational harmony, mainly through negotiations each generation made of their time and their respective roles.

The impact of grandchild disability was felt across the entire family unit (other grandchildren, other grandparents, other adult children). Recognition of the impact of child disability on the whole family system is important in developing strategies to support families. The adjustment and acceptance of the wider family is vital to maintain intergenerational harmony and reduce conflict or tension within the family. Much of this work fell on the grandmothers and mothers in these families, as has been consistently found in Western cultures (Rosenthal, 1985; Brown and DeRycke, 2010). There was a wealth of emotional work being carried out by the mothers and grandmothers to make sure the family as a whole kept functioning harmoniously. It has been highlighted how conceptualising this as a form of work challenged the assumptions that care is natural, effortless and without consequences (England, 1986; Erickson, 1993). Strazdins' (2002) work has shown how emotional work is a part of many relationships and family relationships with time and effort needed to meet others emotional needs, improve others wellbeing and maintain harmony. As was seen in this study, much of this work is done by women (Duncombe and Marsden, 1995; Erickson and Ritter, 2001; Erickson, 2005). Emotional work can include listening to other’s problems, giving advice, and taking a load off another member. Grandparents and parents in these families were constantly carrying out these tasks to support each other and maintain family harmony. However, in these families there was a greater need for emotional support, taking the load off others and giving advice. Mothers were also carrying out emotional work by showing their appreciation to grandmothers for their support.

None of the grandparents expressed a wish not to be involved in supporting their grandchild and the parent, however all would have appreciated broader and more stable assistance to the entire family from formal support services to reduce the intensity and greater need for support from grandparents. A main source of the tension described was parents’ dependence on grandparents for care and grandparents’ feelings of obligation to provide intense levels of support. This dependence came from a lack of flexible, affordable, and high-quality childcare and overnight respite services. For parents of children with disabilities, childcare options can be very limited with some facilities being unable and unwilling to accommodate disabilities, being inaccessible, or not providing the needed therapies or assistants. There was also a need for these types of facilities and support for longer than would be typically expected. The grandchildren were growing into adolescents and young adults but still required intense supervision and support. Again, finding appropriate facilities was challenging; therefore, grandparents filled this gap.

Literature has suggested that intergenerational interdependency may result in intergenerational ambivalence (Lendon *et al.*, 2014). As described in the literature review, intergenerational ambivalence is a concept that has been coined to account for the co-existence of both solidarity and conflict within intergenerational relationships (Connidis, 2010). Variables such as strong kin-keeping responsibilities and competing obligations such as those described within this chapter may be related to experiences of ambivalence (Pillemer and Suitor, 2002). The challenges in accessing services and the cuts to formal support services (as described in Chapter 1, section 1.4.1), mean more care is being drawn inwards, becoming a family matter where parents and grandparents are the central actors of care. Grandparents were becoming the ‘grandchild-savers’ and ‘mother-savers’ in response to the needs of the grandchildren and parents (Herlofson and Hagestad, 2012). Grandparents were doing what they could to make themselves as available as possible to support their adult child and grandchild, even when managing multiple demands on their time.

The amount of support required by parents and offered by grandparents reflects the lack of policy and services supporting families of children with a disability (Russell, 2003; Mitchell, 2007). This research, along with much of the other research in the area of grandparenthood and grandchild disability, has pointed to the vital role grandparents play in place of formal support services. There needs to be much more recognition of the grandparent role and the value of their role to families and wider society. The findings of this chapter also point to the much greater intensity of the support provided by grandparents. The support required demanding physical and emotional work by grandparents. This intensity of support was likely to continue to be needed by the grandchild, therefore families need to plan for how this support will continue and what the impact of this support will be on grandparents, as is explored in the next chapter.

Chapter 6. Growing Older: Changes in the Dynamics of Intergenerational Support

6.1 Introduction

The previous chapter described the current experience of intergenerational relationships within the interviewed families, and how the grandchild disability had influenced those relationships. However, these relationships are subject to change, especially as the generations age (Connidis, 2015). With increases in life expectancy, some grandparents can expect to experience their family role for 30 years or more. The availability and willingness of grandparents to provide care, as well as the needs and preferences of parents and grandchildren, change over the lifecourse influencing the extent of support provided by grandparents (Hagestad and Burton, 1986; Hank and Buber, 2008). Reviews of research on grandparenting in the context of grandchild disability have highlighted the need to consider the changing roles of grandparents as they age to further understand grandparenting in this context (Mitchell, 2007; Gallagher *et al.*, 2010; Lee and Gardner, 2010). They highlight that much of the current research focusses on either young children or focusses on the point of diagnosis. However, as life expectancies rise and medical advances have meant children with a disability are surviving into adulthood, it is important to understand how the grandparent-grandchild relationship and support continues to develop. Understanding the potential differences in the family trajectories could highlight how grandparenting in this context differs and highlight other important support needs for families in this context. In this chapter, I explore within the accounts how the dynamics of support had changed within these families over time and their thoughts on how the relationships and support will continue to change as everyone ages. This is set out in two sections: the *changing grandparental role* and *looking to the future.*

In general it is reported that as the grandparent and grandchild age the level of practical support from the grandparent decreases (Hoff, 2007; Moorman and Stokes, 2014), and other support such as advice and companionship become more important within the relationship (Harwood and Lin, 2000; Kemp, 2005; Taylor *et al.*, 2005). Whilst literature in the context of grandchild disability suggests a similar pattern in terms of practical support (Heller *et al.*, 2000; D'Astous *et al.*, 2013), there is very little research on how grandparent roles continue to play out with advancing age in this context.

It is widely recognised that looking after grandchildren can be demanding both physically and emotionally (Grinstead *et al.*, 2003), and even more so when the grandchild has a disability. As well as the grandchild’s disability, the increased likelihood of grandparents experiencing illness and disability as they grow older may also impinge on the grandchild-grandparent relationship.

Though older adults are living longer, these extra years may not necessarily be in good health, with women in particular having shorter gains in disability-free life expectancy (Salomon *et al.*, 2012; Jagger *et al.*, 2016; Kingston *et al.*, 2017). As well as gender differences, social class inequalities in life expectancy and health life-expectancy have been found, with those least affluent showing trends of a worsening healthy life-expectancy (Rahman *et al.*, 2016; Nazroo, 2017). This subsequently raises concerns about the level of care that grandparents may require. Austerity measures in the UK have resulted in significant cuts to this provision, as is also the case for provision of care for the grandchild's generation, resulting in the responsibility of care falling on the family to support both younger and older generations (Age UK, 2018).

6.2 Changing Grandparental Role

"So, I think we'll still be as active within the boys' lives just not to the extent we were. Because obviously holiday times we'll have them and stuff like that. And I suppose, I think at the minute the boys would spend all their life here. But I'm sure that will change as they get older." (Amanda, Samuel's paternal grandmother)

It is reasonable to expect that as a grandchild and a grandparent age, the types of activities they share with each other may change. Across the grandparent and parent interviews there were accounts about how the grandparent role had changed from when the grandchildren were younger to their involvement with older grandchildren. However, while 'typical' grandparents may experience a decrease in need for physical support from the adult child and grandchild, this change for grandparents of children with a disability was experienced very differently. There were three main factors described as changing the grandparent role and the dynamics of support between the grandparent and the grandchild: *stepping back, introduction of formal support services*, and *physical demands of support.*

6.2.1 Stepping back

As the grandchild aged, a significant transition for the families was the grandchild starting school. In England, educational settings (nurseries, schools and colleges) have a legal duty to support children and young people with additional needs and disabilities (Department for Education, 2015). Children with complex needs will have their educational support needs assessed as part of their Education, Health and Care Plan. All the grandchildren with a disability discussed by grandparents had started nursery/school. Ten of the grandparents spoke about their grandchildren attending Specialist Provision schools, two grandchildren attended mainstream school, and three attended mainstream schools with classroom support. Attendance at Specialist Provision schools meant that many of the children received some of their therapy (e.g., speech and language therapy, physiotherapy) at school, rather than attending additional appointments. This meant that grandparents were not needed as much to help with travel or attendance at hospital appointments. Starting school also meant grandparents did not need to provide childcare during the day. Rather than full days, childcare time was reduced to wrap-around care before and after school hours;

> *"I think we manage alright doing the wrap-around care, but I would hate to go back three years and do what we done, looking after two babies and double buggies and [sigh]. I couldn't do that again."*
>
> *(Judy, Jesse's maternal grandmother)*

Some grandparents expressed how this took some of the pressure off them to be as frequently available as before and gave them a break during the day. Although most grandparents expressed a sense of relief at the grandchild attending school in terms of the reduced practical support they needed to give, some did report a sense of loss of involvement in the grandchild's life. They had gone from knowing everything about the grandchild's life to now being left out of conversations and not receiving much (or any) feedback from the school. For example, Paula (Jack's maternal grandmother) felt she was missing out on knowing what Jack was doing at school since he started at a Specialist Provision school and received school transport;

> *"There is a home school diary but it's just one line- Jack [grandson] went swimming or Jack has…just nothing very much at all. And I like to get involved and know who his friends are and what he's been doing and things like this. I do feel, erm, as if I have no idea what's going on really."*
>
> *(Paula, Jack's maternal grandmother)*

Previously Paula had picked her grandson up from nursery and had been able to talk to teachers about his day, whereas now she had no contact with his teachers. This experience has also been described by parents of children with a disability and the struggles they have communicating with staff at schools about their child's activities and structure (Hess *et al.*, 2006). The grandparents were having to readjust and renegotiate their role as the grandchild grew older and accessed other sources of support and input.

As was described in the previous chapters, the initial stage of diagnosis was often a difficult and emotional time for both the parents and the grandparents. Grandparents provided a wealth of emotional support and practical support at that time to their family. Over time the families began to 'settle' into new routines and their roles, therefore the initial intensity of need passed for some families;

> *"Because I think now, we're at the stage with Aiden where everything's kind of fit into place. We know that we can manage things, it's not quite as stressful as what it was. So, it's not, like I kind of don't need their [grandparents] support as much."*
>
> *(Melissa, Aiden's mother)*

Parents and grandparents spoke about how family life had become more ‘settled’ and how they found some of the circumstances less stressful than when the grandchild was initially diagnosed. In some cases, this meant grandparents felt they were no longer needed as much to provide both emotional and practical support. Grandparents described their role changing as a consequence of a reduction in what they perceived to be the parents’ and grandchildren’s level of need. This could be due to additional support from other sources, the family having settled into a new routine, or changes such as the grandchild starting school. Therefore, they felt they were able to take a step back from some of the intensity of the support they had been providing. For example, Elsie (Jacob’s paternal grandmother) had been very involved when her grandson was being diagnosed and she had provided a lot of practical and emotional support to her daughter-in-law and son in the initial few years. However, now the parents were more ‘settled’, understood their son’s disability and had practices/processes in place to support his needs, Elsie felt she was no longer needed as much;

> *“And I think for all, we all needed to be there, I think when he’s* [grandson] *okay it’s nice for them just to have a normal, the normal, because I am, I know what I’m like, I can be quite pushy. It’s not that you’re being pushy for the wrong reason, you’re just trying to help but sometimes I think, I’ve got to make myself take a step back. Because when they don’t need you, you don’t really need to be there. You need to let them, for all I love to be there, to be part of everything, you have got to think, well he’s not yours.”*
>
> *(Elsie, Jacob’s paternal grandmother)*

When things were ‘settled’ and going well for the family Elsie described learning to take a step back and leaving the parents and grandson to their own family life. The boundaries of the role were shifting to what Elsie perceived as a more ‘typical’ grandparent role. Whereas previously they may have spent all their time together, they were now spending more time apart. This was not always an easy transition for grandparents to make and sometimes circumstances meant stepping back was not an option for grandparents. The family structure (e.g., single-parent families, number of grandparents) and the complexity of the grandchild’s healthcare needs (e.g., need for intimate care, at-home medical care) could have a large impact on how much support grandparents gave and how easy the grandparents found the transition of stepping back. For example, Patricia and Terry (Dylan’s maternal grandparents) found the transition of stepping back much more difficult given the intense role they had played in most of Dylan’s life, being the only source of support to their daughter who had been a young single mother.

Like Patricia and Terry, some grandparents’ role identity involved the intense support they gave to the family; without it, they felt uncertainty about what their role now was as a grandparent. The boundaries of the role needed to be re-established to what they perceived to be more typical boundaries of a grandparent-parent-grandchild relationship. They had gone from feeling as if they were "*more than a grandparent*" due to the intensity of their role to now potentially having a more 'typical' grandparent role;

> *Patricia:* *Well I find sometimes we're not needed as much as a grandparent. Apart from taking him [grandchild] out and doing little things. Whereas he used to live with us.*
>
> *Terry:* *He was more like a son than a grandson, wasn't he?*
>
> *Patricia:* *Yeah.*
>
> *But equally, as he's got older, obviously we have to pull back a bit, but it can be difficult, as we know, it can be difficult seeing her [mother] doing, thinking or not doing or saying something we don't agree with, but we have to try and keep back a bit. But you know.*
>
> *Terry:* *Yeah, the differentiation between parent and a grandparent is totally blurred isn't it?*
>
> *(Patricia and Terry, Dylan's paternal grandparents)*

Patricia and Terry were a specific example of how the intensity of their role with their grandson had almost changed their identity as grandparents, and their feelings that it had merged with their parent identity. This made stepping back from their role harder as they subsequently took part in what would be seen as more 'typical' grandparent activities like taking their now young adult grandson out occasionally for lunch or a coffee. Their daughter, Kelly, also spoke about the changing boundaries of the role and the struggle she had had trying to re-establish her parental role;

> *"I mean they [grandparents], not took over, but I did have to sort of claw control back a bit once I was mentally able. Erm, yeah… I would say for the first, [sigh], good year and a half, they were more the parents and we [herself and Dylan] were the two, you know [kids]. Erm I think it was that moment when we found out Dylan was blind, something sort of clicked and you know, but I did struggle to sort of get that control back."*
>
> *(Kelly, Dylan's mother)*

Dylan's family circumstances, with Kelly being a young single mother when Dylan was born, meant the grandparents role intensified greatly when he was diagnosed. They were taking care of him on a regular basis, taking him to and from appointments and heavily involved in his medical care and education. However, all the grandparents in this study described an intensification of the grandparent role once they knew about or began to notice the needs of the grandchild. Intensification refers to both the hours performing tasks and the types of activities and tasks grandparents were involved in.

This intensification of the grandparent role has been described in the existing literature, including for grandparents of children without a disability (Fuller-Thomson and Minkler, 2001; Mitchell, 2007; Baker *et al.*, 2008). A convergence in the grandparent and parent role has been described with there no longer being a clear division between the parent role and grandparent role (Meyer, 2014). Grandparents are involved in several similar tasks to parents such as taking grandchildren to and from school, taking them to activities and hobbies, and feeding and bathing them. In some cases, grandparents substituted the parents in carrying out these care tasks. The grandparents in this study had accepted this convergence of their role, however, as the intensification of need was perceived to reduce, there were attempts to create some divergence in roles and establish new boundaries between the grandparent and parent role. The divergence in the roles was also influenced by the input of formal support services as is explored in the next section.

6.2.2 Introduction of formal support services

While not always equally available or accessible to the families, the input from formal support services such as school support, paid caregivers and home equipment was described as altering the role of grandparents. Most of the initial care work was kept in the family, as described in the previous chapter, but once the family moved past the initial stages of diagnosis and the grandchild began to grow older, families came into contact (or tried to contact) numerous different support agencies. As grandchildren grew up from babies to children some parents were able to access funds through assessments for home adaptations to make care tasks easier for both the parent, grandparent and the grandchild, such as lifting the grandchild in and out of bed and intimate care tasks. Some parents had equipment such as hoists and ramps, specialised feeding chairs and beds in the family home that made some of the physical caring tasks easier. However, the majority of the grandparents did not have the capacity to have this type of equipment in their own homes or did not have the training to use that equipment, despite the grandchild no longer being small enough to easily lift/move. For example, Aiden (grandchild) needed stair lifts, access to oxygen tanks and suction machines, and an adapted car for his wheelchair. His grandparents were able to adapt their home using their own finances, so they could have him stay at their house;

> *"Yeah, my mam and dad do everything for Aiden* [grandchild]*. They've got a stair lift* at their house *because Aiden is in a wheelchair. Erm, they've got a car that his wheelchair can fit in."*
>
> *(Melissa, Aiden's mother)*

Melissa's parents had the material resources and willingness to adapt their home and buy a car that meant they could help with picking their grandson up from school. Many of the grandparents did not have access to the resources (either their own finances or state funding) to adapt their homes to support the needs of the grandchild or have homes that could be easily adapted. Without these adaptations or specialised equipment grandparents were not able to continue to be involved in the same way as their grandchild was getting older.

> *"I used to have him here, but we haven't got the bed. Thomas's [grandchild] got to have a special bed and there is no way that we would get funding. If we did that would be brilliant because I could have him. You know, he's, I mean, just changing his nappies and that sort of thing here, you can imagine. And it's so undignified the whole process. It's alright when he's only little but when he's [10-14]. And he ends up on the floor, I'm changing him on the floor then I'm, can't get up and oh dear me, you know. And there is no way we can do the job properly anymore."*
>
> *(Alice, Thomas's maternal grandmother)*

If they could not provide a safe and comfortable environment for the grandchild this again changed an aspect of their grandparent role as everyone was growing older. As Alice highlights in her account above, grandchildren were needing support with tasks such as dressing and intimate personal care (e.g., changing pads, bathing) beyond the years grandparents would typically expect to be doing these tasks. This raised concerns about being physically able to perform these care tasks on a growing grandchild, but also being able to perform them in a way that still gave the grandchild dignity in their care. The lack of equipment at the grandparent home and the physical implications of everyone ageing was putting restrictions on the amount or type of care grandparents could provide.

Parents and grandparents spoke about how as the grandchild was growing up, sometimes the complexity of their disability and care needs also increased (e.g., finding appropriate post-school activities, easily moving the grandchild in and out of bed). This had resulted in many of the families trying to engage with support services to help the family manage some of the complexities of the grandchild's care such as respite care or in-home formal carers. Five of the grandchildren were described as accessing formal support, usually after a struggle by the parents and a long period without any input from formal support services. This input again altered the grandparent involvement, usually in a way that reduced how much they were required to deliver some of the hands-on support tasks such as providing respite for the parent;

> *"And, really worked part time in order to lend a hand with Thomas [grandchild] basically because up until Thomas arrived life was pretty straight forward. [Giggle] And then it was, everything changed and so I went part time and then retired about 3 or 4 years ago now. So now I'm all hands-on deck. Actually, not so much with Thomas now, because we've got respite care [overnight, out of home care], three nights a week now."*
>
> *(Alice, Thomas's maternal grandmother)*

Access to formal carers and respite care offered a much-needed break to parents, but also to the grandparents as well who would, prior to formal support input, often take on the respite care themselves. Respite support offered a break but also created a sense of loss in the grandparents involvement as the grandchild aged and grandparents could no longer provide suitable respite.

Harrison's mother was able to arrange support from formal carers for a few days a week, when the amount of support being provided was becoming too much for the grandparents. Following an incident when the mother was injured and on crutches for a while, the level of support needed reached a crisis point. Albert and Pearl (Harrison's maternal grandparents) briefly moved in with Harrison and Diane while Diane was physically limited. At this point Diane spoke to a social worker and was able to get formal carers to help at home and was able to keep this support three mornings a week once she had recovered. The grandparents described their confusion as to why formal support had not been able to be in place before they reached this crisis point;

> **Albert:** *We moved in, thinking we were doing the right thing. Not realising we could have got her care in. And when we said we had to struggle, Diane got in touch and they said well you should have got in touch sooner.*
>
> **Pearl:** *But it, I found. I mean I was beginning to come home at 5 or 6 o'clock or go to bed. I was so tired from being at her house every day. So, being there all the time, whereas here I could come and relax for the night, you know from 6 o'clock til 10, watch the telly or whatever, but when we were there it was just, we were constantly doing things.*
>
> **Albert**: *And of course, Diane couldn't do anything initially. It was at the same time Henry got his new electric chair. And we had trouble with the car. We couldn't get it in the blinkin' winch and that.*
>
> **Pearl**: *And then when they finally got help in hand. I felt annoyed because, Diane was saying we cannot get.*
>
> *(Albert and Pearl, Harrison's maternal grandparents)*

In most cases, when formal support was obtained, often replacing what grandparents were providing, it was welcomed by both parents and grandparents. However, these services were not easy to access for all the families and, as was the case with Diane, some families were not aware of the support available to them. It was only when a crisis point had been reached that the family were able to reach out and find formal support services to assist them. Finding suitable places and carers was a long and difficult task. When appropriate support could be found it did allow some grandparents to take a step back from some of the more intense and physically demanding aspects of their role.

Grandparents seemed to have conflicting emotions about the involvement of formal support services; on the one hand grandparents expressed a sense of obligation to fill unmet need when there were no formal support services available, but on the other hand they also expressed a sense of loss when formal support services became involved. The introduction of formal support services meant roles needed to be renegotiated again. The support they provided was an expression of their functional solidarity (Bengtson and Roberts, 1991) and had become a part of grandparenthood for them. Changing this aspect of the relationship meant changing an aspect of how grandparents expressed their solidarity and maintained their relationship with their grandchild. Although, there was never complete stepping back from their role, as grandparents were often the 'back up' when formal carers were not available, for example because of annual leave or sickness. Part of the conflicting emotions grandparents felt about formal support was in considering the potential positive impact of formal support on the grandchild and the parent, as well as on themselves. For example, Alice (maternal grandmother) expressed the view that it was initially hard to see her grandson go into respite care three nights a week, but she also saw the benefits for him;

> *"You know we think, oh it would be great to have Thomas [grandchild] here, but it wouldn't, it wouldn't for him. Because it would be too stressful for him because we can't look after him the way he should be looked after. And the other thing as well, that now when he's at home he gets very stressed because of these little kids [siblings], running about, and you know he sort of scratches his ears and ooh, and I think oh Thomas. And for my daughter, I'm sure she must, she must think, I mean we never. I have to be careful what I say to her. But she must think Thomas is happier when he's not here. He's actually happier at [RESPITE]. He's calm there and he's, you know, he's in his own, he's where he's, uh, he's where he belongs, I suppose. That environment I mean, where they've got everything there that Thomas needs that we don't have here."*
>
> *(Alice, Thomas's maternal grandmother)*

Grandparents recognised the limits in what they could provide for their grandchild in terms of care as the grandchild aged. As much as they wanted to continue to be involved in the practical care work, grandparents also recognised what was best for the grandchild and their needs, and sometimes this meant them taking a step back and relying more on formal support where it was available. They were still involved in helping out their adult child when needed and spending time with the grandchild, but they were not as involved in providing respite care and spent less time on their own with the grandchild; thereby reducing the intensity of the role.

6.2.3 Physical demands of support and ageing

It is common for grandparents of children without a disability to step back from providing as much practical support as the grandchild ages, due to the grandchild no longer needing that practical support, and emotional closeness becoming more important within the grandparent-grandchild relationship (Giarrusso *et al.*, 2001; Sheehan and Petrovic, 2008). Nonetheless, for families of children with a disability, there may still be a high level of need for practical support, whether this comes from grandparents or elsewhere. Amongst the families interviewed, most of the time the grandparents' availability, flexibility and experience with the grandchild made them the ideal and preferred support person. However, when the grandparents were beginning to show signs of not being able to provide the practical support anymore (due to health problems, physical ability) this was when some of the parents had begun to seek out other sources of support. Notable across all the interviews, especially the grandparent interviews, was an awareness of 'getting older' and the physical implications of ageing. Nearly all the grandparents described health problems commonly associated with later life. These included diabetes, hip and knee replacements, heart conditions, and diagnoses of cancer;

> *"I've stepped back as far as doing anything. Which is bad for her [daughter]. Because I've got arthritis in my back and my neck, I've got diabetes too. I've got lots of things wrong now. I've got iron deficiency."*
>
> *(Pearl, Harrison's maternal grandmother)*

These health conditions had implications for the grandparents' ability to provide the needed support. Along with health problems, the process of ageing and the decrease in energy and strength that comes with ageing was affecting grandparents' ability to carry out the extensive care work they were previously providing (Silverstein and Marenco, 2001). The grandparents' recounted experiences of being physically unable to provide the level of support they wanted to or were previously able to;

> *"And as I say just practical things. He [grandchild] loves being in the bath but then when it's time to get out, if he stands up I can lift him out but he wanted to lie down and I'd like let all the water out, and he wouldn't stand up so I'm bent over and I'm only little, and he's nearly [5-10] so he's quite big and heavy. And I'm thinking he's only going to get bigger and heavier; I'm going to get older and weaker. How much more can we keep doing this, you know? Or if his iPad runs out of charge, he has major meltdown and he'll fight, he'll kick, he'll throw himself about so it's quite difficult now that he's bigger just to pick him up."*
>
> *(Hazel, Tyler's maternal grandmother)*

The physical effort required to provide practical support (e.g., lifting grandchildren up, bathing grandchildren, helping with housework and providing childcare) was consistently reported as becoming increasingly difficult for the grandparents as they aged. This is consistent with previous research that has shown a decline in the amount of practical support offered due to advancing age and health issues (Heller *et al.*, 2000; McNee and Jackson, 2012). As Hazel mentions above, it was not only the care tasks such as toileting and bathing that were becoming more physically demanding, it was also the ability to manage difficult behaviour (e.g., stop a grandchild running out into a busy street) that she reported as getting harder with the simultaneous ageing of the grandparent and grandchild. This seemed to be a particular concern for the grandmothers compared to grandfathers in this study, who described themselves as the main informal caregiver. In a couple of cases where the grandmother had health problems, the grandfathers were described as ‘stepping-up’ to do tasks previously done by the grandmother;

> *David:* *I think my dad’s stepped up though.*
>
> *Whitney:* *Your dad’s been awesome.*
>
> *David:* *But since me mum’s been ill.*
>
> *Whitney:* *Oh, he’s been absolutely…*
>
> *David:* *He’s stepped up.*
>
> *Whitney:* *Shirley [grandmother] can’t sing his praises enough. He’s kept the house going.*
>
> *David:* *But when Malachi [grandson] comes around, I think he does all the work now, whereas before it was a bit of both probably.”*
>
> *(Whitney and David, Malachi’s parents)*

The division of care tasks between the grandparent couples changed with each individual’s health and ability to perform the tasks. However, this was only reported to be a short-term solution in most cases as the grandfathers faced the impacts of ageing and their own health problems as well.

Clara (Miles’ maternal grandmother), was particularly aware of how her physical ability to play with and care for her grandchildren was limited by some of her health problems. Clara described the action she took to try to reverse some of the health problems she was experiencing to make herself as physically fit as possible. This included losing weight, walking more and eventually joining a running group. All of this was so that she could be around for as long as possible for her grandchildren;

> “*Well yeah, I will, I do look ahead, hence the changes I’ve made. But I intend to stay fit and well for as long as I can.”*
>
> *(Clara, Miles’ maternal grandmother)*

For Clara, her role as grandmother and her desire to be involved as much as possible with her grandchildren for as long as possible had benefits for her physical health. From interviews with non-custodial grandparents, Moore and Rosenthal (2016) described the potential of grandparenthood to act as an “antidote for ageing” (p.29), in which the responsibilities and pleasure of grandparenthood were motivators for changes in behaviour to improve health so that grandparents can stay active in their grandchild’s life. For grandparents of children with a disability it may be more than just the enjoyment of the role giving grandparents a motivation to stay healthy and active. Other grandparents in the study expressed an awareness of making sure they were fit and ready for taking care of their grandchildren when the parents called upon them. This often put them in a ‘catch 22’ position as their intensive role in supporting their family would often leave very little time to take part in activities that would be conducive to health, especially when children were pre-school age and required long hours of care.

The impact of childcare on grandparent health has received some research attention with analysis of data from databases such as SHARE indicating that grandchild care is beneficial for grandparent health (Christiansen, 2014; Hilbrand *et al.*, 2017; Danielsbacka and Tanskanen, 2018), but positive effects have not always been found (Coall and Hertwig, 2010; Glaser *et al.*, 2010). In particular when grandparent investment is higher, for example in custodial grandparenting negative effects on grandparent health may arise (Grinstead *et al.*, 2003; Baker *et al.*, 2008; Taylor *et al.*, 2016). Such effects may also be seen with the greater investment, intensity and demands of grandparent support in the context of grandchild disability.

Grandparents were either the only or one of very few sources of support due to the lack of availability or affordability of more formal support services, or no other trusted options for childcare support. In Margaret’s (Oscar’s maternal grandmother) account there was a real sense of obligation that she could not get ill or have an accident as the parents were so dependent on her for childcare;

> *“I mean, one of the reasons I didn’t go out last week [in the snow] was because erm, late last year I fell and broke me wrist. Was just, you know, an accident. And all last week I was thinking I can’t afford to go out in the snow and fall again and be out of action. Erm, **we’ve got to**, we’ve said **we’ve got to** keep ourselves healthy, **we’ve got** to keep ourselves fit just to look after these children.”*
>
> *(Margaret, Oscar’s maternal grandmother)*

As demonstrated by Margaret above with the repetition of “*we’ve got to*”, grandparents expressed the necessity for them to stay healthy and able to provide support. If they did not, there were serious implications for how the parents would continue to cope with some of the extra demands of caring for a child with a disability while also trying to stay in work and avoid the heavy financial costs of formal childcare. Six of the parents in the study worked shift patterns that were not compatible with formal childcare hours (typically 09:00-17:00). Grandparents were relied on for childcare when the parent worked unsociable hours, or where parents’ working patterns overlapped. Childcare for these types of flexible working contracts is hard to access (Coleman and Cottell, 2019), and even harder to find or access when the child has additional needs. As was discussed in Chapter 5 (section 5.5), parents felt they could not access other forms of childcare such as local babysitters, afterschool clubs or other parents, especially ones that were suitable for older grandchildren.

Grandparents were increasingly aware of their own ageing and their own abilities, but at the same time they were aware of the continued dependence of the parents on them for support. There was a perception that they needed to be physically able to provide support to the grandchild and the parent for as long as possible. However, while Clara was able to improve her fitness, this was not an option for all due to age-related health problems. Grandparents who recognised their physical limitations in providing practical support to the parent and grandchild, expressed a struggle in accepting there were certain tasks they could not help with anymore;

> *"It upsets us actually that I can't look after Kayla [granddaughter] the way I used to. Like if I babysit her on a night-time, not that Ruth [mother] goes out very often, I can't carry Kayla up the stairs. So, she's usually lying asleep for when her mam comes in coz she can carry her. I find that hard to accept. You know, difficult getting her in and out of the car now and things. But that's life, you've gotta, gotta adapt it."*
>
> *(Mary, Kayla's maternal grandmother)*

Mary had a number of health problems which meant she did not have the ability or energy to provide the type of practical support her grandchildren and adult daughters needed. Grandparents had to adapt the level and type of support they provided in their role as a consequence of their ageing and the grandchild ageing. While practical support was reducing, grandparents were maintaining similar levels of emotional support, as has been reported in other research in this context (Heller *et al.*, 2000).

Parents' recognition of grandparents' ageing and the potential need for them to take a step back from the physical involvement was not always expressed. Pearl (Harrison's maternal grandmother), had previously provided a lot of practical support to her daughter, doing housework, ironing and cooking, as well as supporting the grandchild with tasks such as toileting and dressing. As well as this she also helped her other daughter with some household chores due to the daughter's own health problems. However, in recent years Pearl's health had declined significantly. The perceived lack of understanding from their two daughters about Pearl's decision and need to take a step back was frustrating for Pearl and Albert;

> *"The two girls [daughters] think she [grandmother] should go out and get active, but she's had to get a walking stick. She goes out in the garden even for an hour and she's got to stop and have a coffee. She stood ironing yesterday for 2 or 3 hours and she had to stop every half hour, every hour, to rest her back. But they do not understand that, and I'm sick of trying to tell them."*
>
> *(Albert, Harrison's maternal grandfather)*

Even though Albert and Pearl had tried to take a step back from their involvement and stop doing tasks they had previously done, they felt their daughters were still expecting them to maintain the same level of support, not understanding how physically demanding Pearl found the tasks. However, when her daughter spoke about the frustration she had seen in her mother, Diane described it as being due to different reasons. Diane (Harrison's mother), suggested the frustration expressed by Pearl was due to her feelings of guilt that she could no longer help as much;

> *"It's her own guilt I suppose, for want of a better word, and frustration that she can't help."*
>
> *(Diane, Harrison's mother)*

Diane thought the frustration was coming from Pearl's inability to help as much anymore, but Pearl described it as not *wanting* to help as much anymore because of her health limitations. When looking across the grandparent and parent interviews a pattern of frustration occurred as grandparents felt an obligation to support, while at the same time the parents were aware of the physical demands and pressures on the grandparents. Both generations were frustrated as there were no other suitable options available (formal or informal) as an alternative to the type of support being provided by grandparents. Both generations were trying to do the best they could for each other but both faced restrictions in what they could do to ease the situation. Grandparents wanted to help but physically could not, and parents wanted to stop asking for help from grandparents but had no other support services or people to turn to.

That said, most parents were aware of the impact ageing was having on grandparents' physical ability to help with supporting the grandchild. While many did not have other places or people to turn to for support, they were working hard to be less of a 'burden' on the grandparent. As was described in Chapter 5 (section 5.5) parents made some negotiations to try to reduce their dependence on grandparents, such as changing their work patterns/hours. The parents spoke about trying not to ask for help as often as they used to, trying to allow the grandparents time to themselves;

> *"Erm, so that has, and I feel [formal support] has took a bit of pressure off because it means that me dad doesn't have to get up as early and things like. And there are some days where you'll ring him, and he'll say "Eee I've only just woke up." And it'll be like 9 o'clock. And I'll say well that's fine dad you haven't got anywhere else to be have you so. Just let yourself have a lie in, it's fine. You've got nowhere to be rushing to."*
>
> *(Diane, Harrison's mother)*

Parents were recognising the limits of the support they could ask for from the grandparents, whether because of the grandparent's health, the physical demand of looking after the grandchild or acknowledging grandparents needed to do other activities as part of their later life. But alongside this was the narrative of having no-one else to turn to, whether that be other informal carers or formal carers. The working patterns parents had and the need to entirely trust others to care for the special requirements of their child, meant other childcare options were few, if at all, which necessitated dependence on grandparents. Grandparents felt obliged, but also wanted, to fill this need as best they could, despite the physical and health limitations they faced. As has been found in other studies, grandparents' and parents' accounts indicated grandparents' strong commitment to supporting their adult child and grandchild regardless of their advancing age and physical limitations (Gardner *et al.*, 1994; Schilmoeller and Baranowski, 1998). Alongside this, the parents in their interviews raised another important issue: the capability of the grandparent to continue to support the grandchild.

This issue was discussed by Ellie and Charlie's mother in her interview. Despite the fact it was something that only appeared in her interview, I feel it is important to discuss and highlight as it may be an issue to families with children with similar levels of need and care. Ellie and Charlie have very severe and complex disabilities that mean they are completely dependent on a carer for support in every task and need constant supervision. Their care also involves a lot of complex medical equipment which required training. Cathy (mother) highlighted how she had concerns about how everyone ageing was affecting how the grandparents could interact with their grandchildren;

> *"So, with Peter's [father] mum she kind of, if we were taking the kids through coz they have chairs in the kitchen, specialist chairs that they sit in for lunch. And Peter's mum would pick Ellie up and carry her through, and I would sort of think of her [grandmothers] back at first. But then I was noticing Ellie wasn't in a great position either. If her chin comes down, she occludes her airway. So, then we had to be really horrible and say it's not you we're worried about, it's the safety of the children as well."*
>
> *(Cathy, Ellie and Charlie's mother)*

Cathy was worried about the impact the support role was having on the grandparents' health, but more of a concern was the safety and comfort of the children. She spoke about a struggle to take this aspect of the role away from the grandparents, but the grandchildren needed specialist care that was now potentially past the capabilities of the grandparents;

> *"Erm so you've got to be really careful how you, I'm very conscious that we have to be careful how we say things because the grandparents, they've had children themselves, they've brought children up, they know how to look after kids, but this is very different. So, it's trying to find that fine line between them being grandparent but knowing that, you know, the limitations of what they can do."*
>
> *(Cathy, Ellie and Charlie's mother)*

Cathy highlighted that while grandparents will have the best intentions and have experience of raising their own children, there is a difference when raising a child with a disability, an expertise the grandparent may not have. A line needed to be drawn between the *'grandparent role'* and a *'carer role',* which was not so easily done when there were limitations or restrictions on how the grandparent role could play out. Cathy expressed concern about the grandparents' desire to continue to be involved in tasks that may be too physically demanding for them, leaving both the grandparent and the grandchild at risk of harm. Where the grandparents had once been the 'trusted people' to help look after the grandchild, they could no longer be completely trusted, as parents had to consider the safety of the grandchild. Cathy expressed this again when talking about her children's grandparents;

> *"Erm, the same with all the grandparents really, now we wouldn't sort of, now we wouldn't really leave the room. I think with my mam and [Peter's] mam we would because they'll notice if there is something wrong, with the grandfathers I wouldn't. Like I say my dad's completely oblivious. I wouldn't sort of leave him in charge in a room. But there will come a time where they physically just aren't able to do anything to help the children."*
>
> *(Cathy, Ellie and Charlie's mother)*

A previous event where a grandfather had not noticed one of the grandchildren choking meant the parent had lost confidence in leaving him alone with the grandchildren. This was a difficult aspect to face given how supportive and involved the grandparents had previously been and how much parents knew the grandparents wanted to continue supporting them. This loss of confidence resulted in potentially significant renegotiations of the grandparent role. In Cathy's case, she was much more aware of not leaving the grandfather alone with the grandchildren.

The health of the grandparent and the age and care needs of the grandchild were all important in understanding the changing role of grandparents across the lifecourse. All the grandparents had experienced a change in their role with their grandchild, whether for reasons of being physically unable to continue their role, or because they were no longer needed in the same way as when the family were first understanding the grandchild's disability. Changes in the physical aspects of the role and level of need are experienced as part of grandparenting in general (Silverstein and Marenco, 2001; Hank and Buber, 2009; Luo *et al.*, 2012). However, this change is perhaps felt more deeply in grandparents of children with a disability due to their high intensity role to begin with, higher level of care needs, feelings of greater investment in the grandchild and, perhaps, awareness of their *own* disabilities.

6.3 Looking to the Future

"It's just, the thing that you can't learn is what the future holds so you've just got to do the very best you can and that's what we all do." (Elsie, Jacob's paternal grandparent)

Reflections on all the generations getting older and some of the changing roles discussed above naturally led to some comments about the future as all the generations continue to age. Findler and Taubman–Ben-Ari (2016) described grandparents expressing fear and anxiety about who would care for them in their old age if their children were too busy addressing the needs of the grandchild. However, in this study no grandparents expressed concerns for themselves when talking about the future. Whilst it would be inaccurate to conclude they did not have any concerns, these were not expressed in any of the interviews, even when asked directly about their own future. Instead, grandparents' concern focussed on the grandchild and the parent. The next sections explore the concerns and thoughts each of the generations reported having about the future: *the grandchild's future*, *the parent's future* and *the parent supporting the grandparent*.

6.3.1 The grandchild's future

In talking about the future, many grandparents and parents spoke about it with vast amounts of uncertainty and were thinking about what would happen when the grandchild was an adult. Most grandparents and parents avoided or could not explicitly discuss the grandchild's future because there were so many uncertainties in terms of who would continue to care for the grandchild when the grandparents were gone and parents were older, and what the grandchildren's care needs might be as they aged. Whilst everyone seemed conscious and aware of these issues, they appeared to have not been discussed within the family, with an almost purposeful avoidance of thinking about it, let alone discussing it. Some parents and grandparents avoided thinking about the future because they knew it was not promised for the grandchild. While none of the grandchildren had a life-limiting condition, the complex health needs of some of the grandchildren (e.g., seizures, side effects of medication, and tracheostomies) meant they were at higher risk for serious health complications;

> *"I don't know how long Thomas* [grandson] *has with us. He might have one seizure too many one day. I don't know that, she* [mother] *doesn't know that. But we're all very aware that it could happen tomorrow. Or he might be here another 10 years. That's the nature of Thomas's disability with his seizures and one thing and another."*
>
> *(Alice, Thomas's maternal grandmother)*

It was upsetting for some parents and grandparents to think about the future and some of the challenges and difficulties it might bring. For some of the parents and grandparents, the grandchild was still very young, they were still learning about their grandchild's disability and adapting to the grandchild's current needs. This meant that the future was not as imperative at the time of the interview;

> *"[The future] is not really thought about because to be honest at the minute it is still trying to get our heads round how things are going to be with Jesse [grandchild]. Because I mean, he's only just going into year 2 [age 6-7] so we've had a lot of, at the end of his reception year, his reception teacher wasn't sure whether he was going to be able to stay in mainstream school."*
>
> *(Sonia, Jesse's mother)*

Grandparents and parents spoke of an attitude of taking family life one day at a time, rather than trying to predict what might be in the future. Daily life with a child with a disability is often full of the unexpected, therefore a coping strategy often used by parents is to focus on one day at a time rather than trying to constantly anticipate and plan for the future (Gray, 2003; Pryce *et al.*, 2017). Grandparents themselves were also aware that they would not be around forever and were not sure how much of their grandchild's future they would see;

> *"I want, I'm very well aware of, I'm not going to see what the end result is. I'm not going to you know, possibly not see him as an adult and how he's coping in life and I'm determined to do everything I can now to help him, you know."*
>
> *(Margaret, Oscar's maternal grandmother)*

The focus for grandparents was on doing what they could now to help support the grandchild, with a hope this would give the grandchild the best chance for their future. The avoidance of talking about or thinking about the future often seemed to reflect the uncertainty grandparents and parents had about the future and what it may look like. The 'typical' trajectories of family life expected by each generation may not play out as expected for these families, leading to feelings of uncertainty of what would happen. Typically, grandparents would expect their grandchildren to grow up, become independent, and go on to have their own families, with the younger generations providing support to the older generations in their later life. However, for these families, this trajectory was either not possible or uncertain;

> *"Obviously, you know that you haven't got what you would expect in that your grandchild isn't growing up to be a normal man and maybe have normal work and life and relationships and be independent. We don't know that."*
>
> *(Elsie, Jacob's paternal grandmother)*

The hopes that the grandparents had for their grandchild with a disability were different than those they had for other grandchildren or what they had had for their own children. Most of the grandparents commented on an uncertainty of whether their grandchild would live independently, have a job, or have a family of their own one day. Parents in this study and also in other research have also expressed the same concerns over what the grandchild's future would look like and what they would achieve in the future (Heiman, 2002; Graungaard and Skov, 2007). The answers to these questions would have implications for the support needs of the grandchild in the future and plans the family would need to make to continue to be able to support the grandchild.

For the grandchildren with more profound disabilities there was a pronounced awareness among the parents and grandparents that there would be a need for continued and constant support and care to the grandchild throughout their adult life. Hazel (Tyler's grandmother), made a very stark comparison between having a child with a life-limiting condition compared to a child, like her grandson, who has a life-long disability requiring support into adulthood;

> *"But then I think, particularly as Tyler's [grandchild] got older and we've realised the implications for him growing up as he is, sometimes you think well (.), it's not very nice having a child with a life-limiting condition but at least when it's over you can move on from it. Whereas Tyler will always have his disability and it's going to be more apparent and more difficult for him to function in society. I think my daughter particularly gets concerned, you know, what if something happened to them?"*
>
> *(Hazel, Tyler's maternal grandmother)*

Hazel's comparison of her grandson's prognosis to a child with a life-limiting condition was quite a shocking statement to hear but really stressed the concern and worry these families had about the future. It highlighted how differently the trajectories of care were going to play out as all the generations got older and as the grandchild's needs changed over time. Hazel had her own children and several grandchildren with disabilities with various degrees of need. Having her own older children with disability raised her awareness of what the longer-term needs of her grandchild would be, especially given he was more profoundly disabled than other family members and required greater levels and intensity of care.

Grandparents and parents did not know how the grandchild's needs and health would change or what complications may arise in the future, therefore could not think about it. There was only one account that discussed the future with less uncertainty. Mary (Kayla's maternal grandmother), described the plans her daughter had made Kayla's future care;

> *"And then she's [mother] of course, she's got Kayla who's going to have to be cared for all her life. That gets tough for her. But her plans are quite good I think for Kayla. Well she says when she's about twenty, twenty-two she's going to look at residential care for her so that she knows that she's settled and in the right place, can form friendships, just in case anything happens to Ruth [Kayla's mother], you know, she said. It's frightening."*
>
> *(Mary, Kayla's maternal grandmother)*

In this case, Mary's previous job experience in the area of disability as well as her own experience of raising a daughter with a disability had made her aware of the importance of planning for the future, which she had passed on to her daughter. Whether this type of support would be available or accessible in the future is not certain but planning in this case eased some of the uncertainty experienced by other parents and grandparents. Even though other grandparents also had similar experience of disability to Mary (as described in Chapter 4, section 4.2.2), they did not set out plans as clearly as Mary did. Mary's daughter had more than one child with a disability therefore it may be possible that this pushed the family to think more about the future support needs of the family.

As has been described in the previous chapters, the care and support for the majority of these grandchildren came from within the family. This leaves serious questions about who will take over this support when there are no immediate family members alive (e.g., parents, siblings, grandparents) or when the trusted grandparents and parents cannot provide the care and support needed. In nine of the families the grandchild had one or more siblings without a disability. Parents and grandparents did not explicitly state that they expected or would presume that the sibling would support and care for the grandchild with a disability when no-one else was around. However, many took comfort in the fact that there would be a family member to look after the grandchild and help advocate for them when they were older;

> *"But I said to Patrick [Brian's father], "Basically Patrick, if it comes to it Brian [child] will be living with us forever." I then I just don't think I'll be able to die basically. And then I have to make sure Blake [Brian's brother] will look after him if I wasn't here. Which he, he would, I know he would. Not that I would mention it now because I wouldn't want him to think oh my god I have to look after Brian for the rest of me life and he gets on me nerves singing Teletubbies all the time. But erm, in the future when they're grown men and that, you think that, hopefully."*
>
> *(Lauren, Brian's mother)*

Parents did not want to put the responsibility for the child with a disability onto their other children, but they hoped in the future the siblings would be supportive to each other. Again, this was just a hope rather than a certainty about who would provide the continued support to the grandchild if needed. Where siblings were present, their support in the future was generally expressed tentatively rather than as something that had been explicitly discussed. Many of the siblings and grandchildren were too young for these conversations to take place. As children with disabilities live longer lives with the advent of medical advancements, and with the difficulties experienced in transition to adult social care (Care Quality Commission, 2014; Colver *et al.*, 2019), and the cuts to adult services (Local Government Association, 2017; Graby and Homayoun, 2019), responsibility for support is more often falling on siblings when parents are no longer alive (Heller and Arnold, 2010). However, just as the parents described in this study, siblings are generally not being included in conversations and plans for caring for their sibling in the future (Heller and Kramer, 2009). It was not just the life trajectory of the grandparents and parents, but also of the other children that was being considered in thinking about the future. In the families where there were no other siblings the concern was then around who *would* be there for the grandchild in the future when both grandparents and parents were no longer around;

> *"And no siblings for Jacob* [grandchild]*. Not that you want to have children to look after him because that's not really the way it works is it. And you wouldn't expect anybody else to do it. But erm, it's just somebody looking out [for him]."*
>
> *(Elsie, Jacob's paternal grandmother)*

Grandparents and parents all expressed concern for the grandchild's future. Most of this concern was related to the fact that there was so much uncertainty about what the grandchild's future would look like. For some this uncertainty was around the complexity of the grandchild's disability and the health complications it could bring, but with an implicit understanding that the grandchild would need lifelong care and support. For others, the uncertainty was based around how much independence the grandchild would have; would the grandchild need lifelong support? Finally, as one family were already experiencing, the lack of suitable provision for adults with a disability also leads to uncertainty about what support would be available for the grandchildren as they grew up.

Transitions into adolescence and adulthood are complex and difficult for young people with disability (Care Quality Commission, 2014; Colver *et al.*, 2019). There is an important role for services in helping families plan for these transitions early, however such service provisions are sporadic in England (Kirk, 2008; Mitchell and Beresford, 2014). Much of the current literature on grandparenting in the context of disability has focussed on children, with very few considering the roles and experiences of grandparents of young adult or older adult grandchildren who are either in residential support or remaining in the family home. This was a future many of these families would be facing.

6.3.2 The parent's future

For the grandparents, it was not just concern for the grandchild's future that was expressed. Many also spoke about their worries for the parent, their adult child, and what their future would be like continuing to raise a child with a disability. All the concerns grandparents had about the grandchild's future led to concerns about the parents' future. Grandparents expressed worries about how the parents would be able to continue to provide the level of care they currently did.

For example, Andrew (Charlie and Ellie's maternal grandfather) was concerned about how his daughter and son-in-law would be able to continue with the level of physical care needed by the children and the impact this was having on the parent's own health;

> *"Within another year they're [parents] definitely going to be in big trouble if they don't have something [house] more suitable. It's er, it's ridiculous the way it is. You feel so helpless when you can't do anything about it for them. We've helped them out in a lot of ways with one thing and another but, erm, with that there's nothing we personally can do to change anything for them unfortunately."*
>
> *(Andrew, Ellie and Charlie's maternal grandfather)*

The grandparents' awareness of their own physical restrictions to support the grandchild raised concerns about the parent's physical health and their continued ability to care for the child, particularly when the right supports were not currently in place. As well as the physical effects, grandparents were also concerned about the parents' levels of stress and ultimately their ability to cope into their own later life. This was particularly prominent for the grandparents of single parents. They worried how the parent would cope when grandparents were no longer around to support them;

> *"I'm more concerned with Diane being on her own. And I can see that she's stressed out."*
>
> *(Pearl, Harrison's maternal grandmother)*

As has been described in the previous two results chapters, grandparents were a vital source of support to the parent. They provided childcare that allowed the parent to work, provided respite for the parent and were a source of much needed emotional support. Grandparents worried how parents would cope and who would take these roles when they were gone. This is consistent with findings from previous studies where grandparents express a fear of dying, not for themselves but because of the possible implications this would have on the family unit (Miller *et al.*, 2012; Moffatt *et al.*, 2019). Grandparents struggled to envision how the parents would manage without their ongoing support. Throughout the interviews this deep concern was rooted in the view that UK services for children with a disability and parents were inadequate. Parents and grandparents told stories about being let down by services and struggling to access appropriate support services;

> *"And as the years have gone by the help has got less and less. They've cut back on so many services, certainly in this area."*
>
> *(Alice, Thomas's maternal grandmother)*

The impact of cuts to welfare payments for people with a disability and public sector services mean the future adequacy and availability of these support services is highly uncertain. Despite this, many of the parents who were not already accessing formal support services suggested them as an alternative when the grandparents were no longer able to support them. For example, Lauren (Brian's mother) spoke about using after school groups or trying to access direct payments[3] for a support worker in place of some of the grandparent support provided. Malachi's parents spoke about looking into respite support for him in the future, especially now that the grandparents were struggling with health problems and spending less time with him;

> *"Yeah, and I think in the future, certainly, well this friend she's got foster children and one thing, we've been offered respite, but I've like, no we're family and we do things as a family. But when these foster kids go to respite, they go to a friend's house they don't go to strangers' house. They absolutely love it. And err, it just made me think, oh perhaps we could look into that, having a friend who looks after him. Because the thought of him going somewhere, I mean he would get used to it, but if I know the person and I know they are good, they'd have to qualify, and they tick all the boxes, you know, because it's a contract agreement isn't it."*
>
> *(Whitney, Malachi's mother)*

The support that interviewees reported was often kept within the family, therefore the thought of an 'outsider' being involved in the support of a child was daunting. Parents spoke about accessing respite care or support workers through direct payments as a way of maintaining some respite when the grandparents could no longer provide it. These were always suggested as a possible idea rather than set plans. As Whitney described above, a key issue in thinking about future care needs of the grandchild was finding a person/service who was capable, trusted and an acceptable substitute to grandparent care.

Families faced the paradox of trying to plan for an uncertain future. The uncertainty of the future, what the support needs of the grandchild might be and when grandparent support might reduce or disappear, meant plans were not spoken about or made, adding to grandparents concerns and worries for the future. Though for the parents their future and the grandchild's future were a concern, it was something they felt would be dealt with when the time came. Of more pressing concern for the parents was what the care and support needs of the grandparents would be, as is discussed next.

---

[3] If a child has been assessed as needing social services support by their local authority or NHS trust, families have the option of asking for Direct Payments instead of receiving the support arranged by the local authority. Direct payments give the family the ability to choose and purchase services or support they feel they need, as agreed by the local authority. For example, employing a carer themselves rather than having a carer organised through the local authority (National Health Service (2019) *Personal budgets and direct payments*. Available at: https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/ (Accessed: 18th July 2019).

6.3.3 Parents supporting grandparents

In contrast to the grandparents' accounts that focussed on what would happen once they were gone, parents were more concerned about the time leading up to that situation. Within the parent accounts, there was a strong sense that they at some point would be the main source of support to their parent. It is typically found that adult children, daughters and daughters-in-law in particular, provide support or assistance to their ageing parents when they start to experience declines in health associated with ageing (Gans and Silverstein, 2006). Some parents were already experiencing this with grandparents needing more support following diagnosis of health problems. Not long before I interviewed Whitney and David, David's mother had been diagnosed with a potentially terminal health condition and she was going through intensive and potentially long-term treatment;

> *Researcher: Yeah so have things sort of flipped over now with you guys providing more support to them [grandparents] now?*
>
> *Whitney: Yeah yeah yeah.*
>
> *David: [Whitney] comes like a day a week and clean and do their house.*
>
> *Whitney: And then Henry [grandfather] got on board with that. And then just making sure, part of her [grandmother's] voluntary work is studying the bible with a lady and she's asked me to join in on that because sometimes the treatments were too awful so, you know. Erm, which is, it's a pleasure, I've enjoyed it. So, it's you know, just making sure that when she's [grandmother] been at home just saying, listen come to ours, you know, you're safe there, you know, you've got everything you need at our house. You feel safe and secure, just come. So, so we've, you know, we've just made more of an effort really, just saying, see what they need and trying to fill it a bit.*
>
> *(Whitney and David, Malachi's parents)*

Within this family there had been a shift in the support dynamics with the grandparents taking a step back from involvement with the grandchildren, to now the parents, particularly Whitney, playing a key role in supporting the grandparents. This permanent shift in support dynamics was met with differing opinions across the families interviewed. For some, such as Whitney and David above, it was seen as a natural progression and something they were more than willing to and capable of doing. For others however, the potential support needs of the grandparents in older age were a great concern. In Malachi's family the support was being shared across a bigger network with high levels of solidarity, therefore both the physical and emotional demands of support across the generations could be shared. Whereas in other families, such as single-parent families, the network for support was smaller. For example, Diane (Harrison's mother), who was a single parent was very worried how she would cope with managing the support needs of her son and the support needs of her parents;

> *"Erm but I do worry about that [support to parent] because then I worry about how, because obviously Harrison's needs are getting more now. I worry how I would cope with that, with having to look after them as well."*
>
> *(Diane, Harrison's mother)*

For Diane, her son was going to need continued support well into his adult life. Despite her having a sister nearby, she felt the duty to support her parents was falling to her. She was the one who had been given instructions on her parents' finances and important documents for when they were needed;

> *"Yeah, and I know that would come down on me. And I've already been shown where all the paperwork is, and everything is. And although I've got me sister, I know for a fact it would be me that did it more than she did it, because I live around the corner."*
>
> *(Diane, Harrison's mother)*

This obligation to potentially support grandparents in the future was described by Green (2001) as an emotional burden for the parents of children with a disability as parents feel torn between the needs of the child and the needs of the grandparents. The parents were facing a future of potentially competing roles as they cared for both their ageing child and their ageing parents, much like the competing care roles the grandparents described in the previous chapter (section 5.5.3).

While parents were thinking about the potential support grandparents would need in the future, the grandparents had an almost 'denial' approach to this aspect of the future. Despite thinking about everyone else's needs, they did not discuss their own potential needs in the future. Two of the grandmothers had considered their death arrangements with one grandmother describing the plans she had made for her funeral and to cover the costs. However, she did not discuss the time leading up to that point and what support she would need before then. Another grandmother spoke about not wanting to be a burden on her sons when she was older, however even then she hoped there would not be a period of ill-health or dependence prior to death;

> *"Only because, I felt like…. I wouldn't say my mum was a burden. I have, there are four of us. I have a brother and two sisters. I was the only one that lived in [PLACE] so I dealt with everything. I dealt with her [mother's] finances, when the house was emptied, everything. So, it fell to me all the time. So, I would go to see her sometimes and she'd be absolutely foul to me and Karl [grandfather] would say "Well why do you go back?" And I would say well I promised me dad I would look after her. Now I would hate to put that onto my boys, I really would. So, like I say, I think I would rather not be here when I get to that stage."*
>
> *(Amanda, Samuel's paternal grandmother)*

Grandparents in this study who had gone through the experience of caring for and supporting a parent at the end of their life, described not wanting their own children to experience that with them. Grandparents really did not want their children to be worrying about taking care of them as well as looking after the needs of the grandchild. This is in contrast to Findler (2016) who described some of the pain grandparents of children with a disability felt was associated with a fear their children would not be able care for them in their old age. This difference may possibly be due to various cultural differences, including in filial obligations, with these being higher in Israel than in England (Lowenstein *et al.*, 2004). Even though grandparents did not wish for this, parents were aware these support needs may fall on them in the future, and some were already providing support to grandparents who had health issues.

6.4 Conclusions

In this chapter I have discussed how the experience of being a grandparent to a child with a disability changed over their time caring for the grandchild. There is limited research that has looked at the changes in grandparent-grandchild relationships as each generation ages in the context of grandchild disability (Heller *et al.*, 2000; D'Astous *et al.*, 2013). Drawing on the perspective of 'linked lives', each individual's life was embedded within the lives of their other family members in generations both older and younger than themselves (Macmillan and Copher, 2005; Gilligan *et al.*, 2018). The life events, trajectories, and transitions experienced by one individual had effects on the lives of other family members (Bengtson *et al.*, 2005). The needs of the grandchild changed as they grew older, with some developing more complex needs and others showing some improvements and greater independence. Alongside this, the grandparents were also ageing and beginning to face health problems and challenges associated with later life. Each generation's ageing posed challenges for the families as the demands of grandchild support, ability to support, and future support needs of each generation changed. Grandparents faced a challenge of no longer being able to provide the practical support their family required, while parents faced the potential challenge of trying to meet the support needs of ageing grandparents. Parents (the adult children) in particular faced a challenge of going from being the receiver of intergenerational support to potentially being the giver of support to generations above and below.

Acknowledging the new challenges posed by grandparents and grandchildren's ageing required continual renegotiation of the support needs and resources. Both grandparents and parents were experiencing changes in their roles over the lifecourse. Adjusting to these changes was not always easy, especially for grandparents. The meaning of grandparenthood to them was tied to the intense level of support they provided to their grandchild with a disability and the knowledge and expertise they had gained in supporting them. There was a continual shift in support dynamics as each generation moved through the lifecourse. Most families will go through these role transitions, with grandparents losing some of the contact time with their grandchildren (Field and Minkler, 1988; Silverstein and Long, 1998), and parents taking some of the responsibility for assisting ageing grandparents (Lowenstein and Daatland, 2006). However, in the context of disability, the “normal” lifecourse was disrupted. The expected trajectory of grandchildren in this study growing up to be independent and needing less parental support was not always attainable. The grandchildren were going to be dependent on parental support and societal provision for support of complex needs throughout their lives. The potential future needs of the grandchild could have an impact on the availability of parents to support grandparents. However, within all this, the accounts from both grandparents and parents showed a strong sense of duty and obligation to support their family for as long as they could. Intergenerational solidarity seemed to encourage continued support from grandparents to their adult child and grandchild. Even though the functional solidarity (i.e. practical support) may change over time, the high affectional solidarity meant grandparents still did the best they could for their family. More so, while their functional solidarity levels may be decreasing, the parents’ functional solidarity to the grandparents was increasing (or was expected to increase) as the grandparents needed it.

There were multiple factors that influenced or could potentially influence the accounts interviewees gave about the future. These included the type of disability, family life, grandparental health, and input from support services. Grandparents ‘denial’ of their own care needs because of their focus on the downwards generations also influenced how the future was discussed. There was no predicting what the future would bring for each of these families. This left many of the parents and grandparents with worries and concerns about the future, the main concern being the continued support of the grandchild, and in turn who would continue to support the parent. Families faced a paradox of planning for an uncertain future and had very little professional support in doing so. With much of the support coming from within the family, support services were suggested as routes to take in the future. However, with the cuts to welfare support and services in the UK for families with children with a disability, this option is also filled with uncertainty (Hastings *et al.*, 2015; Horridge and Laing, 2015). The narratives from these interviews highlighted the importance of looking at the ageing trajectories of the family as a whole rather than an individual’s ageing. The trajectory of disability and need within each of the generations had infinite possibilities, which created vast amounts of uncertainty that needed to be managed within these families.

Chapter 7. Discussion

7.1 Summary

The opening chapters of this thesis outlined the importance of grandparents in contemporary family life, particularly within families of children with a disability experiencing the impacts of austerity in the UK. The literature review drew attention to the limited knowledge of the experience of grandparents of children with a disability in the UK, in particular from the grandparent perspective. Chapters 4 to 6 have provided insights into the experience of grandparenthood in the context of grandchild disability that have been largely undocumented in the UK and build on the literature presented elsewhere. This thesis has provided important understandings about, and advances in scholarship on, the experiences of grandparenthood, experiences of ageing, and experiences of providing care across generations.

To briefly summarise, Chapter 4 detailed the grandparent experience of diagnosis, revealing the range of experiences in receiving the diagnosis, with grandparents' reactions being affected by the timing and the experience leading up to the diagnosis. Grandparents found strategies to adapt and adjust to having a grandchild with a disability including continuously modifying expectations, taking extra pride in the achievements of the grandchild, and becoming an 'expert grandparent'. In this chapter the emotional work carried out by grandparents was highlighted and this was further explored in Chapter 5 with efforts to maintain intergenerational harmony. By gaining both the parent and grandparent perspective on the relationship and support, many of the complexities behind the provision of support were revealed, including managing conflict, negotiating the boundaries of roles, and managing competing roles. Finally, in Chapter 6 the ways in which this intergenerational support changed over time as the grandparents, parents, and grandchildren aged were described, and issues of the interplay between family and state support (or lack thereof) of both a younger and older generation in need of help were raised. The main theme in discussions of the future from both the parents and the grandparents was uncertainty. Families faced the paradox of planning for an uncertain future.

In this final Chapter I present some interlinking themes that draw the findings together and provide some novel perspectives on the experience of grandparenthood in the context of grandchild disability. The implications of the findings for both practice and policy in the UK and further afield, will be presented as well as the limitations of the study and suggestions for future research.

7.2 Key Issues for Grandparenting in the Context of Grandchild Disability

Within the interviews grandparents often described themselves as just doing what grandparents do. They described their role as playing out the 'normal' role of grandparents, but at the same time they made comparisons to 'normal' grandparents and described how their role was different to how they expected. There were many aspects of grandparents' roles and the types of support they were providing that would be seen across all grandparents, regardless of whether the grandchild had a disability or not. Grandparents of grandchildren without a disability also provide vital practical, emotional, and financial support to their adult children and grandchildren (Dunning, 2006; International Longevity Centre, 2017). There is a wealth of evidence in particular for the role grandparents are playing in providing childcare to working parents, especially working mothers, or providing 'complimentary' childcare for parents who work evenings or weekends (Wheelock and Jones, 2002; Gray, 2005; Glaser *et al.*, 2013). This type of support mirrors that which grandparents of children with a disability are providing and therefore raises the question of whether their roles are any different. In my opinion from the results of this study, while some types of support may seem similar on the surface, the intensity of support provided by grandparents of children with a disability, the amount of emotional work with these families and the uncertain futures faced by families makes the experience of grandparenthood in the context of grandchild disability very different.

There are challenges that all grandparents have to negotiate when defining and enacting their role as grandparent. The negotiations that grandparents in this study made in terms of balancing "being there but not interfering", balancing their own and parents' paid employment with childcare, and balancing supporting their family versus having their own life, are negotiations that grandparents of children without a disability are also making (Mason *et al.*, 2007; Meyer, 2012). This is perhaps especially true of contemporary grandparents who have multiple roles in their social life, family life and working life (Arber and Timonen, 2012; Leeson, 2018).

Within the current literature on grandparenting children with a disability, some findings have indicated no difference in the amounts of support provided by grandparents of children with or without a disability (Pit-ten Cate *et al.*, 2007; Findler, 2014). Woodbridge *et al.* (2011), in their study of 22 Australian grandparents of children with a disability, also determined that similar grandparenting styles (e.g., surrogate parent, fun-seeker and reservoir of knowledge) and functioning grandparent identities were experienced by grandparents. They concluded that the type of role is similar, it is just the way in which it is enacted or the context in which it is enacted that differ. Though I did not conduct a comparative study, throughout my analysis I also found myself considering how the experience of grandparenthood was different in the context of disability compared to grandparents of children without a disability. At first glance the role may look similar, but the results of this study highlighted important differences in the reasons behind grandparent support and the experience of grandparenthood in the context of disability. Grandparents appeared to be trying to enact the grandparent role as they expected it be by spending regular time with the grandchild, being there for their family, and helping the family with practical and emotional support. However, the way they could enact the role was not necessarily affected by the fact the grandchild had a disability but by the wider social context grandparenthood was taking place in. There were some cases in which the grandchild's disability put some restrictions on how the grandparent role could be enacted but there were many factors outside the grandchild's disability that impacted the way the grandparent role is experienced in the context of grandchild disability. This included the influence of the social care available to the families, the grandparents' own health and ability, and the availability of appropriate and supportive social environments.

In the following sections I draw attention to five key issues arising from the analyses presented in the results chapters that I believe distinguish the differences in being a grandparent in the context of grandchild disability and add to the understanding of the experience of grandparenthood in this context: intensity of the grandparent role, emotional work, grandparents as a substitute for formal support, level of grandparent agency, and the family trajectory.

7.2.1 Intensity of the grandparent role in the context of grandchild disability

The first key issue concerns the intensity of being a grandparent to a child with a disability. The volume of support, type of support and skills required to support a grandchild with a disability and the parents intensified the grandparenting role. The grandparents and parents had expectations of what grandparenthood would be like, however for many, the realities of the role were different from the idealised vision they had, with the intensity of their role being much greater. This was both in terms of the time spent providing care and support, but also in terms of the emotional and physical demands of providing support. Their role as a grandparent entailed additional tasks including carrying out important care tasks, administering medications, giving therapy, and acting as an advocate to try to gain appropriate schooling and formal support for the grandchildren. Grandparents had become expert informal carers. They knew detailed information about their grandchild's disability, the needs of their grandchild, which health professionals were involved in their grandchild's medical care and knew teachers and teaching assistants at their grandchildren's schools. They had acquired new skills they never imagined they would need or ever learn. This is a big undertaking for many people, and while it is recognised that many parents go on a sharp learning curve when a child is diagnosed with a disability, it is less recognised the masses of skills and knowledge grandparents are acquiring as well. Other research has highlighted the extent of grandparents information needs (Engstrand *et al.*, 2019; Prendeville and Kinsella, 2019), however in this study grandparents demonstrated the vast amount of work they had put in themselves to gain this knowledge and the necessary skills to take care of their grandchildren. This was a continual process as the grandchild aged, the disability became more complex and as the grandchild and family engaged with new services and supports.

The responsibility of some of these tasks increased the intensity of the role. For example, childcare took on a different meaning for these families compared to other families. Childcare did not mean keeping an eye on their grandchild as they played, watched television, or did their homework. Childcare in the context of disability was watching over the child constantly for several hours, making sure they were safe, checking if they needed medication, and providing intimate personal care. The consequences of grandparents not fully engaging in these tasks when taking care of the grandchild were also much greater. Missing medication, or the grandchild experiencing a health crisis, could result in a stay in hospital or could potentially be life-threatening. This greater responsibility, and sometimes length of time spent with the grandchild, intensified the grandparent role both physically and emotionally.

Finally, another aspect of intensity of grandparenthood in this context was the double-jeopardy grandparents experienced in their role. They were both a concerned parent and a concerned grandparent. The ‘double concern’ experienced at the time of diagnosis changed to ‘double worry’ within their relationships and when thinking about the future. As described in Chapter 6, the impact of events for each individual family member was felt by all the family members. Grandparents were feeling the impact of the diagnosis on the grandchild and the impact of this on their adult child. When new diagnoses, events, or crises occurred, while parents would be focussed on the grandchild, grandparents were considering how this would affect both the grandchild and their adult child and were focussed on trying to provide support to both generations. This double-jeopardy increased the intensification of grandparenthood in the context of grandchild disability.

7.2.2 Emotional work of grandparenting in the context of grandchild disability

Throughout the results chapters part of the intensity of the role was the amount of ‘emotional work’ being exerted by the grandparents. This emotional work could come with as much cost to the grandparents’ and parents’ health as much as the physical work involved in caring for a child with a disability. In Chapter 4 the emotional work of managing and masking their own emotions was described by grandparents, and then in Chapter 5 the vast amounts of emotional work carried out by both grandparents and parents was described to maintain intergenerational harmony. Hochschild's (2003), ‘The Managed Heart’, focussed on the ‘emotional labour’ carried out by air hostesses through the regulation and management of their feelings in order to make others feel safe and cared for. The concept of emotional labour has continued to be investigated in the work place, in particular in paid care work such as nursing (James, 1989; McQueen, 2004). This emotional labour can be as demanding and skilled as the physical care being provided (James, 1992). There has been a growing appreciation of the emotional control, management, and training associated with care work, leading to this being described as a form of labour (McQueen, 1997). Attention to emotional labour in paid care work settings has also drawn attention to the ‘emotional work’ carried out by family caregivers. Emotional work, in contrast to labour, refers to unpaid efforts of looking after another individual and supressing feelings (Hochschild, 2003). Research with family caregivers of individuals with schizophrenia (Winefield, 2000) and ASD (Beckett, 2018) have drawn attention to the emotional work within these roles, including supressing their own emotions, following ‘feeling rules’ by hiding feelings of being overwhelmed or stressed, and managing conflicting feelings of love and frustration. Work by Exley and Letherby (2001) also demonstrated how emotional work can have an important role in managing life disruptions. This research with women with terminal illnesses, infertility and voluntary childlessness, described the emotional work in managing their own identities and emotions in front of others, and in managing the emotions of others. In a similar way, having a grandchild with a disability may be seen a disruption in the lifecourse of a family. Grandparents were carrying out vast amounts of emotional work to help with their own and their adult child’s processing of this potential disruption in their lifecourse. It is widely acknowledged that grandparents provide emotional support, however the findings of this study highlighted the amount of emotional work that went into grandparents being able to provide the support that they did. This aspect of the role has not been previously acknowledged or discussed in detail in other literature in this context or considered when comparing grandparents of children with and without a disability.

The concept of emotional work could hold a lot of importance in the understanding of the experience of grandparents in the context disability. Throughout the interviews there were descriptions of grandparents struggling over decisions of whether to raise their concerns about their grandchild with the parent, masking their emotions (e.g., upset at diagnosis), and working to protect their adult child and grandchild from any distress. The grandparents were constantly making decisions about how best to support their family, to whom and when to disclose information or their concerns, and how to respond to their family’s distress. All the while they were also trying to manage their own emotions. Grandparents' management of some of the ambivalence that they experienced in their role could also be described as emotional work. Grandparents described managing their feelings of enjoyment of being a grandparent and huge amounts of love for their family, alongside expressing the hardships of their role sometimes and frustration at the circumstances. Margetts *et al.* (2006) described grandparents as keeping the family intact and Miller *et al.* (2012) discuss grandparents holding on to their emotions. These are all forms of emotional work that grandparents are carrying out. This emotional work is largely invisible in comparison to the practical support grandparents provide and goes largely unrecognised by professionals and policy currently. It is also important to recognise that this emotional work came with a lot of skill as well. Just as grandparents were learning new medical skills or communication skills, they had also become very skilled in doing this emotional work. Such emotional work also appeared to be highly gendered, with grandmothers much more likely to describe this form of work within their role.

Most researchers using the concepts of 'emotional work' or 'emotional labour' agree there is a gendered division of the work, with women most likely to be doing the work (Frith and Kitzinger, 1998; Exley and Letherby, 2001; Strazdins and Broom, 2004). Emotional work is often assumed to be a 'natural' responsibility or role of women and is potentially tied in with the gendered division of kin-keeping activities as well (Eisenberg, 1988; Wiscott and Kopera-Frye, 2000; Dubas, 2001). While gaining this skill was helpful in maintaining intergenerational harmony, it could also take an emotional toll on the grandmothers, intensifying their experience of grandparenthood in the context of grandchild disability. Authors have also highlighted the "costs of caring" (Kessler and McLeod, 1984) and how the gender imbalance of emotional work may be an additional cost (Strazdins and Broom, 2004). Costs can come from emotional exhaustion, emotional dissonance, lack of control and emotional contagion. Within these families the amount of emotional work being conducted means there could be greater costs to these mother and grandmothers of carrying out emotional work. Not only are they taking on the majority of the physical care work, they are also taking on the majority of the emotional work, increasing the gender cost of caring in the context of grandchild disability.

7.2.3 Grandparents as a substitute for formal care

Another question I often asked when analysing the transcripts was about how much grandparents of children with a disability were acting as a substitute for formal support services and care. As described earlier, it would not be unusual to see grandparents providing childcare for working parents who cannot afford the high prices of formal childcare or need complimentary support (Dunning, 2006; Glaser *et al.*, 2013; Di Gessa *et al.*, 2016a). For a minority of the families in this study, grandparents were only providing complimentary childcare when needed at weekends or occasional evenings. However, for the majority of the families there was no other choice/option but to turn to grandparents for regular daily childcare. As has been stated throughout this thesis, parents of children with a disability struggle to access appropriate childcare facilities in terms of finding available and affordable places (Every disabled child matters, 2011). The recent report from Contact a Family (2018) on the costs of care reports how the provision of affordable and suitable childcare for parents with children with a disability is still very limited. Alongside this, the additional costs of having a child with a disability are increasing (John *et al.*, 2019), while financial support is decreasing through major changes to the UK's welfare system (Horridge and Laing, 2015; Horridge *et al.*, 2019). Alongside this Local Authorities have faced drastic budget reductions since 2010 (Hastings *et al.*, 2015; Gray and Barford, 2018) with severe consequences for funding of their own support services, in addition to the funding they give to charities supporting families with children with a disability (Hastings *et al.*, 2015). A clear example of the effects of these cuts was the closure of our collaborators service, Contact North East, during the course of this study.

Furthermore, issues of trust in the capabilities of staff to care for the child and fully meet their needs have been raised (Cramer and Carlin, 2007; Emira and Thompson, 2011; Contact a Family, 2015). The parents in this study were experiencing these struggles in terms of childcare and access to support services, therefore grandparents had become the only alternative option. For parents of children with a disability, respite care services are an important support in coping with some of the demands of caring for a disabled child (Chadwick *et al.*, 2002; Kelly *et al.*, 2019). In many cases grandparents were acting as this respite support for their family, again for reasons of availability and perceived suitability of the respite services being offered. The lack of availability, affordability and trustworthiness of support services was creating an unmet need and a dependency of parents on grandparents to fill this care gap and act as a substitute for formal support.

The political economy approach to grandparent support suggests the level of support provided by grandparents is to fill the unmet needs of families due to a lack of formal support services and welfare support (Estes, 2001; Luo *et al.*, 2012; Phillipson, 2015). This hypothesis has been supported by evidence of differences in grandparent involvement across countries with differing welfare provision. Where there is higher welfare state support for childcare, there is lower grandparent involvement in childcare and vice versa (Daatland and Lowenstein, 2005; Saraceno and Keck, 2010). Certainly, in my interviews there was an unmet need described by parents and grandparents in support for the grandchild, especially when the parents were working. In particular, mothers who worked shift patterns (e.g., evenings, weekends, night shifts) described difficulties finding childcare options that could accommodate flexible working and shift patterns. What came out clearly from this research was that the 'usual options' of childcare such as the local babysitter or asking a school friend's parent to look after the child for a couple of hours, were not options to them because of the grandchild's additional needs.

The UK welfare state has, since the passing of the *Welfare Reform Act* (2012), undergone the biggest reduction in welfare provision and spending since World War II. This means more care is coming from within the family rather than from external agencies, particularly with changes in the state welfare benefits system leaving families worse off financially than previously (Contact a Family, 2018). This has created a sense of dependency in families of children with a disability on grandparents to fill the care gap. Grandparents in particular have become the main source of support due to their perceived availability (retired or reducing work hours) and a normative pressure to be involved in childcare duties (Mason *et al.*, 2007; Jappens and Van Bavel, 2012). In Chapter 5 these dependencies were explored, and grandparents described feeling pressure to be there for their family, discussing changes they made to their own plans, including work, social activities, and even trying to make sure they stayed as healthy as possible to be available for as long as possible. Grandparents were filling the care gap.

That said, it is also important to consider the relationships between the generations within families that allow grandparents to step in and fill the unmet need. The intergenerational solidarity theory (Bengtson and Roberts, 1991) has guided much of the study of support in parent-child relationships across the lifespan. The theory posits that relationships high in affectional solidarity tend to involve frequent support (Bengtson and Roberts, 1991; Silverstein and Long, 1998). The families in this study all expressed high levels of affectional solidarity towards each other which seemed to be conducive to a positive supportive relationship between the generations. Affectional solidarity has been found to be a significant factor in predicting grandparents' involvement in families with children with a disability, with those higher in affectional solidarity in the grandparent-parent relationship, having greater involvement (Mirfin-Veitch *et al.*, 1997; Schilmoeller and Baranowski, 1998; Baranowski and Schilmoeller, 1999).

These expressions of solidarity that I observed lead me to postulate that it is more than filling an unmet need that motivated grandparents' levels of support. The complexity of the interactions between intergenerational support and formal support services was highlighted in Chapters 5 and 6 when families were beginning to think about the future care needs of the grandchild as grandparents became less able or available to provide the level of support they had previously. Grandparents' strong emotional connection with their adult child and grandchild gave them a desire to be involved in care, but the unmet need, and the dependency this created, was also having an influence on the grandparent support. Evidence from other European countries and analysis of the interaction of intergenerational support and welfare supports suggests that grandparent care and formal childcare/supports could complement each other and reduce the intensity of the role for grandparents (Igel and Szydlik, 2011). In the context of grandchild disability, grandparent support and formal support complementing each other, rather than always compensating or substituting for each other could be an optimal situation for families. In terms of thinking about contemporary grandparents who may have, or wish to have, an active lifestyle or still be in employment, a 'crowding out' of the intensity would allow for a greater balance between childcare and maintaining their own life, possibly decreasing some of the ambivalence grandparents currently felt towards their role, and allowing grandparents a greater level of agency in their role.

7.2.4 Grandparent agency

Leading on from the discussion above, while the parents may have felt they had no choice of who to turn to for support, grandparents were exerting some degree of choice over what support and the amount of support they provided. The findings highlighted the considerable amount of negotiation and grandparental agency that enabled grandparental support. Grandparents set boundaries on their role to make sure their involvement remained at a level they were satisfied with (to an extent). For example, grandparents described keeping certain days or hours 'free' from childcare to be able to see friends and described discussing with their adult children when the level of support they provided was becoming too much. Similarly, when looking at grandparent's decisions to remain in work, the work place served a number of functions for the grandparents; it protected grandparents' time from being asked to be more involved in support activities, it provided some financial security in later life, a form of emotional support for the grandparents, and provided structure and social engagement beyond the family (Carmichael and Charles, 2003).

Grandparents were also expressing agency in how they built a relationship with their grandchild. Many of the themes identified by Timonen and Doyle's (2012) work on grandparenting after adult children's divorce were also described by this group of grandparents. In both cases grandparents are responding to a form of crisis where they try to fill a gap from perceived loss (financial loss, free time), they negotiate boundaries around the support they provide, and they exert agency by finding strategies and activities that allowed for more optimal contact and interaction with their grandchildren. The adaptations and adjustments described in

Chapter 4 and negotiations in Chapter 5, were methods grandparents were using to try to build their desired relationship with their grandchild. However, as Timonen and Doyle (2012) highlight, while grandparent agency can be present, it can be compromised by an adult child's dependency. In this study grandparents' agency was constrained by the welfare provision and size of the family network. Parents often had no choice but to turn to grandparents for support. This dependency, alongside grandparents' strong feelings of kin-keeping responsibilities and obligation reduced grandparents' ability to exert agency when they wanted, leading to feelings of ambivalence. This effect of dependency was seen in contrasting accounts by grandmothers in this study. When I interviewed Clara (Miles's maternal grandmother), she was very clear that it was <u>her choice</u> to be as involved as she was with her grandchildren. She asked to have her grandchildren to stay with her every weekend and wanted to spend that time with them. Her daughter worked part-time hours that fitted around school hours and had support from her partner and the paternal grandparents as well; therefore, the level of dependency might be seen as lower. In contrast, Patricia and Terry (Dylan's maternal grandparents) felt they had <u>no choice</u> but to provide the amount of support they did because their daughter was a young single mother, worked shift patterns and because there were no other grandparents or sources of support available. If it were their choice, they would not have given the same hours of support, but the parents' work and lack of options meant their daughter was dependent on them. The contrast in examples demonstrates how grandparent agency may be affected by parents' level of dependency. This level of dependency was influenced by the complexity of the grandchild's needs, parents' relationship status (e.g., single parent, divorced), the family network, parents' working patterns, and by the availability of welfare support.

Grandparent agency in how they enacted their role was also compromised by limitations of the social and structural context that make it difficult or impossible for children with a disability to access suitable facilities or support outside the family. Grandparents spoke about wanting to take their grandchildren to soft play or having their grandchildren to stay overnight. However, being able to find suitable environments that would support their grandchild's needs was difficult or being able to access funding for specialist equipment for the home that would allow them to care for the child in their own home (e.g., hoists, special beds) was not possible. Connidis and McMullin (2002) refer to this as a type of structural ambivalence where social structural arrangements conflict with individuals' attempts to exercise agency. Environmental barriers to children and young people's participation in leisure activities when they have a disability has been widely reported, with issues of transport to facilities, the physical design of spaces, and the availability of programs that can accommodate for a child's needs acting as barriers to participation (Shikako-Thomas *et al.*, 2008; Anaby *et al.*, 2013; Shields and Synnot, 2016). For grandparents of children with a disability their ability to exercise agency not only in the amount of support they provide to their grandchild, but also in how they enact their role as a grandparent, was affected by factors outside of the family unit, including the physical and social environments.

Another form of structural ambivalence important to consider is the rise in UK State Pension age, in particular for women, and the effect that may have on grandparent availability to provide support and choice in being able to provide that support. As was presented in Chapter 5, one of the main negotiations grandparents described was balancing paid employment and providing childcare. Twelve grandparents (8 grandmothers, 4 grandfathers) had reached State Pension age before the beginning of the study. Ten of these grandparents had not been affected by the increase in State Pension age introduced in 2016, while the other two (both grandmothers) had received their State Pension 3-3.5 years later than they had expected. For the remaining nine grandparents, who had not reached State Pension age yet, five had already retired with private pensions, three were still working and one was looking for employment again due to financial constraints. Margaret (Oscar's maternal grandmother) was an example of the effect of the change in State Pension age in Chapter 5, section 5.5.2, where she had made the decision to stop working but was now faced with a much longer period before receiving her State Pension. This issue will become increasingly important for women and men becoming grandparents in the future when they are more likely to still be participating in paid employment when they become a grandparent. As they face a longer working life and later pensions, how will families, especially families of children with a disability with additional support needs, negotiate paid employment and care? The availability of grandparents and grandparents level of agency to fill the care gap, which could potentially grow with increasing cuts to support services and welfare support, will decrease. This could consequently lead to more mothers making decisions about their own participation in the workforce and their own financial security in the future.

Findings from this study would suggest that grandparents of children with a disability were trying, where they could, to exercise some agency in their role. However, for this group of grandparents, social, structural and welfare contexts created a greater dependency of parents on them for support, compromising these grandparents ability to exercise agency, potentially to a greater extent than other grandparents.

7.2.5 Different family trajectory/ the longer-term trajectory of grandparenting

Everything listed above was important in understanding the grandparent role in this context; however, what really makes it stand out from other forms of grandparenting is the impact on the trajectory of the family life. These grandchildren would need life-long support in some way.

It was not a temporary ‘disruption’ or ‘crisis’; the support needs would need addressing for the child’s life which had consequences on the roles and experiences of the entire family. A key finding from this research is the importance of taking a lifecourse approach when understanding the grandparent role in the context of grandchild disability. However, little research has considered how family roles play out when grandparents and grandchildren are older, especially in the context of grandchild disability. Grandparents described how the physical demands of the role are harder to manage as they and the grandchild age. While many families would expect to see a decrease in physical support and therefore not be concerned with physical ability within their grandparent-grandchild relationship, in the context of grandchild disability continued physical ability was important. As one grandmother so simply put it, “*he’s only going to get bigger and heavier; I’m going to get older and weaker*” (Hazel, maternal grandmother). This is important to consider in the context of the health of older adults in later life. Longer life expectancies are not necessarily being matched with more healthy years, especially for women (Jagger *et al.*, 2016; Kingston *et al.*, 2017). Given that women, grandmothers, are most likely to be providing the kind of support described there needs to be consideration of how the role of grandmothers changes as they age and potentially face their own health problems and disability.

Little is known about the grandparenting experience of adult grandchildren in general, with the limited literature so far investigating adolescent/young adult grandchildren’s relationship with a grandparent with dementia (Celdrán *et al.*, 2011; Celdrán *et al.*, 2014). Much of this literature looks at how adult grandchildren begin to provide some types of support to grandparents and maintain the grandparent-grandchild relationship (Villar *et al.*, 2010). There is an expectation that family will follow a trajectory of the grandchild growing older, becoming more independent, less dependent on older generations and eventually reciprocating support to older generations (Gans and Silverstein, 2006; Silverstein *et al.*, 2006). However, for the families in this study the ‘normal’ lifecourse trajectory was not expected. For many of the parents the level of care needed by their child would continue indefinitely, with parents continuing to provide advocacy support, personal care, helping with finances, and arranging and attending medical appointments (Walker and Hutchinson, 2018). Currently, parents have the support of grandparents to help with some of this, but families described concern for a potential situation where grandparents would no longer be able to help with this or were no longer alive to help. The longer-term support required by grandchildren is likely to have considerable consequences for the middle generation as they are potentially faced with providing support to their adolescent/adult child and ageing parents.

Although most of the grandchildren discussed in this study were still of school age, parents and grandparents were concerned about who would continue to support the grandchild in the future. A number of studies have highlighted parents' apprehension and difficulty in engaging with services to plan future support for their child (e.g., accommodation, financial support, employment) (Heller and Caldwell, 2006; Walker and Hutchinson, 2018). This apprehension may be due to a lack of information about planning for the future and a continued uncertainty about the suitability and availability of alternative accommodation options (Bibby, 2013). As was found by Walker and Hutchinson (2018), many of the families in my study had not thought in detail about the future but expected to plan for it, as they knew the family trajectory would be different.

Furthermore, it is not just the grandchild support that needs to be considered when thinking about the future, the provision of support for ageing grandparents becomes a concern as well. The ageing population, the severe cuts to local government and social services, and a lack of sector reform has meant the UK's social care services are facing severe pressures and challenges (Dromey and Hochlaf, 2018; Bottery *et al.*, 2019). A recent report commissioned by the charity Age UK (Incisive Health, 2018) described 'care deserts' where areas of England do not have sufficient social services, meaning there is significant unmet need in care for ageing adults. Such care is therefore being drawn into the family (Department of Health and Social Care, 2018). Some of the grandparents in this study were supporting ageing parents, their adult child and their grandchild. Parents of children with a disability are also facing the prospect of providing informal care for both their ageing child and their ageing parents. These scenarios have potential severe physical and mental health consequences for grandparents and parents participation in the labour market, contributions to pensions and hence financial security in later life. In the field of gerontology this has been referred to as the 'sandwich generation', with several studies looking at the impact on middle-generations' health and wellbeing (Stephens *et al.*, 2001; Do *et al.*, 2014; McGarrigle *et al.*, 2014). However, this literature has not acknowledged the sandwich caregivers who provide ongoing and substantial support to multiple generations with disability/ill-health. More recently psychologist Elizabeth Perkins, has referred to a concept of 'compound caregiving' when looking at the multiple caregiving roles of parents of adult children with intellectual disabilities. Studies of 'compound caregiving' so far have reported mixed findings with some describing decreases in social support networks and difficulty managing the extensive care needs (Perkins, 2010; Perkins and Haley, 2010), while others have reported some individuals feeling their experience of caring for a child with a disability has equipped them with the necessary skills to manage and organise an ageing parent's care as well (Green, 2013). Parents and grandparents in this study expressed concern about each generation's life trajectory and about how the support needs of each generation would be met. This situation warrants considerable concern if demand for informal carers continues to rise for both older and younger generations.

To summarise, in the context of grandchild disability the level of dependency on grandparents to fill an unmet need, the masses of unrecognised emotional work, and the physical demands of the role increased the intensity of grandparenthood and the toll it took on grandparents and intergenerational relationships. Grandparents were filling an unmet need, however for many, it was through this support that they were able to build a relationship with their grandchild. Grandparents had to constantly renegotiate their role and ways to interact with their grandchild as they all grew older, continuing to readjust expectations of the life trajectories of each generation with the interactions (or lack of) with welfare support systems. This was something grandparents would need to continually do in their role with the intensity potentially getting greater and certainly not likely to dissipate.

7.3 Implications for Practice and Policy

There are a number of implications my findings have for practice and policy:

7.3.1 Implications for practice

Grandparents play a key role in the family life within families of children with a disability. It is imperative that health professionals, social care staff, and education staff recognise grandparent involvement and the vital role they perform in supporting the family. As well as recognising the role they play, the findings from this thesis also demonstrate the importance of supporting the grandparent with some of the challenges they face in adjusting to and supporting a grandchild with a disability. Previous research has suggested the importance of clinicians taking a family-centred approach and including grandparents in appointments and treatments (Hastings, 1997; Anderson, 2010). From the interviews conducted in this research it appears this was happening to some extent with several of the grandparents describing attending, and being actively involved, in hospital appointments when parents encouraged involvement. Even where grandparents are not present in appointments, there would be an advantage to health professionals having discussions with parents and the grandchild about sharing information with the wider family or asking parents about their support networks. This could help with appropriate signposting for support and sharing of information leaflets that would be helpful for grandparents or other family caregivers. Education was one of the main areas where grandparents felt excluded, especially as the grandchild was ageing. Some of this was because of parental choice, but given many grandparents were the ones collecting grandchildren from school or meeting school transport, there may be an advantage of being more inclusive of grandparents in decision making and sharing information. There needs to be a consistent invitation and willingness to include and acknowledge grandparents' contribution from appointments at diagnosis, through to school decisions, and eventually post-16 service provision (where the parent allows it).

In a similar vein, opening up support groups and information sessions to grandparents would improve access to information for grandparents, help improve their understanding of disabilities and provide information on strategies to help grandparents with the challenges they face in managing their families and their grandchild's needs. Some of the grandparents were able to access support groups such as National Autistic Society Early Bird sessions (a group to help parents learn strategies for communicating with their child), however regular access to and availability of these types of groups for grandparents would be helpful in improving grandparents' confidence and understanding of the disabilities. This in turn would help with grandparents building a relationship with their grandchild by being able to communicate effectively and confidently with them. These groups would also offer grandparents a place for social support. Having other grandparents with grandchildren with a disability to talk to and share experiences with may be helpful for grandparents, rather than trying to compare themselves to grandparents of children without disability. Support groups for grandparents have begun to emerge in the UK and some disability charities such as Contact do recognise the needs of grandparents, organising specific workshops for them, but these are often sporadic events rather than ongoing support. There are also more grandparent specific charities, such as Grandparents Plus who provide specialised support for grandparents providing kinship/custodial care. Similar specialised support groups for grandparents of children with a disability would be beneficial for supporting grandparents with the challenges they may face and provide an opportunity for sharing positive experiences.

Finally, there is an important role for social services in helping families of children with a disability to think about the longer-term care needs of the grandchild and help families plan for the future where possible. Encouraging communication between parents, grandparents, the grandchild, and possibly siblings as potential organisers/providers of care, about the future is essential to ensure care needs are met and family members remain satisfied with their level of involvement. This could potentially be encouraged through support groups suggested above and key workers (if present).

7.3.2 Implications for policy

Nearly all the research on grandparenting in general, as well as specifically in the context of grandchild disability, has highlighted the lack of policy recognition about the contribution grandparents make to families, communities, and society in general (Broad, 2007). In her review over a decade ago, Mitchell (2007) raised the question of whether individualised budgets could be used as a way of compensating grandparents for the care work they are providing to families. Much more research would need to be done to see how this would work in families of children with a disability, how it may affect other benefits the family receives, how comfortable grandparents would be in receiving payments, and the effect payments would have on the family relationships. Compensation or rewards for grandparents providing this essential contribution to the care of their grandchildren could be a way of ensuring the continuation of support, especially in the face of extending working lives and increased State Pension ages.

Current UK policy is creating a significant care gap for families of children with a disability with both its encouragement of mothers returning to the labour market, and its encouragement for grandparents to remain in the labour market (Gray, 2005; Glaser *et al.*, 2010). If mothers and grandparents are to remain in work, then employment policies for both generations need to allow for caring responsibilities and more flexibility of job roles to allow families to balance both their working role and their caring responsibilities. This could include carers leave for grandparents, flexible hours, or compressed hours (longer but fewer working days). Policy makers need to consider families as a whole rather than individual generations. Price *et al.* (2019) have also pointed to the need for policy to take a two-generational approach, particularly considering how childcare policy has implications for grandmothers and mothers. In terms of thinking about the middle generation (the parents of a child with a disability), they are facing an increasing pressure to manage and provide the care for both their child with a disability and their ageing parents. This is a situation that could become unmanageable for many and have serious consequences on their own financial stability and care needs in their later life. This situation could have economic consequences for the UK, and other similar countries, with the risk of overburden for some individuals (Zelezná, 2018). The impact of this burden on the individual’s health and wellbeing may result in a need for increased spending on supporting the health of caregivers, as well as the recipients of care. Given that there are approximately one million families with children with a disability, many of which will also include ageing grandparents, greater investment in support that compliments informal support for both older and younger generations is needed. This may have longer economic advantages with savings in costs of caring for caregivers who are unable to cope with the burden of care.

Most importantly there needs to be a review of the supports and welfare provision to families of children with a disability. This includes improving the provision of respite services and ‘Short Break’ programmes, the provision of inclusive childcare services, and provision of support for adolescent and adult children with a disability. Current campaigns from the Disabled Children’s Partnership are highlighting the absolute necessity for the way services for families of children with a disability are funded and provided to change (Disabled Children's Partnership, 2017). Most of the families in the study were dependent on the support of grandparents, with formal support only being received when crisis was reached. This is adding unnecessary stress and worry, to an already potentially challenging situation. Grandparents want to be involved in their grandchildren’s lives, but they should not be relied on by families and governments to fill the gap created by a lack of formal support.

7.4 Strengths and Limitations

This study adds to the very limited literature on the grandparent experience of grandparenthood in the context of grandchild disability in the UK (Margetts *et al.*, 2006; Moffatt *et al.*, 2019). A strength of the study was giving a voice to grandparents in this context as their perspective has been lacking in the international literature as well as the UK literature. Adding to this strength, this research was one of the first in the UK to use qualitative methods to collect both the grandparent and parent perspectives on the experience of grandparenthood in the context of grandchild disability. Despite the fact the grandchild interviews were not as successful as hoped, having both grandparents and parents from the same family provided a unique opportunity to directly compare each generation’s perspective on the grandparent role. This allowed me to gain an understanding of the complexity of intergenerational support and the factors, both within and outside the family that influence support exchanges in the context of grandchild disability.

Collaborating with Contact North East also added to the strengths of this research. The research partners from Contact were involved in reading the initial proposal for the research and in establishing the research aims and questions, ensuring that data collected would be relevant to the organisation in order to develop more support for grandparents accessing their services. Working with the research partners ensured that the research was meaningful and accessible to families and ensured that recruitment for the project was successful. Unfortunately, the closure of the office during the course of this PhD, meant that the members of staff I had been working with moved on to new jobs in different organisations. Consequently, analysis of the data and emerging themes could not be discussed with the research partners at Contact, however, one partner remained involved in the Advisory Group, who were able to comment and give feedback on the themes emerging from the analysis adding to the validation of the findings.

There are limitations of the study that need to be considered when interpreting the results. In Chapter 3 the limitations of the sample were described, including the limited range of experiences captured within the sample, limiting the generalisability of the findings. Although the sample size is larger than previous studies in the UK (Margetts *et al.*, 2006; Moffatt *et al.*, 2019), it is still relatively small and is limited to families living in North East England. All the previous qualitative research in the UK exploring the grandparent perspective in the context of grandchild disability has also been conducted in North East England where the involvement of grandparents in the lives of their grandchildren has been found to be greater than other parts of the country (Wheelock and Jones, 2002). Grandparents may have different experiences in different areas of the UK, especially as the availability of formal support services varies across regions in England and the other three nations of the UK. As highlighted in the Introduction Chapter (Chapter 1, section 1.3), North East England differs from the south in terms of the age of the population, wealth and health, all of which may change the experience of grandparenting in the context of grandchild disability.

7.5 Future Research

There are a number of different directions for future research that would develop the findings presented here. Further qualitative and quantitative research is needed across the UK to ascertain the transferability of the findings from this research to other localities. While I was able to conduct some short interviews with three grandchildren, it would be helpful to seek the views of more grandchildren representing different ages, family structures, and type and severity of disability. The grandchild voice is currently absent in this area of research; therefore, the inclusion of the grandchild voice would be extremely beneficial in understanding grandparent-grandchild relationships in the context of disability. The issues experienced in conducting the grandchild interviews in this study (Chapter 3, section 3.8.4) indicate that further consideration of how to include the grandchild voice in research is needed. Grandchildren with a disability will not always be able to answer direct questions verbally, therefore consideration of alternative methods to interviewing will be of value. A range of strategies could be helpful in including the voice of children with a disability such as, using alternative communication methods or visual cues, using artistic methods (e.g., drawing or photography), arranging pre-interview meetings to prepare participants collaboratively, alternative locations for interviews (e.g., in school), or allowing the child to choose a support person to aid their participation (Carpenter and McConkey, 2012; Bailey *et al.*, 2015; Goodwin, 2019). Having training and the availability of other communication methods may also help alleviate gatekeepers (e.g., parents) assumptions that their child will not be able to take part or contribute in the way they presume the researcher expects (Rabiee *et al.*, 2005; Mitchell, 2010). Using methods that allow the grandchild to express their views, with and without the use of spoken language, will also help ensure the grandchild’s own experiences and opinions can be collected without potential influence from parents.

One area of particular importance is the need for further research amongst families with grandchildren aged 18 years and older, as the grandchildren transition from child to adult services, and how this changes the grandparent role. It is important to understand how families with adolescent and adult grandchildren with a disability currently manage intergenerational support. Likewise, a longitudinal study following families as they experience the transition from adolescence to adulthood of the grandchild and taking a lifecourse perspective would highlight the impact of childhood disability on the later life outcomes for these families in terms of support needs and family relationships. Longitudinal research would provide more insight into how the perspectives and worries expressed in this study were borne out and how patterns of behaviour and support developed over the lifecourse. The patterns of support and behaviour in families could be deeply rooted in past behaviours that may not be easily changed even with the input of more services.

This research included grandchildren with a range of disabilities, including ASD, cerebral palsy and Down’s syndrome. These are similar to disabilities that have been included in previous research in the context of grandchild disability. Most often the research participants have a range of abilities within the samples recruited. The literature to date has not explored how factors related to the grandchild’s disability, such as physical disability, intellectual disability, or types of behavioural problems (e.g., sleep problems, aggressive behaviour) may affect how the grandparent role is experienced. Future research may also benefit from investigating the grandparent role in contexts where the grandchild has a mental health problem. Given the increasing prevalence of mental health concerns in young people in the UK (Pitchforth *et al.*, 2018), more grandparents may be involved in supporting their grandchild in this context. This may raise new and unique areas of support for grandparents.

Finally, research considering the welfare context and the impact of cuts in welfare benefits that disproportionately affect people with a disability (Horridge *et al.*, 2019) is required. This study took place after several years of austerity cuts; however, interviews did not focus specifically on the impact of these changes. Taking an intergenerational approach and looking at both support to younger generations as well as policy changes and welfare support to older generations, such as the increase in State Pension age will help draw out some of the complexities of intergenerational support in this context.

7.6 Conclusion

Grandparents were a vital and necessary source of support, aiding families to adapt and continually adjust to the needs of the grandchild. Importantly, this thesis brought attention to the grandparents’ own experiences. They recounted their own hardships, which included financial challenges, long hours of care, and a lack of engagement in third age activities. Capturing both parent and grandparent perspectives demonstrated the extensive intergenerational negotiation, and at times conflict, around employment, role boundaries, types of support, and the emotional work that is needed to support grandchildren with a disability where state care is largely absent. Intergenerational support shifted and was continually renegotiated over the lifecourse trajectory, due to interactions with formal support services and changing circumstance within the family. There was one constant in these families, that the grandchild would most likely need lifelong support. This impacted parents and grandparents views of their own futures and significantly impacted thinking about future intergenerational care within these families. The results of this study will resonate with ‘traditional’ grandparenting, in particular the impact of UK government policies of extending working lives and cuts to state welfare benefits. However, these effects are greatly exacerbated and heightened in the context of grandchild disability, warranting further care, consideration, and policy action.

References

Abell, J., Amin-Smith, N., Banks, J., Batty, G.D., Breeden, J., Buffel, T., Cadar, D., Crawford, R., Demakakos, P., de Oliveira, C., Hussey, D., Lassale, C., Matthews, K., Nazroo, J., Norton, M., Oldfield, Z., Oskala, A., Prattley, J., Steptoe, A. and Zaninotto, P. (2018) *The Dynamics of Ageing: Evidence from the English Longitudinal Study of Ageing 2002-16 (Wave 8)*. London: The Institute for Fiscal Studies.

Abramson, T.A. (2015) 'Older Adults: The "Panini Sandwich" Generation', *Clinical Gerontologist*, 38(4), pp. 251-267.

Age UK (2018) *Why call it care when nobody cares? An Age UK campaign report about how older people and their families experience the crisis in social care.* London: Age UK. [Online]. Available at: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/care--support/RB_mar18_social_care_campaignreport.pdf.

Ahern, K. (2000) '" Something is Wrong with My Child": A Phenomenological Account of a Search for a Diagnosis', *Early Education and Development*, 11(2), pp. 187-201.

Aho, A.L., Inki, M. and Kaunonen, M. (2018) 'Grandmothers' Grief after the Loss of a Grandchild', *Mental Health and Family Medicine*, 14(1), pp. 676-680.

Alexander, S. (2015) 'Grandparents save mums and dads £15.7 billion a tear', *Daily Telegraph*edn). (Accessed: 10th October 2019).

Altmann, R. (2015) *A new vision for older workers: retain, retrain, recruit*. London: Department for Work and Pensions. [Online]. Available at: https://www.gov.uk/government/publications/a-new-vision-for-older-workers-retain-retrain-recruit.

American Psychiatric Association (2013) 'Diagnostic and statistical manual of mental disorders', *BMC Medicine* 17, pp. 133-137.

Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A. and Law, M. (2013) 'The effect of the environment on participation of children and youth with disabilities: a scoping review', *Disability and Rehabilitation*, 35(19), pp. 1589-1598.

Anderson, C. and Kirkpatrick, S. (2016) 'Narrative interviewing', *International Journal of Clinical Pharmacy*, 38(3), pp. 631-4.

Anderson, C.M. (2010) *Interactive Autism Network (IAN) research reports #14 (part 1) and #15 (part 2): Grandparents of children with ASD.* Kennedy Krieger Institute, B., MD. [Online]. Available at: https://www.iancommunity.org/cs/ian_research_reports/ian_research_report_apr_2010.

Anderson, L.R., Sheppard, P. and Monden, C.W. (2018) 'Grandparent effects on educational outcomes: a systematic review', *Sociological Science*, 5(1), pp. 114-142.

Angel, J.L. and Mudrazija, S. (2011) 'Chapter 12 - Aging, Inheritance, and Gift-Giving', in Binstock, R.H. and George, L.K. (eds.) *Handbook of Aging and the Social Sciences (Seventh Edition)*. San Diego: Academic Press, pp. 163-173.

Arber, S. and Timonen, V. (2012) *Contemporary grandparenting. Changing family relationships in global contexts*. Bristol: The Policy Press.

Ariel, C.N. and Naseef, R.A. (2005) *Voices from the spectrum: Parents, grandparents, siblings, people with autism, and professionals share their wisdom*. London: Jessica Kingsley Publishers.

Arpino, B. and Bordone, V. (2014) 'Does grandparenting pay off? the effect of child care on grandparents' cognitive functioning', *Journal of Marriage and Family*, 76(2), pp. 337-351.

Arpino, B. and Bordone, V. (2015) 'Regular provision of grandchild care and participation in social activities', *Review of Economics of the Household*, 15(1), pp. 1-40.

Atchley, R.C. (1989) 'A Continuity Theory of Normal Aging', *The Gerontologist*, 29(2), pp. 183-190.

Ayres, L. (2000) 'Narratives of family caregiving: Four story types', *Research in Nursing and Health*, 23(5), pp. 359-371.

Bailey-Rodriguez, D., Frost, N. and Elichaoff, F. (2018) 'Narrative analysis', in Sullivan, C. and Forrester, M.A. (eds.) *Doing qualitative research in psychology. A practical guide*. 2nd edn. London: SAGE Publications Ltd, pp. 209-232.

Bailey, D.B., Golden, R.N., Roberts, J. and Ford, A. (2007) 'Maternal depression and developmental disability: Research critique', *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4), pp. 321-329.

Bailey, S., Boddy, K., Briscoe, S. and Morris, C. (2015) 'Involving disabled children and young people as partners in research: a systematic review', *Child: care, health and development*, 41(4), pp. 505-514.

Baker, L.A., Silverstein, M. and Putney, N.M. (2008) 'Grandparents raising grandchildren in the United States: Changing family forms, stagnant social policies', *Journal of Societal and Social Policy*, 7(1), pp. 53-69.

Balen, R., Blyth, E., Calabretto, H., Fraser, C., Horrocks, C. and Manby, M. (2006) 'Involving Children in Health and Social Research: ‘Human becomings’ or ‘active beings’?', *Childhood*, 13(1), pp. 29-48.

Banks, J., Lessof, C., Nazroo, J., Rogers, N., Stafford, M. and Steptoe, A. (2010) *Financial circumstances, health and well-being of the older population in England. The 2008 English*

Longitudinal Study of Ageing (Wave 4). London: Institute for Fiscal Studies. [Online]. Available at: https://www.ifs.org.uk/elsa/report10/elsa_w4-1.pdf.

Baranowski, M.D. and Schilmoeller, G.L. (1999) 'Grandparents in the lives of grandchildren with disabilities: Mothers' perceptions', *Education & Treatment of Children*, 22(4), pp. 427-446.

Barnard, H. (2019) *End the benefit freeze to stop people people swept into poverty*. Available at: https://www.jrf.org.uk/report/end-benefit-freeze-stop-people-being-swept-poverty (Accessed: 9th October 2019).

Barnett, M.A., Scaramella, L.V., Neppl, T.K., Ontai, L. and Conger, R.D. (2010) 'Intergenerational relationship quality, gender, and grandparent involvement', *Family Relations*, 59(1), pp. 28-44.

Bauer, J.M. and Sousa-Poza, A. (2015) 'Impacts of informal caregiving on caregiver employment, health, and family', *Journal of Population Ageing*, 8(3), pp. 113-145.

Baxter, C., Cummins, R.A. and Yiolitis, L. (2000) 'Parental stress attributed to family members with and without disability: A longitudinal study', *Journal of Intellectual and Developmental Disability*, 25(2), pp. 105-118.

Becker, G. (1997) *Disrupted lives: How people create meaning in a chaotic world*. California, US: University of California Press.

Beckett, J. (2018) 'A Labour of Love: The Emotional Work Associated with Parenting Children on the Autistic Spectrum', *International Journal of Learning, Teaching and Educational Research*, 17(12), pp. 1-17.

Ben Shlomo, S. and Taubman – Ben-Ari, O. (2016) 'Grandparenthood—Grand Generativity', in Findler, L. (ed.) *Grandparents of Children with Disabilities*. Cham, Switzerland: Springer International Publishing, pp. 1-18.

Bengtson, V., Giarrusso, R., Mabry, J.B. and Silverstein, M. (2002) 'Solidarity, conflict, and ambivalence: Complementary or competing perspectives on intergenerational relationships?', *Journal of Marriage and Family*, 64(3), pp. 568-576.

Bengtson, V.L. (1975) 'Generation and family effects in value socialization', *American Sociological Review*, pp. 358-371.

Bengtson, V.L. (2001) 'Beyond the nuclear family: The increasing importance of multigenerational bonds', *Journal of Marriage and Family*, 63(1), pp. 1-16.

Bengtson, V.L., Elder Jr, G.H. and Putney, N.M. (2005) 'The life course perspective on ageing: Linked lives, timing, and history', in Johnson, M.L. (ed.) *The Cambridge Handbook of age and ageing*. New York, NY: Cambridge University Press, pp. 493-509.

Bengtson, V.L., Giarrusso, R., Silverstein, M. and Wang, H. (2000) 'Families and intergenerational relationships in ageing societies', *International Journal of Aging* 2(1), pp. 3-10.

Bengtson, V.L. and Putney, N.M. (2006) 'Two Future ‘Conflicts’ Across Generations and Cohorts?', in Vincent, J.A., Phillipson, C. and Downs, M. (eds.) *The futures of old age*. London: SAGE Publications, pp. 20-29.

Bengtson, V.L. and Roberts, R.E.L. (1991) 'Intergenerational Solidarity in Aging Families: An Example of Formal Theory Construction', *Journal of Marriage and the Family*, 53(4), p. 856-870.

Bengtson, V.L., Rosenthal, C. and Burton, L. (1996) 'Paradoxes of Families and Aging. S. 253-282 in: Binstock, R.H. and George L.K. (4th Edition): Handbook of Aging and the Social Sciences'. San Diego: Academic Press.

Beresford, B., Rabiee, P. and Sloper, P. (2007) *Priorities and perceptions of disabled children and young people and their parents regarding outcomes from support services*. University of York, Social Policy Research Unit York.

Beresford, B.A. (1994) 'Resources and strategies: How parents cope with the care of a disabled child', *Journal of Child Psychology and Psychiatry*, 35(1), pp. 171-209.

Bibby, R. (2013) '‘I hope he goes first’: Exploring determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues? A literature review', *British Journal of Learning Disabilities*, 41(2), pp. 94-105.

Biggs, S. (2001) 'Toward critical narrativity: Stories of aging in contemporary social policy', *Journal of Aging Studies*, 15(4), pp. 303-316.

Biggs, S., Phillipson, C., Leach, R. and Money, A.-M. (2008) 'The mature imagination and consumption strategies: age & generation in the development of a United Kingdom baby boomer identity', *International Journal of Ageing and Later Life*, 2(2), pp. 31-59.

Birditt, K.S., Tighe, L.A., Fingerman, K.L. and Zarit, S.H. (2012) 'Intergenerational relationship quality across three generations', *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 67(5), pp. 627-638.

Blackburn, C.M., Spencer, N.J. and Read, J.M. (2010) 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', *BMC Pediatrics*, 10(1), p. 21.

Block, C.E. (2000) 'Dyadic and gender differences in perceptions of the grandparent-grandchild relationship', *International Journal of Aging and Human Development*, 51(2), pp. 85-104.

Bojczyk, K.E., Lehan, T.J., McWey, L.M., Melson, G.F. and Kaufman, D.R. (2011) 'Mothers’ and their adult daughters’ perceptions of their relationship', *Journal of Family Issues*, 32(4), pp. 452-481.

Bongaarts, J. (2006) 'How long will we live?', *Population and Development Review*, 32(4), pp. 605-628.

Boon, S.D., Shaw, M.J. and MacKinnon, S.L. (2008) 'Grandparent Health and Young Adults' Judgments of Their Grandparent-Grandchild Relationships', *Journal of Intergenerational Relationships*, 6(2), pp. 155-173.

Bordone, V., Arpino, B. and Aassve, A. (2016) 'Patterns of grandparental child care across Europe: the role of the policy context and working mothers' need', *Ageing and Society*, 37(4), pp. 1-29.

Bottery, S., Ward, D. and Fenney, D. (2019) *Social care 360*. London: Fund, K.s. [Online]. Available at: https://www.kingsfund.org.uk/publications/social-care-360 (Accessed: 25th October 2019).

Bracke, P., Christiaens, W. and Wauterickx, N. (2008) 'The pivotal role of women in informal care', *Journal of Family Issues*, 29(10), pp. 1348-1378.

Brandon, P. (2007) 'Time away from “smelling the roses”: Where do mothers raising children with disabilities find the time to work?', *Social Science & Medicine*, 65(4), pp. 667-679.

Brandt, M. and Deindl, C. (2013) 'Intergenerational transfers to adult children in Europe: Do social policies matter?', *Journal of Marriage and Family*, 75(1), pp. 235-251.

Broach, S., Clementa, L. and Read, J. (2016) *Disabled children: a legal handbook*. 2nd edn. London: Council for Disabled Children.

Broad, B. (2007) *Being a Grandparent: Research Evidence, Key Themes and Polcy Recommendations*. UK: The Grandparents' Association.

Brown, L.H. and DeRycke, S.B. (2010) 'The Kinkeeping Connection: Continuity, Crisis and Consensus', *Journal of Intergenerational Relationships*, 8(4), pp. 338-353.

Bryman, A. (2012) *Social research methods*. 4th edn.. Oxford: Oxford University Press.

Buckner, L.J. and Yeandle, S. (2017) *Caring More Than Most: A profile of UK families caring or disabled children*. London: Contact a Family with University of Leeds.

Bulanda, J.R. and Jendrek, M.P. (2016) 'Grandparenting roles and volunteer activity', *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 71(1), pp. 129-140.

Burchardt, T., Obolenskaya, P. and Vizard, P. (2015) *The Coalition's record on adult social care: Policy, spending and outcomes 2010–2015. Social policy in a cold climate Working Paper 17*. London: London School of Economics.

Burn, K. and Szoeke, C. (2015a) 'Grandparenting predicts late-life cognition: Results from the Women's Healthy Ageing Project', *Maturitas*, 81(2), pp. 317-322.

Burn, K. and Szoeke, C. (2015b) 'Is grandparenting a form of social engagement that benefits cognition in ageing?', *Maturitas*, 80(2), pp. 122-125.

Burr, V. (2004) *Social constructionism*. 2nd ed: Hoboken, NJ, US: Taylor and Francis.

Byrne, G., Sarma, K.M., Hendler, J. and O'Connell, A. (2018) 'On the spectrum, off the beaten path. A qualitative study of Irish parents' experiences of raising a child with autism spectrum conditions', *British Journal of Learning Disabilities*, 46(3), pp. 182-192.

Cain, R. (2016) 'Responsibilising recovery: Lone and low-paid parents, Universal Credit and the gendered contradictions of UK welfare reform', *British Politics*, 11(4), pp. 488-507.

Care Quality Commission (2014) 'From the pond into the sea: children's transition to adult health services', *London: Care Quality Commission*.

Care Quality Commission (2017) 'The state of adult social care serivces 2014 to 2017'. *London: Care Quality Commission.*

Carers UK (2019) *Juggling work and unpaid care. A growing issue*. London: Carers UK.

Carmichael, F. and Charles, S. (2003) 'The opportunity costs of informal care: does gender matter?', *Journal of Health Economics*, 22(5), pp. 781-803.

Carmichael, F., Charles, S. and Hulme, C. (2010) 'Who will care? Employment participation and willingness to supply informal care', *Journal of Health Economics*, 29(1), pp. 182-190.

Carpenter, J. and McConkey, R. (2012) 'Disabled children's voices: The nature and role of future empirical enquiry', *Children & Society*, 26(3), pp. 251-261.

Carr, E., Fleischmann, M., Goldberg, M., Kuh, D., Murray, E.T., Stafford, M., Stansfeld, S., Vahtera, J., Xue, B., Zaninotto, P., Zins, M. and Head, J. (2018) 'Occupational and educational inequalities in exit from employment at older ages: evidence from seven prospective cohorts', *Occupational and Environmental Medicine*, 75(5), p. 369-377.

Celdrán, M., Triadó, C. and Villar, F. (2011) '“My Grandparent Has Dementia” How Adolescents Perceive Their Relationship With Grandparents With a Cognitive Impairment', *Journal of Applied Gerontology*, 30(3), pp. 332-352.

Celdrán, M., Villar, F. and Triadó, C. (2014) 'Thinking about my grandparent: How dementia influences adolescent grandchildren's perceptions of their grandparents', *Journal of Aging Studies*, 29(1), pp. 1-8.

Chadwick, O., Beecham, J., Piroth, N., Bernard, S. and Taylor, E. (2002) 'Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it?', *Child and Adolescent Mental Health*, 7(2), pp. 66-72.

Chan, T.W. and Boliver, V. (2013) 'The grandparents effect in social mobility: Evidence from British birth cohort studies', *American Sociological Review*, 78(4), pp. 662-678.

Chan, Z.C. (2007) 'The Grandfather-Grandson Relationship in Hong Kong', *International Journal of Men's Health*, 6(2), pp. 115-126.

Charmaz, K. (2006) *Constructing grounded theory*. Thousand Oaks, Calif.: London, Sage Publications.

Cheetham, M., Moffatt, S., Addison, M. and Wiseman, A. (2019) 'Impact of Universal Credit in North East England: a qualitative study of claimants and support staff', *BMJ Open*, 9(7), p. e029611, doi: 10.1136/bmjopen-2019-029611

Cheng, S.-T. (2014) 'Defining successful aging: the need to distinguish pathways from outcomes', *International Psychogeriatrics*, 26(4), pp. 527-531.

Cherlin, A. and Furstenberg, F.F. (1985) 'Style and strategies of grandparenting', in Bengtson, V.L. and Robertson, J.F. (eds.) *Grandparenthood*. Thousand Oaks, CA, US: SAGE Publications, pp. 97-116.

Great Britain. *Children Act: Elizabeth II*. (1989) London: The Stationary Office.

Great Britain. *Children and Families Act: Elizabeth II.* (2014) London: The Stationary Office.

Cho, J., Martin, P. and Poon, L.W. (2012) 'The older they are, the less successful they become? Findings from the Georgia Centenarian Study', *Journal of Aging Research*, pp.1-8. doi:10.1155/2012/695854

Choi, M., Sprang, G. and Eslinger, J.G. (2016) 'Grandparents raising grandchildren', *Family & Community Health*, 39(2), pp. 120-128.

Christensen, F.B. and Smith, T.A. (2002) 'What is happening to satisfaction and quality of relationships between step/grandparents and step/grandchildren?', *Journal of Divorce & Remarriage*, 37(1-2), pp. 117-133.

Christensen, K., Doblhammer, G., Rau, R. and Vaupel, J.W. (2009) 'Ageing populations: the challenges ahead', *The Lancet*, 374(9696), pp. 1196-1208.

Christiansen, S.G. (2014) 'The association between grandparenthood and mortality', *Social Science & Medicine*, 118(1), pp. 89-96.

Clarke, L. and Roberts, C. (2003) *Grandparenthood: its meaning and its contribution to older people's lives*. ESRC Growing Older Programme Findings Number 22.

Clavering, E.K. and McLaughlin, J. (2010) 'Children's participation in health research: from objects to agents?', *Child: care, health and development*, 36(5), pp. 603-611.

Coall, D.A. and Hertwig, R. (2010) 'Grandparental investment: Past, present, and future', *Behavioral and Brain Sciences*, 33(1), pp. 1-19.

Coleman, L. and Cottell, J. (2019) *Childcare Survey 2019*. Corum Family and Childcare, Corum Family and Childcare. [Online]. Available at: https://www.familyandchildcaretrust.org/sites/default/files/Resource%20Library/Childcare%20Survey%202019_Coram%20Family%20and%20Childcare.pdf (Accessed: 1st September 2019).

Colver, A., Rapley, T., Parr, J.R., McConachie, H., Dovey-Pearce, G., Le Couteur, A., McDonagh, J.E., Bennett, C., Hislop, J. and Maniatopoulos, G. (2019) *Facilitating the transition of young* *people with long-term conditions through health services from childhood to adulthood: the Transition research programme.* Southampton,UK: NIHR Journals Library.

Connidis, I.A. (2010) *Family Ties and Aging*. Los Angeles, US: Pine Forge Press.

Connidis, I.A. (2015) 'Exploring ambivalence in family ties: Progress and prospects', *Journal of Marriage and Family*, 77(1), pp. 77-95.

Connidis, I.A. and McMullin, J.A. (2002) 'Ambivalence, family ties, and doing sociology', *Journal of Marriage and Family*, 64(3), pp. 594-601.

Contact *Advice and Support* Available at: contact.org.uk/advice-and-support (Accessed: 9th October 2019).

Contact (2017) *Universal Credit and Disabled Children*. Contact. [Online]. Available at: https://contact.org.uk/media/1055330/universal_credit_and_disabled_children.pdf (Accessed: 16th September 2018).

Contact (2018) *Annual Report 2017/18*. Contact [Online]. Available at: https://www.contact.org.uk/media/1407739/annual_review_2017-18.pdf.

Contact (2019) *Our Story*. Available at: https://contact.org.uk/about-us/who-we-are/our-story/ (Accessed: 17th August 2019).

Contact a Family (2015) *Levelling the playing field: equal access to childcare for disabled children*. London, UK [Online]. Available at: https://www.cafamily.org.uk/media/907126/levelling_the_playing_field_-_equal_access_to_childcare_for_disabled_children.pdf (Accessed: 10/12/2015).

Contact a Family (2018) *Counting the costs. Research into the finances of more than 2700 families across the UK in 2018*. London, UK. [Online]. Available at: https://contact.org.uk/get-involved/campaigns-research/counting-the-costs-2018/.

Corlett, A., Clarke, S. and Tomlinson, D. (2017) *The Living Standards Audit 2017*. Resolution Foundation: London, UK. [Online]. Available at: https://www.resolutionfoundation.org/app/uploads/2017/07/The-Living-Standards-Audit-2017-FINAL.pdf.

Cosco, T.D., Prina, A.M., Perales, J., Stephan, B.C. and Brayne, C. (2014) 'Operational definitions of successful aging: a systematic review', *International Psychogeriatrics*, 26(3), pp. 373-381.

Craig, L. and Jenkins, B. (2016) 'Grandparental childcare in Australia: gender differences in the correlates of providing regular grandparental care while parents work', *Community, Work & Family*, 19(3), pp. 281-301.

Cramer, H. and Carlin, J. (2007) 'Family-Based Short Breaks (Respite) for Disabled Children: Results from the Fourth National Survey', *The British Journal of Social Work*, 38(6), pp. 1060-1075.

Creswell, J.W. (2013) *Qualitative inquiry & research design : choosing among five approaches*. 3rd ed. London : SAGE Publications.

Cridland, J. (2016) *Independent review of the state pension age: Interim report October 2016*.Department for Work and Pensions. [Online]. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/559943/independent-review-of-the-state-pension-age-interim-report.pdf (Accessed: 18th August 2019).

Crotty, M. (1998) *The foundations of social research : meaning and perspective in the research process*. London: Sage Publications.

Crowe, T.K. and Florez, S.I. (2006) 'Time use of mothers with school-age children: A continuing impact of a child's disability', *The American Journal of Occupational Therapy*, 60(2), pp. 194-203.

Crystal, S., Shea, D.G. and Reyes, A.M. (2016) 'Cumulative Advantage, Cumulative Disadvantage, and Evolving Patterns of Late-Life Inequality', *The Gerontologist*, 57(5), pp. 910-920.

Cumming, E. and Henry, W.E. (1961) *Growing old, the process of disengagement*. New York, NY, US: Basic Books.

D'Astous, V., Wright, S.D., Wright, C.A. and Diener, M.L. (2013) 'Grandparents of Grandchildren With Autism Spectrum Disorders: Influences on Engagement', *Journal of Intergenerational Relationships*, 11(2), pp. 134-147.

Daatland, S.O. and Lowenstein, A. (2005) 'Intergenerational solidarity and the family–welfare state balance', *European Journal of Ageing*, 2(3), pp. 174-182.

Danielsbacka, M. and Tanskanen, A.O. (2018) 'Marital disruption and intergenerational relations among older Finns', *Contemporary Social Science*, 13(2), pp. 1-16.

Danielsbacka, M., Tanskanen, A.O., Coall, D.A. and Jokela, M. (2019) 'Grandparental childcare, health and well-being in Europe: A within-individual investigation of longitudinal data', *Social Science & Medicine*, 230(1), pp. 194-203.

Dannefer, D. (2003) 'Cumulative advantage/disadvantage and the life course: Cross-fertilizing age and social science theory', *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 58(6), pp. S327-S337.

Davies, B., Collins, J., Steele, R. and Cook, K. (2007) 'Parents' and children's perspectives of a children's hospice bereavement program', *Journal of Palliative Care*, 23(1), pp. 14-23.

Davies, S.C. (2012) *Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays*. London: Department of Health.

Davis, K. and Gavidia-Payne, S. (2009) 'The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities', *Journal of Intellectual & Developmental Disability*, 34(2), pp. 153-162.

de St Aubin, E.E., McAdams, D.P. and Kim, T.C.E. (2004) *The generative society: Caring for future generations*. Washington DC, US: American Psychological Association.

Dellmann-Jenkins, M., Blankemeyer, M. and Pinkard, O. (2000) 'Young adult children and grandchildren in primary caregiver roles to older relatives and their service needs', *Family Relations*, 49(2), pp. 177-186.

Dench, G. and Ogg, J. (2002) *Grandparenting in Britain: A baseline study*. London: Institute of Community Studies.

Dennis, A.A., Foy, M.J., Monrouxe, L.V. and Rees, C.E. (2018) 'Exploring trainer and trainee emotional talk in narratives about workplace-based feedback processes', *Advances in Health Sciences Education*, 23(1), pp. 75-93.

Department for Education (2015) *Special educational needs and disability code of practice 0 to 25 years. Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities*. London: Department for Education. [Online]. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf.

Department for Work and Pensions (2014) *State Pension age timetable*. London: Department for Work and Pensions. [Online]. Available at: https://www.gov.uk/government/publications/state-pension-age-timetable.

Department for Work and Pensions (2017a) *Fuller Working Lives: a partnership approach*. London: Department of Work and Pensions. [Online]. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/587654/fuller-working-lives-a-partnership-approach.pdf (Accessed: 24/04/2017).

Department for Work and Pensions (2017b) *Universal Credit: support for a maximum of 2 children: information for claimants*. London: Department for Work and Pensions. [Online]. Available at: https://www.gov.uk/guidance/universal-credit-and-families-with-more-than-2-children-information-for-claimants (Accessed: 1st October 2019).

Department for Work and Pensions (2018) *Universal Credit Full Service Survey*. London: Department for Work and Pensions.

Department for Work and Pensions (2019a) *Economic labour market status of individuals aged 50 and over, trends over time*. London: Department for Work and Pensions. [Online]. Available at: https://www.gov.uk/government/statistics/economic-labour-market-status-of-individuals-aged-50-and-over-trends-over-time-september-2019#history (Accessed: 22nd October 2019).

Department for Work and Pensions (2019b) *Family Resource Survey: financial year 2017/18*. London: Department for Work and Pensions. [Online]. Available at: https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201718.

Department for Work and Pensions (2019c) *Specified Adult Childcare credits: fact sheet*. London: Department for Work and Pensions. [Online]. Available at: https://www.gov.uk/government/publications/national-insurance-credits-for-adults-who-care-for-a-child-under-12-fact-sheet/specified-adult-childcare-credits-fact-sheet.

Department of Health (2008) *Better Care, Better Lives: Improving outcomes and experiences for children and experiences for children, young people and their families living with life-limiting and life-threatening conditions*. London: Department of Health.

Department of Health and Social Care (2004) *Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services*. London: Department of Health.

Department of Health and Social Care (2018) *Carers action plan 2018-2020*. London: Department of Health and Social Care.

Depp, C.A. and Jeste, D.V. (2006) 'Definitions and Predictors of Successful Aging: A Comprehensive Review of Larger Quantitative Studies', *The American Journal of Geriatric Psychiatry*, 14(1), pp. 6-20.

Di Gessa, G., Glaser, K., Price, D., Ribe, E. and Tinker, A. (2016a) 'What drives national differences in intensive grandparental childcare in Europe?', *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 71(1), pp. 141-153.

Di Gessa, G., Glaser, K. and Tinker, A. (2016b) 'The impact of caring for grandchildren on the health of grandparents in Europe: A lifecourse approach', *Social Science & Medicine*, 152(1), pp. 166-175.

Dillaway, H.E. and Byrnes, M. (2009) 'Reconsidering Successful Aging: A Call for Renewed and Expanded Academic Critiques and Conceptualizations', *Journal of Applied Gerontology*, 28(6), pp. 702-722.

Disabled Children's Partnership *About Us*. Available at: https://disabledchildrenspartnership.org.uk/about-us/ (Accessed: 27th September 2019).

Disabled Children's Partnership (2017) *Secret life of us campaign: the case for a Disabled Children's Fund*. Disabled Children's Partnership. [Online]. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2018/07/Case-for-a-Disabled-Childrens-Fund.pdf.

Do, E.K., Cohen, S.A. and Brown, M.J. (2014) 'Socioeconomic and demographic factors modify the association between informal caregiving and health in the Sandwich Generation', *BMC Public Health*, 14(1), p. 362.

Dobson, B. and Middleton, S. (1998) *Paying to care: The cost of childhood disability* (1899987754). York: Joseph Rowntree Foundation.

Donnelly, J.P., Huff, S.M., Lindsey, M.L., McMahon, K.A. and Schumacher, J.D. (2005) 'The needs of children with life-limiting conditions: a healthcare-provider-based model', *American Journal of Hospice and Palliative Medicine®*, 22(4), pp. 259-267.

Doucet, A. (2004) '" It's Almost Like I Have a Job, but I Don't Get Paid": Fathers at Home Reconfiguring Work, Care, and Masculinity', *Fathering: A Journal of Theory, Research & Practice about Men as Fathers*, 2(3), pp. 277-303.

Dowling, M. and Dolan, L. (2001) 'Families with children with disabilities-inequalities and the social model', *Disability & Society*, 16(1), pp. 21-35.

Drew, L.M. and Silverstein, M. (2007) 'Grandparents' psychological well-being after loss of contact with their grandchildren', *Journal of Family Psychology*, 21(3), pp. 372-379.

Drew, L.M. and Smith, P.K. (2002) 'Implications for grandparents when they lose contact with their grandchildren: Divorce, family feud, and geographical separation', *Journal of Mental Health and Aging*, 8(2), pp. 95-120.

Dribe, M. and Helgertz, J. (2016) 'The lasting impact of grandfathers: class, occupational status, and earnings over three generations in Sweden 1815–2011', *The Journal of Economic History*, 76(4), pp. 969-1000.

Dromey, J. and Hochlaf, D. (2018) *Fair care: A workforce strategy for social care*. London: Institute for Public Policy Research. [Online]. Available at: http://www.ippr.org/research/publications/fair-care.

Du Bois, W. and Wright, R.D. (2002) 'What is humanistic sociology?', *The American Sociologist*, 33(4), pp. 5-36.

Dubas, J.S. (2001) 'How gender moderates the grandparent-grandchild relationship: A comparison of kin-keeper and kin-selector theories', *Journal of Family issues*, 22(4), pp. 478-492.

Duncombe, J. and Marsden, D. (1995) '‘Workaholics’ and ‘whingeing women’: Theorising intimacy and emotion work—the last frontier of gender inequality?', *The Sociological Review*, 43(1), pp. 150-169.

Dunning, A. (2006) 'Grandparents-An Intergenerational Resource for Families: A UK Perspective', *Journal of Intergenerational Relationships*, 4(1), pp. 127-135.

Eisenberg, A.R. (1988) 'Grandchildren's perspectives on relationships with grandparents: The influence of gender across generations', *Sex Roles*, 19(3-4), pp. 205-217.

Ekas, N.V., Lickenbrock, D.M. and Whitman, T.L. (2010) 'Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder', *Journal of Autism and Developmental Disorders*, 40(10), pp. 1274-1284.

Ellis, A. and Fry, R. (2010) 'Regional health inequalities in England', *Regional Trends*, 42(1), pp. 60-79.

Emerson, E., Shahtahmasebi, S., Lancaster, G. and Berridge, D. (2010) 'Poverty transitions among families supporting a child with intellectual disability', *Journal of Intellectual and Developmental Disability*, 35(4), pp. 224-234.

Emira, M. and Thompson, D. (2011) 'In the quest for their trust: the perceptions of families on accessing leisure services for disabled children', *Leisure Studies*, 30(1), pp. 33-48.

Engelhardt, H., Buber, I., Skirbekk, V. and Prskawetz, A. (2010) 'Social involvement, behavioural risks and cognitive functioning among older people', *Ageing & Society*, 30(5), pp. 779-809.

England, P. (1986) *Households, employment, and gender : a social, economic, and demographic view*. New York, US: Aldine Publishing Company.

Engstrand, R.Z., Roll-Pettersson, L., Allodi, M.W. and Hirvikoski, T. (2019) 'Needs of Grandparents of Preschool-Aged Children with ASD in Sweden', *Journal of Autism and Developmental Disorders*, (1), pp. 1-17.

Erickson, R.J. (1993) 'Reconceptualizing family work: The effect of emotion work on perceptions of marital quality', *Journal of Marriage and the Family*, pp. 888-900.

Erickson, R.J. (2005) 'Why emotion work matters: Sex, gender, and the division of household labor', *Journal of marriage and family*, 67(2), pp. 337-351.

Erickson, R.J. and Ritter, C. (2001) 'Emotional labor, burnout, and inauthenticity: Does gender matter?', *Social Psychology Quarterly*, 64(2), pp. 146-163.

Erikson, E.H. (1963) *Childhood and Society*. 2nd edn. New York, US: Norton.

Erikson, E.H., Erikson, J.M. and Kivnick, H.Q. (1986) *Vital involvement in old age*. New York, US: Norton.

Erlinghagen, M. and Hank, K. (2006) 'The participation of older Europeans in volunteer work', *Ageing and Society*, 26(4), pp. 567-584.

Estes, C.L. (2001) *Social policy and aging: A critical perspective*. Thousand Oaks, CA, US: Sage Publications Ltd.

European Commission (2017) *European Innovation Partnership on Active and Healthy Ageing*. Available at: https://ec.europa.eu/eip/ageing/home_en (Accessed: 3rd May 2017).

Evandrou, M. and Falkingham, J. (2000) 'Looking back to look forward: lessons from four birth cohorts for ageing in the 21st century', *Population trends*, 99(1), pp. 27-36.

Every disabled child matters (2011) *Breaking down barriers: making work pay for families with disabled children*. Every disabled child matters. [Online]. Available at: https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/breakingdownbarriers.pdf (Accessed: 13th July 2019).

Every disabled child matters (2015) *Short Breaks in 2015: An uncertain future*. London. [Online]. Available at: https://www.familyfund.org.uk/Handlers/Download.ashx?IDMF=d6f63898-d22d-4550-af81-cb83305a132a (Accessed: 13th July 2019).

Exley, C. and Letherby, G. (2001) 'Managing a disrupted lifecourse: issues of identity and emotion work', *Health:*, 5(1), pp. 112-132.

Ferguson, J.L. and Ready, D.D. (2011) 'Expanding notions of social reproduction: Grandparents' educational attainment and grandchildren's cognitive skills', *Early Childhood Research Quarterly*, 26(2), pp. 216-226.

Field, D. and Minkler, M. (1988) 'Continuity and change in social support between young-old and old-old or very-old age', *Journal of Gerontology*, 43(4), pp. 100-106.

Finch, D. (2017) *Live long and prosper? Demographic trends and their implications for living standards*. London: Resolution Foundation 2017. [Online]. Available at: http://dera.ioe.ac.uk/id/eprint/28290 (Accessed: 2017/03/30/14:03:36).

Finch, J. (2007) 'Displaying families', *Sociology*, 41(1), pp. 65-81.

Finch, J. and Mason, J. (1993) 'Negotiating family obligations', *The Sociological Review*, 38(2), pp. 219-246.

Findler, L. (2000) 'The Role of Grandparents in the Social Support System of Mothers of Children with a Physical Disability', *Families in Society: The Journal of Contemporary Social Services*, 81(4), pp. 370-381.

Findler, L. (2014) 'The Experience of Stress and Personal Growth Among Grandparents of Children With and Without Intellectual Disability', *Intellectual and Developmental Disabilities*, 52(1), pp. 32-48.

Findler, L. (2016) 'Being a Grandparent of a Child with a Disability', in Findler, L. and Taubman – Ben-Ari, O. (eds.) *Grandparents of Children with Disabilities: Theoretical Perspectives of Intergenerational Relationships*. Cham, Switzerland: Springer International Publishing, pp. 39-67.

Findler, L. and Taubman–Ben-Ari, O. (2016) *Grandparents of Children with Disabilities: Theoretical Perspectives of Intergenerational Relationships*. Cham, Switzerland: Springer International Publishing.

Fingerman, K.L. (2000) '" We Had a Nice Little Chat" Age and Generational Differences in Mothers' and Daughters' Descriptions of Enjoyable Visits', *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 55(2), pp. 95-106.

Fingerman, K.L. (2004) 'The role of offspring and in-laws in grandparents' ties to their grandchildren', *Journal of Family Issues*, 25(8), pp. 1026-1049.

Fingerman, K.L., Pitzer, L.M., Chan, W., Birditt, K., Franks, M.M. and Zarit, S. (2010) 'Who gets what and why? Help middle-aged adults provide to parents and grown children', *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 66(1), pp. 87-98.

Fivush, R. (2008) 'Remembering and reminiscing: How individual lives are constructed in family narratives', *Memory studies*, 1(1), pp. 49-58.

Fivush, R., Bohanek, J.G. and Marin, K. (2010) 'Patterns of family narrative co-construction in relation to adolescent identity and well-being', in McLean, K. and Pasupathi, M. (eds.) *Narrative development in adolescence. Advancing Responsible Adolescent Development*. Boston, MA, US: Springer, pp. 45-63.

Flaherty, E.M. and Masters Glidden, L. (2000) 'Positive adjustment in parents rearing children with Down syndrome', *Early Education and Development*, 11(4), pp. 407-422.

Folkman, S. (2008) 'The case for positive emotions in the stress process', *Anxiety, stress, and coping*, 21(1), pp. 3-14.

Folkman, S. and Moskowitz, J.T. (2000) 'Positive affect and the other side of coping', *American Psychologist*, 55(6), pp. 647-654.

Forrest, L.F., Hodgson, S., Parker, L. and Pearce, M.S. (2011) 'The influence of childhood IQ and education on social mobility in the Newcastle Thousand Families birth cohort', *BMC Public Health*, 11(1), pp. 895-904.

Foster, L. and Walker, A. (2015) 'Active and successful aging: A European policy perspective', *Gerontologist*, 55(1), pp. 83-90.

Frensch, K.M., Pratt, M.W. and Norris, J.E. (2007) 'Foundations of generativity: Personal and family correlates of emerging adults' generative life-story themes', *Journal of Research in Personality*, 41(1), pp. 45-62.

Frith, H. and Kitzinger, C. (1998) 'Emotion work'as a participant resource: a feminist analysis of young women's talk-in-interaction', *Sociology*, 32(2), pp. 299-320.

Frost, D.M. (2013) 'Stigma and intimacy in same-sex relationships: A narrative approach', *Qualitative Psychology*, 1(S), pp. 49-61.

Frost, D.M. and Ouellette, S.C. (2011) 'A search for meaning: Recognizing the potential of narrative research in social policy-making efforts', *Sexuality Research and Social Policy*, 8(3), pp. 151-161.

Fuller-Thomson, E. and Minkler, M. (2001) 'American grandparents providing extensive child care to their grandchildren: Prevalence and profile', *Gerontologist*, 41(2), pp. 201-209.

Gallagher, P.A., Kresak, K. and Rhodes, C.A. (2010) 'Perceived needs of grandmothers of children with disabilities', *Topics in Early Childhood Special Education*, 30(1), pp. 56-64.

Gans, D. and Silverstein, M. (2006) 'Norms of filial responsibility for aging parents across time and generations', *Journal of Marriage and Family*, 68(4), pp. 961-976.

Gardner, J.E., Scherman, A., Mobley, D., Brown, P. and Schutter, M. (1994) 'Grandparents' beliefs regarding their role and relationship with special needs grandchildren', *Education and Treatment of Children*, 17(2), pp. 185-196.

Gattai, F.B. and Musatti, T. (1999) 'Grandmothers' involvement in grandchildren's care: Attitudes, feelings, and emotions', *Family Relations*, 14(1), pp. 35-42.

Giarrusso, R., Feng, D., Silverstein, M. and Bengtson, V.L. (2001) 'Grandparent-adult grandchild affection and consensus', *Journal of Family Issues*, 22(4), pp. 456-477.

Giarrusso, R., Silverstein, M., Gans, D. and Bengtson, V.L. (2005) 'Ageing Parents and Adult Children: New Perspectives on Intergenerational Relationships', in Johnson, M.L. (ed.) *The Cambridge Handbook of Age and Ageing*. Cambridge: Cambridge University Press, pp. 413-421.

Giarrusso, R., Stallings, M. and Bengtson, V.L. (1995) 'The intergenerational stake hypothesis revisited: Parent–child differences in perceptions of relationships 20 years later', in Bengtson, V.L., Schaie, K.W. and Burton, L.M. (eds.) *Adult intergenerational relations: Effects of societal change*. New York, NY, US: Springer Publishing Company, pp. 227-296.

Gilligan, M., Karraker, A. and Jasper, A. (2018) 'Linked lives and cumulative inequality: A multigenerational family life course framework', *Journal of Family Theory & Review*, 10(1), pp. 111-125.

Ginn, J. and Arber, S. (1991) 'Gender, class and income inequalities in later life', *British Journal of Sociology*, 42(3), pp. 369-396.

Ginn, J. and MacIntyre, K. (2013) 'UK Pension Reforms: Is Gender Still an Issue?', *Social Policy and Society*, 12(1), pp. 91-103.

Glaser, B.G. (1967) *The discovery of grounded theory : strategies for qualitative research*. New Brunswick: New Brunswick : Aldine de Gruyter.

Glaser, K., Di Gessa, G. and Tinker, A. (2014) *Grandparenting in Europe.The health and wellbeing ofgrandparents caring for grandchildren: the role of cumulative advantage/disadvantage*. London: Grandparents Plus.

Glaser, K., Ribé, E., Montserrat, U.W., Price, D., Stuchbury, R. and Tinker, A. (2010) *Grandparenting in Europe*. London: Grandparents Plus. [Online]. Available at:

https://www.grandparentsplus.org.uk/Handlers/Download.ashx?IDMF=824ab153-cb03-4b34-91b5-e610c09bde55 (Accessed: 26th October 2016).

Glaser, K., Ribé Montserrat, E., Waginger, U., Price, D., Stuchbury, R. and Tinker, A. (2013) *Grandparenting in Europe. Family policy and grandparent's role in providing childcare*. London: Grandparents Plus. [Online]. Available at: http://www.academia.edu/download/44920950/Grandparenting-in-Europe-0613_Electronic.pdf (Accessed: 7th October 2017).

Goodsell, T.L., Bates, J.S. and Behnke, A.O. (2011) 'Fatherhood stories: Grandparents, grandchildren, and gender differences', *Journal of Social and Personal Relationships*, 28(1), pp. 134-154.

Goodwin, J. (2019) 'Qualitative research in childhood neurodisability', *Developmental Medicine & Child Neurology*, 61(12), 1356, doi: 10.1111/dmcn.14277

Gov.uk (2019) *Help if you have a disabled child*. Available at: https://www.gov.uk/help-for-disabled-child/home-adaptations (Accessed: 9th October 2019).

Graby, S. and Homayoun, R. (2019) 'The crisis of local authority funding and its implications for independent living for disabled people in the United Kingdom', *Disability & Society*, 34(2), pp. 320-325.

Graham, A., Powell, M.A., Anderson, D., Fitzgerald, R. and Taylor, N.J. (2013) *Ethical research involving children* (8865220236). Innocenti Florence: UNICEF Office of Research Publications, I. [Online]. Available at: unicef-irc-org/publications/706-ethical-research-involving-children.html.

Graungaard, A.H. and Skov, L. (2007) 'Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled', *Child: Care, Health and Development*, 33(3), pp. 296-307.

Gray, A. (2005) 'The Changing Availability of Grandparents as Carers and its Implications for Childcare Policy in the UK', *Journal of Social Policy*, 34(4), pp. 557-577.

Gray, D.E. (2003) 'Gender and coping: the parents of children with high functioning autism', *Social Science & Medicine*, 56(3), pp. 631-642.

Gray, M. and Barford, A. (2018) 'The depths of the cuts: the uneven geography of local government austerity', *Cambridge Journal of Regions, Economy and Society*, 11(3), pp. 541-563.

Green, S.E. (2001) 'Grandma's hands: Parental perceptions of the importance of grandparents as secondary caregivers in families of children with disabilities', *The International Journal of Aging and Human Development*, 53(1), pp. 11-33.

Green, S.E. (2007) '"We're tired, not sad": Benefits and burdens of mothering a child with a disability', *Social Science & Medicine*, 64(1), pp. 150-163.

Green, S.E. (2013) 'Convergent Caregiving: Exploring Eldercare in Families of Children with Disabilities', *Journal of Loss & Trauma*, 18(4), pp. 289-305.

Grinstead, L.N., Leder, S., Jensen, S. and Bond, L. (2003) 'Review of research on the health of caregiving grandparents', *Journal of Advanced Nursing*, 44(3), pp. 318-326.

Grundy, E. and Henretta, J.C. (2006) 'Between elderly parents and adult children: a new look at the intergenerational care provided by the ‘sandwich generation’', *Ageing & Society*, 26(5), pp. 707-722.

Hagestad, G.O. (2006) 'Transfers between grandparents and grandchildren: The importance of taking a three-generation perspective', *Journal of Family Research*, 18(3), pp. 315-332.

Hagestad, G.O. and Burton, L.M. (1986) 'Grandparenthood, life context, and family development', *American Behavioral Scientist*, 29(4), pp. 471-484.

Hammarström, G. (2005) 'The construct of intergenerational solidarity in a lineage perspective: A discussion on underlying theoretical assumptions', *Journal of Aging Studies*, 19(1), pp. 33-51.

Hank, K. (2011) 'How “Successful” Do Older Europeans Age? Findings From SHARE', *The Journals of Gerontology: Series B*, 66B(2), pp. 230-236.

Hank, K. and Buber, I. (2008) 'Grandparents Caring for their Grandchildren: Findings From the 2004 Survey of Health, Ageing, and Retirement in Europe', *Journal of Family Issues*, 30(1), pp. 53-73.

Hank, K. and Buber, I. (2009) 'Grandparents caring for their grandchildren: Findings from the 2004 Survey of Health, Ageing, and Retirement in Europe', *Journal of Family Issues*, 30(1), pp. 53-73.

Hank, K. and Stuck, S. (2008) 'Volunteer work, informal help, and care among the 50+ in Europe: Further evidence for ‘linked’ productive activities at older ages', *Social Science Research*, 37(4), pp. 1280-1291.

Harper, S. (2003) 'Changing families as European societies age', *European Journal of Sociology*, 44(2), pp. 155-184.

Harper, S. (2006) 'Addressing the implications of global ageing', *Journal of Population Research*, 23(2), pp. 205-223.

Hartman, L., Mandich, A., Magalhães, L. and Polgar, J.M. (2016) 'Young adults’ experiences of parental divorce or separation during their adolescence: An occupational perspective', *Journal of Occupational Science*, 23(2), pp. 234-244.

Harwood, J. (2001) 'Comparing grandchildren's and grandparents' stake in their relationship', *International Journal of Aging and Human Development*, 53(3), pp. 195-210.

Harwood, J. and Lin, M.C. (2000) 'Affiliation, pride, exchange, and distance in grandparents' accounts of relationships with their college-aged grandchildren', *Journal of Communication*, 50(3), pp. 31-47.

Hastings, A., Bailey, N., Bramely, G., Gannon, M. and Watkins, D. (2015) *The cost of the cuts: the impact on local government and poorer communities*. York: Foundation, J.R. [Online]. Available at: https://www.jrf.org.uk/report/cost-cuts-impact-local-government-and-poorer-communities (Accessed: 6th December 2017).

Hastings, R.P. (1997) 'Grandparents of Children with Disabilities: a review', *International Journal of Disability, Development and Education*, 44(4), pp. 329-340.

Hastings, R.P. and Brown, T. (2002) 'Behavior problems of children with autism, parental self-efficacy, and mental health', *American Journal on Mental Retardation*, 107(3), pp. 222-232.

Hastings, R.P. and Taunt, H.M. (2002) 'Positive perceptions in families of children with developmental disabilities', *American Journal on Mental Retardation*, 107(2), pp. 116-127.

Hastings, R.P., Thomas, H. and Delwiche, N. (2002) 'Grandparent support for families of children with Down's syndrome', *Journal of Applied Research in Intellectual Disabilities*, 15(1), pp. 97-104.

Hayslip, B., Fruhauf, C.A. and Dolbin-MacNab, M.L. (2017) 'Grandparents raising grandchildren: What have we learned over the past decade?', *The Gerontologist*, 59(3), pp. e152-e163.

Hayslip, B., Jr., Henderson, C.E. and Shore, R.J. (2003) 'The Structure of Grandparental Role Meaning', *Journal of Adult Development*, 10(1), pp. 1-11.

Hayslip, B. and Kaminski, P.L. (2005) 'Grandparents Raising Their Grandchildren: A Review of the Literature and Suggestions for Practice', *The Gerontologist*, 45(2), pp. 262-269.

Great Britain. Health and Social Care Act (2012). London: The Stationary Office.

Hebblethwaite, S. (2015) 'Understanding ambivalence in family leisure among three-generation families:‘It's all part of the package’', *Annals of Leisure Research*, 18(3), pp. 359-376.

Heiman, T. (2002) 'Parents of children with disabilities: Resilience, coping, and future expectations', *Journal of Developmental and Physical Disabilities*, 14(2), pp. 159-171.

Helff, C.M. and Glidden, L.M. (1998) 'More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities', *Mental Retardation*, 36(6), pp. 457-464.

Heller, T. and Arnold, C.K. (2010) 'Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning', *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), pp. 16-25.

Heller, T. and Caldwell, J. (2006) 'Supporting aging caregivers and adults with developmental disabilities in future planning', *Mental Retardation*, 44(3), pp. 189-202.

Heller, T., Hsieh, K. and Rowitz, L. (2000) 'Grandparents as Supports to Mothers of Persons with Intellectual Disability', *Journal of Gerontological Social Work*, 33(4), pp. 23-34.

Heller, T. and Kramer, J. (2009) 'Involvement of Adult Siblings of Persons With Developmental Disabilities in Future Planning', *Intellectual and Developmental Disabilities*, 47(3), pp. 208-219.

Herlofson, K. and Hagestad, G.O. (2012) 'Transformations in the role of grandparents across welfare states', in Arber, S. and Timonen, V. (eds.) *Contemporary grandparenting: Changing family relationships in global contexts*. Bristol, UK: The Policy Press, pp. 25-51.

Hess, R.S., Molina, A.M. and Kozleski, E.B. (2006) 'Until somebody hears me: Parent voice and advocacy in special educational decision making', *British Journal of Special Education*, 33(3), pp. 148-157.

Hiam, L., Harrison, D., McKee, M. and Dorling, D. (2018) 'Why is life expectancy in England and Wales ‘stalling’?', *Journal of Epidemiological Community Health*, 72(5), pp. 404-408.

Higgs, P. and Gilleard, C. (2010) 'Generational conflict, consumption and the ageing welfare state in the United Kingdom', *Ageing & Society*, 30(8), pp. 1439-1451.

Hilbrand, S., Coall, D.A., Meyer, A.H., Gerstorf, D. and Hertwig, R. (2017) 'A prospective study of associations among helping, health, and longevity', *Social Science & Medicine*, 187, pp. 109-117.

Hillcoat-Nallétamby, S. and Phillips, J.E. (2011) 'Sociological Ambivalence Revisited', *Sociology*, 45(2), pp. 202-217.

Hillman, J. (2007) 'Grandparents of Children with Autism: A Review with Recommendations for Education, Practice, and Policy', *Educational Gerontology*, 33(6), pp. 513-527.

Hillman, J.L. and Anderson, C.M. (2019) 'It’sa Battle and a Blessing: The Experience and Needs of Custodial Grandparents of Children with Autism Spectrum Disorder', *Journal of Autism and Developmental Disorders*, 49(1), pp. 260-269.

Hillman, J.L., Wentzel, M.C. and Anderson, C.M. (2017) 'Grandparents’ Experience of Autism Spectrum Disorder: Identifying Primary Themes and Needs', *Journal of Autism and Developmental Disorders*, 47(10), pp. 2957-2968.

HM Treasury (2009) *H.M. Treasury annual report and accounts 2008 to 2009*.HM Treasury. [Online]. Available at: https://www.gov.uk/government/publications/hm-treasury-annual-report-and-accounts-2008-to-2009 (Accessed: 19th March 2019).

HM Treasury (2015) *Budget 2015*.HM Treasury. [Online]. Available at: https://www.gov.uk/government/publications/budget-2015-documents (Accessed: 19th March 2019).

Hochman, O. and Lewin-Epstein, N. (2013) 'Determinants of early retirement preferences in Europe: The role of grandparenthood', *International Journal of Comparative Sociology*, 54(1), pp. 29-47.

Hochschild, A.R. (1975) 'Disengagement Theory - Critique And Proposal', *American Sociological Review*, 40(5), pp. 553-569.

Hochschild, A.R. (2003) *The managed heart : commercialization of human feeling*. 20th anniversary ed. , with a new afterword.. edn. Berkeley, CA: University of California Press.

Hoff, A. (2007) 'Patterns of intergenerational support in grandparent-grandchild and parent-child relationships in Germany', *Ageing and Society*, 27(05), pp. 643-665.

Hollway, W. (2000) *Doing qualitative research differently : free association, narrative and the interview method*. London: SAGE

Hoppmann, C.A. and Klumb, P.L. (2010) 'Grandparental investment facilitates harmonization of work and family in employed parents: A lifespan psychological perspective', *Behavioral and Brain Sciences*, 33(1), pp. 27-28.

Hornby, G. and Ashworth, T. (1994) 'Grandparents' support for families who have children with disabilities', *Journal of Child and Family Studies*, 3(4), pp. 403-412.

Horridge, K. and Laing, G. (2015) *Impact of Austerity Measures on Families with Disabled Children. Survey of BACCH and BACD Members and Child Development Team Leads*. [Online]. Available at: www.bacdis.org.uk/policy/documents/ImpactofAusterityMeasuresonfamiliewithDisabledChildren16Jan2015.pdf (Accessed: 21st August 2019).

Horridge, K.A., Dew, R., Chatelin, A., Seal, A., Macias, L.M., Cioni, G., Kachmar, O., Wilkes, S. and On behalf of the European Academy of Childhood Disability (2019) 'Austerity and families with disabled children: a European survey', *Developmental Medicine & Child Neurology*, 61(3), pp. 329-336.

Horsfall, B. and Dempsey, D. (2015) 'Grandparents doing gender: Experiences of grandmothers and grandfathers caring for grandchildren in Australia', *Journal of Sociology*, 51(4), pp. 1070-1084.

Hoskin, J. (2019) 'Aspiration, austerity and ableism: to what extent are the 2014 SEND reforms supporting young people with a life-limiting impairment and their families to get the lives they want?', *British Journal of Special Education*, 46(3), pp. 265-291.

Howard, K. and Singleton, J.F. (2001) 'The forgotten generation: The impact a grandmother with Alzheimer's disease has on a granddaughter', *Activities, Adaptation & Aging*, 25(2), pp. 45-57.

Howlin, P. (1988) 'Living with impairment: The effects on children of having an autistic sibling', *Child: care, health and development*, 14(6), pp. 395-408.

Hughes, K. (2019) 'Are you missing out on £5,000 in 'unknown' benefits while caring for children?', *Independent*edn). [Online] Available at: https://www.independent.co.uk/money/spend-save/carers-benefits-claim-dwp-family-elderly-state-pension-income-budget-a8917641.html.

Igel, C. and Szydlik, M. (2011) 'Grandchild care and welfare state arrangements in Europe', *Journal of European Social Policy*, 21(3), pp. 210-224.

Incisive Health (2018) *Care deserts: the impact of a dysfunctional market in adult social care provision*. Incisive Health Research [Online]. Available at: https://www.incisivehealth.com/wp-content/uploads/2019/05/care-deserts-age-uk-report.pdf (Accessed: 23rd January 2019).

International Longevity Centre (2017) *The Grandparent Army*. Centre, I.L. [Online]. Available at: https://ilcuk.org.uk/wp-content/uploads/2018/10/The-Grandparent-Army.pdf (Accessed: 20th July 2018).

Jagger, C., Matthews, F.E., Wohland, P., Fouweather, T., Stephan, B.C.M., Robinson, L., Arthur, A. and Brayne, C. (2016) 'A comparison of health expectancies over two decades in England: results of the Cognitive Function and Ageing Study I and II', *The Lancet*, 387(10020), pp. 779-786.

James, N. (1989) 'Emotional labour: skill and work in the social regulation of feelings', *The Sociological Review*, 37(1), pp. 15-42.

James, N. (1992) 'Care= organisation+ physical labour+ emotional labour', *Sociology of Health and Illness*, 14(4), pp. 488-509.

Jan-Erik, R. and Kenyon, G. (1996) 'Biography in adult development and aging', in Kenyon, G., Birren, J.E., Jan-Erik, R., Schrools, J.J.F. and Svennsson, T. (eds.) *Aging and biography: Explorations in adult development*. New York, US: Springer Publishing Company, pp. 1-20.

Jappens, M. and Van Bavel, J. (2012) 'Regional family norms and childcare by grandparents in Europe', *Demographic Research*, 27(4), pp. 85-120.

Jenkins, B. (2010) 'Grandparent childcare in Australia: A literature review', *Elder Law Review*, 6, pp. 1-19.

John, E., Thomas, G. and Touchet, A. (2019) *The Disability Price Tag 2019*. Scope. [Online]. Available at: https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/ (Accessed: 29th September 2019).

Jolanki, O. (2004) 'Moral argumentation in talk about health and old age', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8(4), pp. 483-503.

Jones, R.L. (2002) '"That's very rude, I shouldn't be telling you that": Older women talking about sex', *Narrative Inquiry*, 12(1), pp. 121-143.

Judt, T. and Snyder, T. (2010) 'Thinking the 20th century'. London, England: William Heinemann.

Katz, S. (2000) 'Busy bodies: Activity, aging, and the management of everyday life', *Journal of Aging Studies*, 14(2), pp. 135-152.

Katz, S. and Calasanti, T. (2014) 'Critical perspectives on successful aging: Does it “appeal more than it illuminates”?', *The Gerontologist*, 55(1), pp. 26-33.

Katz, S. and Kessel, L. (2002) 'Grandparents of children with developmental disabilities: perceptions, beliefs, and involvement in their care', *Issues in Comprehensive Pediatric Nursing*, 25(2), pp. 113-128.

Kaufman, G. and Elder, G.H. (2003) 'Grandparenting and age identity', *Journal of Aging Studies*, 17(3), pp. 269-282.

Keck, W. and Saraceno, C. (2010) 'Caring for a parent while working for pay in the German welfare regime', *International Journal of Ageing and Later Life*, 5(1), pp. 107-138.

Kellas, J.K. (2005) 'Family ties: Communicating identity through jointly told family stories', *Communication Monographs*, 72(4), pp. 365-389.

Kelly, C., Craig, S. and McConkey, R. (2019) 'Supporting family carers of children and adults with intellectual disability', *Journal of Social Work*, doi.org/10.1177/1468017319860312 doi.org/10.1177/1468017319860312

Kelly, S.E. (2005) '“A Different Light” Examining Impairment through Parent Narratives of Childhood Disability', *Journal of Contemporary Ethnography*, 34(2), pp. 180-205.

Kemp, C.L. (2004) '"Grand" expectations: The experiences of grandparents and adult grandchildren', *Canadian Journal of Sociology*, 29(4), pp. 499-525.

Kemp, C.L. (2005) 'Dimensions of grandparent-adult grandchild relationships: From family ties to intergenerational friendships', *Canadian Journal on Aging*, 24(2), pp. 161-177.

Kenyon, G.M., Clark, P.G. and De Vries, B. (2001) *Narrative gerontology: Theory, research, and practice*. New York, NY, US: Springer Publishing Company.

Kessler, R.C. and McLeod, J.D. (1984) 'Sex differences in vulnerability to undesirable life events', *American sociological review*, 49(5), pp. 620-631.

King, G., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P. and Bates, A. (2006) 'A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome', *Child: care, health and development*, 32(3), pp. 353-369.

King, V. and Elder, G.H. (1995) 'American Children View Their Grandparents: Linked Lives Across Three Rural Generations', *Journal of Marriage and the Family*, 57(1), pp. 165-178.

Kingsmill, D. (2001) *Women's employment and pay*. London: Cabinet Office and Department of Trade and Industry. [Online]. Available at: www.kingsmillreview.gov.uk/ (Accessed: 20th February 2017).

Kingston, A., Robinson, L., Booth, H., Knapp, M., Jagger, C. and for the MODEM project (2018) 'Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model', *Age and Ageing*, 47(3), pp. 374-380.

Kingston, A., Wohland, P., Wittenberg, R., Robinson, L., Brayne, C., Matthews, F.E., Jagger, C., Green, E., Gao, L. and Barnes, R. (2017) 'Is late-life dependency increasing or not? A comparison of the Cognitive Function and Ageing Studies (CFAS)', *The Lancet*, 390(10103), pp. 1676-1684.

Kirk, S. (2008) 'Transitions in the lives of young people with complex healthcare needs', *Child: care, health and development*, 34(5), pp. 567-575.

Kivett, V.R. (1991) 'The Grandparent-Grandchild Connection', *Marriage & Family Review*, 16(3-4), pp. 267-290.

Kivnick, H.Q. (1982) 'Grandparenthood: An overview of meaning and mental health', *The Gerontologist*, 22(1), pp. 59-66.

Kleres, J. (2011) 'Emotions and narrative analysis: A methodological approach', *Journal for the Theory of Social Behaviour*, 41(2), pp. 182-202.

Knecht, C., Hellmers, C. and Metzing, S. (2015) 'The Perspective of Siblings of Children With Chronic Illness: A Literature Review', *Journal of Pediatric Nursing*, 30(1), pp. 102-116.

Knigge, A. (2016) 'Beyond the Parental Generation: The Influence of Grandfathers and Great-grandfathers on Status Attainment', *Demography*, 53(4), pp. 1219-1244.

Ko, H.-J., Hooker, K., Manoogian, M.M. and McAdams, D.P. (2019) 'Transitions to Older Adulthood: Exploring Midlife Women's Narratives Regarding Purpose in Life', *Journal of Positive Psychology and Wellbeing*, 3(2), pp. 1-19.

Kohli, M., Hank, K. and Künemund, H. (2009) 'The social connectedness of older Europeans: Patterns, dynamics and contexts', *Journal of European Social Policy*, 19(4), pp. 327-340.

Kontis, V., Bennett, J.E., Mathers, C.D., Li, G., Foreman, K. and Ezzati, M. (2017) 'Future life expectancy in 35 industrialised countries: projections with a Bayesian model ensemble', *The Lancet*, 389(10076), pp. 1323-1335.

Kornhaber, A. (1996) *Contemporary grandparenting*. Thousand Oaks, CA, US: Sage Publications.

Krauss, S.E. (2005) 'Research paradigms and meaning making: A primer', *The qualitative report*, 10(4), pp. 758-770.

Kulik, L. (2007) 'Contemporary midlife grandparenthood', in Muhlbauer, V. and Chrisler, J.C. (eds.) *Women Over 50*. Boston, MA.: Springer, pp. 131-146.

Kvale, S. (1999) 'The psychoanalytic interview as qualitative research', *Qualitative inquiry*, 5(1), pp. 87-113.

Lain, D. (2017) *Reconstructing retirement: work and welfare in the UK and USA*. Bristol, UK: Policy Press.

Lain, D., Airey, L., Loretto, W. and Vickerstaff, S. (2019a) 'Understanding older worker precarity: the intersecting domains of jobs, households and the welfare state', *Ageing & Society,* 39(10), pp. 2219-2241.

Lain, D., van der Horst, M. and Vickerstaff, S. (2019b) 'Extended Working Lives: Feasible and Desirable for All?', in *Current and Emerging Trends in Aging and Work*. Cham, Switzerland: Springer International Publishing, pp. 101-119.

Lakomý, M. and Kreidl, M. (2015) 'Full-time versus part-time employment: Does it influence frequency of grandparental childcare?', *European Journal of Ageing*, 12(4), pp. 321-331.

Lamont, D.W., Parker, L., Cohen, M.A., White, M., Bennett, S.M.A., Unwin, N.C., Craft, A.W. and Alberti, K. (1998) 'Early life and later determinants of adult disease: a 50 year follow-up study of the Newcastle Thousand Families cohort', *Public Health*, 112(2), pp. 85-93.

Lapadat, J.C. and Lindsay, A.C. (1999) 'Transcription in research and practice: From standardization of technique to interpretive positionings', *Qualitative inquiry*, 5(1), pp. 64-86.

Laslett, P. (1991) *A fresh map of life: The emergence of the third age*. Cambridge, MA, US: Harvard University Press.

Lavers, C.A. and Sonuga-Barke, E.J. (1997) 'Annotation: On the grandmothers' role in the adjustment and maladjustment of grandchildren', *Child Psychology & Psychiatry & Allied Disciplines*, 38(7), pp. 753-757.

Lawford, H., Pratt, M.W., Hunsberger, B. and Mark Pancer, S. (2005) 'Adolescent generativity: A longitudinal study of two possible contexts for learning concern for future generations', *Journal of Research on Adolescence*, 15(3), pp. 261-273.

Lawton, L., Silverstein, M. and Bengtson, V. (1994) 'Affection, social contact, and geographic distance between adult children and their parents', *Journal of Marriage and the Family*, 56(1), pp. 57-68.

Lee, M. and Gardner, J.E. (2010) 'Grandparents' Involvement and Support in Families with Children with Disabilities', *Educational Gerontology*, 36(6), pp. 467-499.

Leeson, G.W. (2014) 'Future prospects for longevity', *Post Reproductive Health*, 20(1), pp. 11-15.

Leeson, G.W. (2017) 'The impact of mortality development on the number of centenarians in England and Wales', *Journal of Population Research*, 34(1), pp. 1-15.

Leeson, G.W. (2018) 'Global demographic change and grandparenthood', *Contemporary Social Science*, 13(2), pp. 145-158.

Leeson, G.W. and Harper, S. (2007) *The Global Ageing Survey (GLAS)–Ageing and Later Life: United Kingdom and Europe*. Research Report 107, Oxford Institute of Ageing, University of

Oxford. [Online]. Available at: https://www.ageing.ox.ac.uk/download/53 (Accessed: 15th November 2016).

Lendon, J.P., Silverstein, M. and Giarrusso, R. (2014) 'Ambivalence in older parent–adult child relationships: Mixed feelings, mixed measures', *Journal of Marriage and Family*, 76(2), pp. 272-284.

Leopold, T. and Skopek, J. (2015) 'The delay of grandparenthood: A cohort comparison in East and West Germany', *Journal of Marriage and Family*, 77(2), pp. 441-460.

Lewis, J. (2006) 'Work/family reconciliation, equal opportunities and social policies: the interpretation of policy trajectories at the EU level and the meaning of gender equality', *Journal of European Public Policy*, 13(3), pp. 420-437.

Liptak, G.S. and Accardo, P.J. (2004) 'Health and social outcomes of children with cerebral palsy', *The Journal of Pediatrics*, 145(2), pp. S36-S41.

Local Government Association (2017) *Adult social care funding: State of the nation- October 2017*. London: Local Government Association [Online]. Available at: https://www.local.gov.uk/sites/default/files/documents/1.69%20Adult%20social%20care%20funding-%202017%20state%20of%20the%20nation_07_WEB.pdf.

Local Government Association (2018) *Local Government funding: Moving the conversation on*. London: Local Government Association. [Online]. Available at: https://local.gov.uk/moving-the-conversation-on/funding (Accessed: 30th September 2019).

Loretto, W. and Vickerstaff, S. (2015) 'Gender, age and flexible working in later life', *Work, Employment and Society*, 29(2), pp. 233-249.

Lowenstein, A. (2007) 'Solidarity–conflict and ambivalence: Testing two conceptual frameworks and their impact on quality of life for older family members', *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 62(2), pp. S100-S107.

Lowenstein, A. and Daatland, S.O. (2006) 'Filial norms and family support in a comparative cross-national context: evidence from the OASIS study', *Ageing & Society*, 26(2), pp. 203-223.

Lowenstein, A., Katz, R. and Daatland, S.O. (2004) 'Filial norms and intergenerational support in Europe and Israel: A comparative perspective', *Annual Review of Gerontology & Geriatrics*, 24(1), pp. 200-223.

Lu, W., Benson, R., Glaser, K., Platts, L.G., Corna, L.M., Worts, D., McDonough, P., Di Gessa, G., Price, D. and Sacker, A. (2017) 'Relationship between employment histories and frailty trajectories in later life: evidence from the English Longitudinal Study of Ageing', *Journal of Epidemiology and Community Health*, 71(5), p. 439.

Luijkx, J., van der Putten, A.A. and Vlaskamp, C. (2019) 'A valuable burden? The impact of children with profound intellectual and multiple disabilities on family life', *Journal of Intellectual & Developmental Disability*, 44(2), pp. 184-189.

Lumsdaine, R.L. and Vermeer, S.J. (2015) 'Retirement timing of women and the role of care responsibilities for grandchildren', *Demography*, 52(2), pp. 433-454.

Luo, Y., LaPierre, T.A., Hughes, M.E. and Waite, L.J. (2012) 'Grandparents providing care to grandchildren: A population-based study of continuity and change', *Journal of Family Issues*, 33(9), pp. 1143-1167.

Lüscher, K. and Pillemer, K. (1998) 'Intergenerational ambivalence: A new approach to the study of parent-child relations in later life', *Journal of Marriage and the Family*, 60(2), pp. 413-425.

Macmillan, R. and Copher, R. (2005) 'Families in the life course: Interdependency of roles, role configurations, and pathways', *Journal of Marriage and Family*, 67(4), pp. 858-879.

Mann, R. (2007) 'Out of the shadows?: Grandfatherhood, age and masculinities', *Journal of Aging Studies*, 21(4), pp. 281-291.

Mann, R. and Leeson, G. (2010) 'Grandfathers in contemporary families in Britain: Evidence from qualitative research', *Journal of Intergenerational Relationships*, 8(3), pp. 234-248.

Mann, R., Tarrant, A. and Leeson, G.W. (2015) 'Grandfatherhood: Shifting masculinities in later life', *Sociology*, 50(3), pp. 594-610.

Mansson, D.H. (2016) 'The joy of grandparenting: A qualitative analysis of grandparents', *Journal of Intergenerational Relationships*, 14(2), pp. 135-145.

Margetts, J.K., Le Couteur, A. and Croom, S. (2006) 'Families in a state of flux: the experience of grandparents in autism spectrum disorder', *Child: Care, Health and Development*, 32(5), pp. 565-574.

Margolis, R. (2016) 'The Changing Demography of Grandparenthood', *Journal of Marriage and Family*, 78(3), pp. 610-622.

Margolis, R. and Wright, L. (2017) 'Older Adults with Three Generations of Kin: Prevalence, Correlates, and Transfers', *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 72(6), pp. 1067-1072.

MarhÁNkovÁ, J.H. (2018) '‘I want (to be) an active grandmother’ – activity as a new normative framework of subjective meanings and expectations associated with the grandmother role', *Ageing and Society*, 39(8), pp. 1667-1690.

Markides, K.S. and Krause, N. (1985) 'Intergenerational solidarity and psychological well-being among older Mexican Americans: A three-generations study', *Journal of Gerontology*, 40(3), pp. 390-392.

Marmot, M., Allen, J., Goldblatt, P., Boyce, T., McNeish, D., Grady, M. and Geddes, I. (2010) 'The Marmot review: Fair society, healthy lives'. London: The Marmot Review.

Marmot, M. and Bell, R. (2012) 'Fair society, healthy lives', *Public health*, 126(S1), pp. S4-S10.

Mason, J. (2002) *Qualitative researching*. 2nd edn. London: SAGE.

Mason, J. (2004) 'Personal narratives, relational selves: residential histories in the living and telling', *The Sociological Review*, 52(2), pp. 162-179.

Mason, J., May, V. and Clarke, L. (2007) 'Ambivalence and the paradoxes of grandparenting', *The Sociological Review*, 55(4), pp. 687-706.

Mason, J., Pearce, M.S., Walls, A.W.G., Parker, L. and Steele, J.G. (2006) 'How Do Factors at Different Stages of the Lifecourse Contribute to Oral-health-related Quality of Life in Middle Age for Men and Women?', *Journal of Dental Research*, 85(3), pp. 257-261.

Materne, C.J. and Luszcz, M.A. (2010) 'Offering to provide child care for preschool grandchildren: Grandparents behaving generatively', *Australasian Journal on Ageing*, 29(1), pp. 47-48.

Maul, C.A. and Singer, G.H.S. (2009) '"Just Good Different Things": Specific Accommodations Families Make to Positively Adapt to Their Children With Developmental Disabilities', *Topics in Early Childhood Special Education*, 29(3), pp. 155-170.

May, V., Mason, J. and Clarke, L. (2012) 'Being there yet not interfering: The paradoxes of grandparenting', in Arber, S. and Timonen, V. (eds.) *Contemporary grandparenting: Changing family relationships in global contexts*. Bristol, UK: The Policy Press, pp. 139-158.

McAdams, D.P. (2008) 'Personal narratives and the life story', in John, O.P., Robins, R.W. and Pervin, L.A. (eds.) *Handbook of personality: Theory and research*. New York, NY, US: The Guildford Press, pp. 242-262.

McAdams, D.P. and Pals, J.L. (2006) 'A new Big Five: fundamental principles for an integrative science of personality', *American Psychologist*, 61(3), pp. 204-217.

McCann Mortimer, P., Ward, L. and Winefield, H. (2008) 'Successful ageing by whose definition? Views of older, spiritually affiliated women', *Australasian Journal on Ageing*, 27(4), pp. 200-204.

McCarthy, J.R., Holland, J. and Gillies, V. (2003) 'Multiple perspectives on the'family'lives of young people: methodological and theoretical issues in case study research', *International Journal of Social Research Methodology*, 6(1), pp. 1-23.

McFaul, S. (2017) *Grandparents who help with childcare at risk of missing out on full state pension-act NOW to protect it*. Available at: https://www.moneysavingexpert.com/news/2017/01/grandparents-who-help-with-childcare-at-risk-of-missing-out-on-full-state-pension---act-now-to-protect-it/ (Accessed: 7th September 2019).

McGarrigle, C.A., Cronin, H. and Kenny, R.A. (2014) 'The impact of being the intermediate caring generation and intergenerational transfers on self-reported health of women in Ireland', *International Journal of Public Health*, 59(2), pp. 301-308.

McInnes, R. (2019) *Benefits Uprating 2019*. House of Commons Library [Online]. Available at: https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-8458#fullreport (Accessed: 20th October 2019).

McKeever, P. and Miller, K.-L. (2004) 'Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices', *Social Science & Medicine*, 59(6), pp. 1177-1191.

McLaughlin, J. (2015) 'Family ties in genes and stories: the importance of value and recognition in the narratives people tell of family', *The Sociological Review*, 63(3), pp. 626-643.

McLaughlin, J. and Clavering, E.K. (2011) 'Questions of kinship and inheritance in pediatric genetics: substance and responsibility', *New Genetics and Society*, 30(4), pp. 399-413.

McLaughlin, S.J., Connell, C.M., Heeringa, S.G., Li, L.W. and Roberts, J.S. (2010) 'Successful aging in the United States: Prevalence estimates from a national sample of older adults', *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 65 B(2), pp. 216-226.

McManus, B.M., Carle, A., Acevedo-Garcia, D., Ganz, M., Hauser-Cram, P. and McCormick, M. (2011) 'Modeling the social determinants of caregiver burden among families of children with developmental disabilities', *American Journal on Intellectual and Developmental Disabilities*, 116(3), pp. 246-260.

McNee, C.M. and Jackson, C.W. (2012) 'The experiences and involvement of grandparents in hearing detection and intervention', *Topics in Early Childhood Special Education*, 32(2), pp. 122-128.

McQueen, A. (1997) 'The emotional work of caring, with a focus on gynaecological nursing', *Journal of Clinical Nursing*, 6(3), pp. 233-240.

McQueen, A.C.H. (2004) 'Emotional intelligence in nursing work', *Journal of Advanced Nursing*, 47(1), pp. 101-108.

Merz, E.-M., Consedine, N.S., Schulze, H.-J. and Schuengel, C. (2009) 'Wellbeing of adult children and ageing parents: Associations with intergenerational support and relationship quality', *Ageing & Society*, 29(5), pp. 783-802.

Meyer, M.H. (2012) 'Grandmothers juggling work and grandchildren in the United States', in Arber, S. and Timonen, V. (eds.) *Contemporary Grandparenting. Changing Family Relationships in Global Contexts*. Bristol, UK: The Policy Press, pp. 71-90.

Meyer, M.H. (2014) *Grandmothers at work: Juggling families and jobs*. New York, US: NYU Press.

Meyer, M.H. and Kandic, A. (2017) 'Grandparenting in the United States', *Innovation in Aging*, 1(2), pp. 1-10.

Michaud, P.-C., Heitmueller, A. and Nazarov, Z. (2010) 'A dynamic analysis of informal care and employment in England', *Labour Economics*, 17(3), pp. 455-465.

Miller, E., Buys, L. and Woodbridge, S. (2012) 'Impact of disability on families: grandparents' perspectives: Grandparents' perspectives', *Journal of Intellectual Disability Research*, 56(1), pp. 102-110.

Miller, S.S. and Cavanaugh, J.C. (1990) 'The meaning of grandparenthood and its relationship to demographic, relationship, and social participation variables', *Journal of Gerontology*, 45(6), pp. 244-246.

Mills, T.L. (1999) 'When grandchildren grow up: Role transition and family solidarity among baby boomer grandchildren and their grandparents', *Journal of Aging Studies*, 13(2), pp. 219-239.

Minkler, M. and Fuller-Thomson, E. (1999) 'The health of grandparents raising grandchildren: results of a national study', *American Journal of Public Health*, 89(9), pp. 1384-1389.

Mirfin-Veitch, B., Bray, A. and Watson, M. (1996) 'They really do care": Grandparents as informal support sources for families of children with disabilities', *New Zealand Journal of Disability Studies*, 2, pp. 136-148.

Mirfin-Veitch, B., Bray, A. and Watson, M. (1997) '"We're Just That Sort of Family" Intergenerational Relationships in Families including Children with Disabilities', *Family Relations*, 46(3), pp. 305-311.

Missiuna, C., Moll, S., Law, M., King, S. and King, G. (2006) 'Mysteries and Mazes: Parents' Experiences of Children with Developmental Coordination Disorder', *Canadian Journal of Occupational Therapy*, 73(1), pp. 7-17.

Mitchell, W. (2007) 'Research Review: The role of grandparents in intergenerational support for families with disabled children: a review of the literature', *Child & Family Social Work*, 12(1), pp. 94-101.

Mitchell, W. (2010) '‘I know how I feel’ Listening to Young People with Life-limiting Conditions who have Learning and Communication Impairments', *Qualitative Social Work*, 9(2), pp. 185-203.

Mitchell, W. and Beresford, B. (2014) 'Young people with high-functioning autism and Asperger's syndrome planning for and anticipating the move to college: what supports a positive transition?', *British Journal of Special Education*, 41(2), pp. 151-171.

Moffatt, S., Tse Laurence, M. and Pennington, L. (2019) 'Experiences of Grandparenting Disabled Children in the UK: A Qualitative Study of Intergenerational Relationships', *Journal of Intergenerational Relationships*, 17(1), pp. 58-73.

Møllegaard, S. and Jæger, M.M. (2015) 'The effect of grandparents’ economic, cultural, and social capital on grandchildren's educational success', *Research in Social Stratification and Mobility*, 82(42), pp. 11-19.

Montes, G. and Halterman, J.S. (2007) 'Psychological functioning and coping among mothers of children with autism: A population-based study', *Pediatrics*, 119(5), pp. e1040-e1046.

Moore, S. and Rosenthal, D. (2016) *Grandparenting: contemporary perspectives*. Oxford, UK: Routledge.

Moore, S.M. and Rosenthal, D.A. (2015) 'Personal growth, grandmother engagement and satisfaction among non-custodial grandmothers', *Aging and Mental Health*, 19(2), pp. 136-143.

Moorman, S.M. and Stokes, J.E. (2014) 'Solidarity in the grandparent–adult grandchild relationship and trajectories of depressive symptoms', *The Gerontologist*, 56(3), pp. 408-420.

Morison, M., Moir, J. and Kwansa, T. (2000) 'Interviewing children for the purposes of research in primary care', *Primary Health Care Research & Development*, 1(2), pp. 113-130.

Moules, N.J., Laing, C.M., McCaffrey, G., Tapp, D.M. and Strother, D. (2012) 'Grandparents’ experiences of childhood cancer, part 1: doubled and silenced', *Journal of Pediatric Oncology Nursing*, 29(3), pp. 119-132.

Mueller, M.M. and Elder, G.H. (2003) 'Family Contingencies Across the Generations: Grandparent-Grandchild Relationships in Holistic Perspective', *Journal of Marriage and Family*, 65(2), pp. 404-417.

Muller, Z. and Litwin, H. (2011) 'Grandparenting and psychological well-being: how important is grandparent role centrality?', *European Journal of Ageing*, 8(2), pp. 109-118.

Myers, G. (1990) 'Demography of Ageing', in Binstock, R.H. and George, L.K. (eds.) *Handbook of ageing and the social sciences*. 3rd edn. New York: Academic Press, pp. 19-44.

National Health Service (2019) *Personal budgets and direct payments*. Available at: https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/ (Accessed: 18th July 2019).

Nauck, B. and Suckow, J. (2006) 'Intergenerational relationships in cross-cultural comparison: How social networks frame intergenerational relations between mothers and grandmothers in Japan, Korea, China, Indonesia, Israel, Germany, and Turkey', *Journal of Family Issues*, 27(8), pp. 1159-1185.

Nazroo, J. (2017) 'Class and health inequality in later life: Patterns, mechanisms and implications for policy', *International Journal of Environmental Research and Public Health*, 14(12), pp. 1533-1552.

Nazroo, J., Zaninotto, P., Gjonça, E., Banks, J., Breeze, E. and Lessof, C. (2008) *Living in the 21st Century: Older People in England. The 2006 English Longitudinal Study of Ageing (Wave 3)*. London: The Institute for Fiscal Studies.

Neely-Barnes, S.L. and Dia, D.A. (2008) 'Families of children with disabilities: A review of literature and recommendations for interventions', *Journal of Early and Intensive Behaviour Intervention*, 5(3), pp. 93-107.

Neuberger, F.S. and Haberkern, K. (2013) 'Structured ambivalence in grandchild care and the quality of life among European grandparents', *European Journal of Ageing*, 11(2), pp. 171-181.

Neugarten, B.L. and Weinstein, K.K. (1964) 'The changing American grandparent', *Journal of Marriage and the Family*, 26(2), pp. 199-204.

NHS Clinical Commissioners *About CCGs*. Available at: https://www.nhscc.org/ccgs/ (Accessed: 17th October 2019).

Norris, J.E., Kuiack, S. and Pratt, M.W. (2004) '"As Long as They Go Back Down the Driveway at the End of the Day": Stories of the Satisfactions and Challenges of Grandparenthood', in Pratt, M.W. and Fiese, B.H. (eds.) *Family stories and the life course: Across time and generation*. Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers

North East Local Enterprise Partnership (2019) *Our Economy 2019*. North East Local Enterprise Partnership, Partnership [Online]. Available at: https://www.northeastlep.co.uk/wp-content/uploads/2019/06/nel605b-our-economy-web-v13.pdf.

Noy, A. and Taubman–Ben-Ari, O. (2016) 'Becoming a grandparent—On transitions and transformations', in Findler, L. (ed.) *Grandparents of Children with Disabilities*. Cham, Switzerland: Springer International Publishing, pp. 19-37.

O'Rand, A.M. (1996) 'The Precious and the Precocious: Understanding Cumulative Disadvantage and Cumulative Advantage Over the Life Course', *The Gerontologist*, 36(2), pp. 230-238.

Office for National Statistics (2015) 'Life Expectancy at Birth and at Age 65 by Local Areas in England and Wales '. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/datasets/lifeexpectancyatbirthandatage65bylocalareasinenglandandwalesreferencetable1 (Accessed: 16th October 2019).

Office for National Statistics [ONS] (2013d) *General health in England and Wales, 2011 and comparison with 2001*. [Online]. Available at: http://www.ons.gov.uk/ons/dcp171776_296871.pdf (Accessed: 10th September 2019).

Organisation for Economic Co-operation and Development (2006) *Ageing and employment policies. Live longer, work longer: A syntheis report* (9264035885). OECD. [Online]. Available at: oecd.org/employment/livelongerworklonger.html (Accessed: 16th June 2018).

Padgett, D.K. (2012) 'Choosing the right qualitative approach(es)', in *Qualitative and Mixed Methods in Public Health*. Thousand Oaks, California: SAGE Publications, Inc., pp. 29-46.

Papathomas, A., Smith, B. and Lavallee, D. (2015) 'Family experiences of living with an eating disorder: A narrative analysis', *Journal of Health Psychology*, 20(3), pp. 313-325.

Payne, G. and Payne, J. (2004) *Key concepts in social research*. London, UK: SAGE Publication Ltd.

Peachey, K. (2019) *Defeat for women in state pension age challenge*. Available at: https://www.bbc.co.uk/news/business-49917315 (Accessed: 3rd October 2019).

Pearce, M.S., Unwin, N.C., Parker, L. and Craft, A.W. (2008) 'Cohort Profile: The Newcastle Thousand Families 1947 Birth Cohort', *International Journal of Epidemiology*, 38(4), pp. 932-937.

Great Britain. *Pensions Act: Elizabeth II*. (1995) London: The Stationery Office.

Great Britain. *Pensions Act: Elizabeth II*. (2011) London: The Stationery Office.

Great Britain. *Pensions Act Elizabeth II*. (2014) London: The Stationery Office.

Perkins, E.A. (2010) 'The Compound Caregiver: A Case Study of Multiple Caregiving Roles', *Clinical Gerontologist*, 33(3), pp. 248-254.

Perkins, E.A. and Haley, W.E. (2010) 'Compound Caregiving: When Lifelong Caregivers Undertake Additional Caregiving Roles', *Rehabilitation Psychology*, 55(4), pp. 409-417.

Peterson, C. and McCabe, A. (1994) 'A social interactionist account of developing decontextualized narrative skill', *Developmental Psychology*, 30(6), pp. 937-948.

Peterson, C.C. (1999) 'Grandfathers' and grandmothers' satisfaction with the grandparenting role: Seeking new answers to old questions', *The International Journal of Aging and Human Development*, 49(1), pp. 61-78.

Phillipson, C. (2015) 'The Political Economy of Longevity: Developing New Forms of Solidarity for Later Life: The Political Economy of Longevity', *The Sociological Quarterly*, 56(1), pp. 80-100.

Phillipson, C. and Baars, J. (2007) 'Social Theory and Social Ageing', in Bond, J., Peace, S., Dittman-Kohli, F. and Westerhof, G.F. (eds.) *Ageing in Society: European perspectives on gerontology*. London, UK: SAGE Publications Ltd.

Phillipson, C., Bernard, M., Ogg, J. and Phillips, J. (2001) *The family and community life of older people: Social networks and social support in three urban areas*. London, UK: Routledge.

Phillipson, C., Vickerstaff, S. and Lain, D. (2016) 'Achieving fuller working lives: Labour market and policy issues in the United Kingdom', *Australian Journal of Social Issues*, 51(2), pp. 187-203.

Pickard, L. (2015) 'A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032', *Ageing and Society*, 35(01), pp. 96-123.

Pickard, S. (2019) 'Age War as the New Class War? Contemporary Representations of Intergenerational Inequity', *Journal of Social Policy*, 48(2), pp. 369-386.

Pillemer, K. and Suitor, J.J. (2002) 'Explaining mothers' ambivalence toward their adult children', *Journal of Marriage and Family*, 64(3), pp. 602-613.

Pit-ten Cate, I., Hastings, R.P., Johnson, H. and Titus, S. (2007) 'Grandparent Support for Mothers of Children With and Without Physical Disabilities', *Families in Society: The Journal of Contemporary Social Services*, 88(1), pp. 141-146.

Pitchforth, J., Fahy, K., Ford, T., Wolpert, M., Viner, R.M. and Hargreaves, D.S. (2018) 'Mental health and well-being trends among children and young people in the UK, 1995–2014: analysis of repeated cross-sectional national health surveys', *Psychological Medicine*, 49(8), pp. 1275-1285.

Plumb, J.C. (2011) *The impact of social support and family resilience on parental stress in families with a child diagnosed with autism spectrum disorder*. Doctor of Social Work thesis. University of Pennsylvania.

Porcellato, L., Carmichael, F., Hulme, C., Ingham, B. and Prashar, A. (2010) 'Giving older workers a voice: constraints on the employment of older people in the North West of England', *Work, Employment and Society*, 24(1), pp. 85-103.

Potter, C.A. (2016) '‘I accept my son for who he is – he has incredible character and personality’: fathers’ positive experiences of parenting children with autism', *Disability & Society*, 31(7), pp. 948-965.

Powell, M.A., Fitzgerald, R.M., Taylor, N. and Graham, A. (2012) 'International literature review: Ethical issues in undertaking research with children and young people'. Oslo: Childwatch International Research Network. Available at: http://childethics.com/wp-content/uploads/2013/09/Powell-et-al-2012.pdf (Accessed: 2nd December 2016).

Pratt, M.W., Norris, J.E., Hebblethwaite, S. and Arnold, M.L. (2008) 'Intergenerational transmission of values: Family generativity and adolescents' narratives of parent and grandparent value teaching', *Journal of Personality*, 76(2), pp. 171-198.

Prendeville, P. and Kinsella, W. (2019) 'The role of grandparents in supporting families of children with autism spectrum disorders: A family systems approach', *Journal of Autism and Developmental Disorders*, 49(2), pp. 738-749.

Price, D. and Ginn, J. (2004) 'Sharing the crust? Partnership status and pension poverty', in Arber, S., Davidson, K. and Ginn, J. (eds.) *Gender and ageing: Changing roles and relationships*. Open University Press, pp. 127-147.

Price, D., Ribe, E., Gessa, G.D. and Glaser, K. (2019) 'Grandparental childcare: a reconceptualisation of family policy regimes', in Timonen, V. (ed.) *Grandparenting practices around the world*. Bristol, UK: Bristol University Press, pp. 43-62.

Pryce, L., Tweed, A., Hilton, A. and Priest, H.M. (2017) 'Tolerating uncertainty: Perceptions of the future for ageing parent carers and their adult children with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, 30(1), pp. 84-96.

Public Health England (2018) *Local Authority Health Profiles. Profiles for North East*.Public Health England. [Online]. Available at: https://fingertips.phe.org.uk/profile/health-profiles/area-search-results/E12000001?search_type=list-child-areas&place_name=North%20East (Accessed: 1st October 2019).

Rabiee, P., Sloper, P. and Beresford, B. (2005) 'Doing research with children and young people who do not use speech for communication', *Children & Society*, 19(5), pp. 385-396.

Rahman, M.M., Khan, H.T.A. and Hafford-Letchfield, T. (2016) 'Correlates of socioeconomic status and the health of older people in the United Kingdom: A review', *Illness Crisis and Loss*, 24(4), pp. 195-216.

Randall, P. and Parker, J. (1999) *Supporting the Families of Children with Autism*. New York, US: Wiley.

Randall, W.L. (2007) 'Narrative and chaos acknowledging the novelty of lives-in-time', *Interchange*, 38(4), pp. 367-389.

Read, J. (1991) 'There was never really any choice: The experience of mothers of disabled children in the United Kingdom', *Women's Studies International Forum*, 14(6), pp. 561-571.

Rees, C.E., Monrouxe, L.V. and McDonald, L.A. (2013) 'Narrative, emotion and action: analysing ‘most memorable’ professionalism dilemmas', *Medical Education*, 47(1), pp. 80-96.

Reichman, N.E., Corman, H. and Noonan, K. (2008) 'Impact of child disability on the family', *Maternal and Child Health Journal*, 12(6), pp. 679-683.

Reitzes, D.C. and Mutran, E.J. (2004) 'Grandparenthood: Factors Influencing Frequency of Grandparent–Grandchildren Contact and Grandparent Role Satisfaction', *The Journals of Gerontology: Series B*, 59(1), pp. S9-S16.

Ribeiro, O., Paúl, C. and Nogueira, C. (2007) 'Real men, real husbands: Caregiving and masculinities in later life', *Journal of Aging Studies*, 21(4), pp. 302-313.

Riessman, C.K. (2008) *Narrative methods for the human sciences*. Thousand Oaks, CA, US: SAGE Publications.

Riesz, E.D. (2004) 'Loss and transitions: A 30-year perspective on life with a child who has down syndrome', *Journal of Loss and Trauma*, 9(4), pp. 371-382.

Roberts, K. and Lawton, D. (2001) 'Acknowledging the extra care parents give their disabled children', *Child: care, health and development*, 27(4), pp. 307-319.

Rodger, S. and Mandich, A. (2005) 'Getting the run around: accessing services for children with developmental co-ordination disorder', *Child: care, health and development*, 31(4), pp. 449-457.

Roger, K.M., Rinaldi, C.M. and Howe, N. (2012) 'Mothers' and fathers' internal state language with their young children: An examination of gender differences during an emotions task', *Infant and Child Development*, 21(6), pp. 646-666.

Rosenthal, C.J. (1985) 'Kinkeeping in the Familial Division of Labor', *Journal of Marriage and Family*, 47(4), pp. 965-974.

Roser, M. (2019) *Fertility Rate*. Available at: https://ourworldindata.org/fertility-rate.

Round, A. (2017) *Extending working lives: A devolved, lifecourse approach to enabling work beyond state pension age*. Institute for Public Policy Research, [Online]. Available at: https://www.ippr.org/publications/extending-working-lives (Accessed: 16th September 2019).

Rowe, J.W. and Kahn, R.L. (1997) 'Successful aging', *Gerontologist*, 37(4), pp. 433-440.

Rubinstein, R.L. and de Medeiros, K. (2014) '"Successful aging," gerontological theory and neoliberalism: A qualitative critique', *The Gerontologist*, 55(1), pp. 34-42.

Russell, P. (2003) '‘Access and achievement or social exclusion?’are the government's policies working for disabled children and their families?', *Children & Society*, 17(3), pp. 215-225.

Rutter, J. (2015) *Childcare Costs Survey 2015*. Trust, F.a.C. [Online]. Available at: https://www.familyandchildcaretrust.org/childcare-survey-2015 (Accessed: 3rd May 2017).

Ryan, G.W. and Bernard, H.R. (2003) 'Techniques to identify themes', *Field methods*, 15(1), pp. 85-109.

Salomon, J.A., Wang, H., Freeman, M.K., Vos, T., Flaxman, A.D., Lopez, A.D. and Murray, C.J. (2012) 'Healthy life expectancy for 187 countries, 1990–2010: a systematic analysis for the Global Burden Disease Study 2010', *The Lancet*, 380(9859), pp. 2144-2162.

Sandler, A.G., Warren, S.H. and Raver, S.A. (1995) 'Grandparents as a Source of Support for Parents of Children With Disabilities: A Brief Report', *Mental Retardation*, 33(4), pp. 248-250.

Saraceno, C. and Keck, W. (2010) 'Can we identify intergenerational policy regimes in Europe?', *European Societies*, 12(5), pp. 675-696.

Scharf, T., Timonen, V., Carney, G. and Conlon, C. (2013) *Changing generations: Findings from new research on intergenerational relations in Ireland*. Dublin: NUI Galway.

Scherman, A., Gardner, J.E., Brown, P. and Schutter, M. (1995) 'Grandparents’ adjustment to grandchildren with disabilities', *Educational Gerontology*, 21(3), pp. 261-273.

Schilmoeller, G.L. and Baranowski, M.D. (1998) 'Intergenerational Support in Families with Disabilities: Grandparents' Perspectives', *Families in Society: The Journal of Contemporary Social Services*, 79(5), pp. 465-476.

Schmuecker, K. (2017) '*Universal Credit: a Joseph Rowntree Foundation briefing*', York, England: Jospeh Rowntree Foundation.

Scott, J. (1997) 'Changing households in Britain: do families still matter?', *The Sociological Review*, 45(4), pp. 591-620.

Seddon, J. and O'Donovan, B. (2013) 'The Achilles' heel of scale service design in social security administration: The case of the United Kingdom's Universal Credit', *International Social Security Review*, 66(1), pp. 1-23.

Seligman, M. (1991) 'Grandparents of disabled grandchildren: Hopes, fears, and adaptation', *Families in Society*, 72(3), pp. 147-152.

Settles, B.H., Zhao, J., Mancini, K.D., Rich, A., Pierre, S. and Oduor, A. (2009) 'Grandparents caring for their grandchildren: Emerging roles and exchanges in global perspectives', *Journal of Comparative Family Studies*, 40(5), pp. 827-848.

Shahtahmasebi, S., Emerson, E., Berridge, D. and Lancaster, G. (2011) 'Child disability and the dynamics of family poverty, hardship and financial strain: Evidence from the UK', *Journal of Social Policy*, 40(4), pp. 653-673.

Shaibu, S. (2013) 'Experiences of grandmothers caring for orphan grandchildren in Botswana', *Journal of Nursing Scholarship*, 45(4), pp. 363-370.

Shakespeare, T. (2006) 'The social model of disability', in Davis, L.J. (ed.) *The Disability Studies Reader*. 4th edn. New York, US: Routledge, pp. 197-204.

Share, M. and Kerrins, L. (2009) 'The Role of Grandparents in Childcare in Ireland: Towards a Research Agenda', *Irish Journal of Applied Social Studies*, 9(1), pp. 33-47.

Sheehan, N.W. and Petrovic, K. (2008) 'Grandparents and Their Adult Grandchildren: Recurring Themes From the Literature', *Marriage & Family Review*, 44(1), pp. 99-124.

Shields, N. and Synnot, A. (2016) 'Perceived barriers and facilitators to participation in physical activity for children with disability: a qualitative study', *BMC Pediatrics*, 16(1), 9.

Shikako-Thomas, K., Majnemer, A., Law, M. and Lach, L. (2008) 'Determinants of Participation in Leisure Activities in Children and Youth with Cerebral Palsy: Systematic Review', *Physical & Occupational Therapy In Pediatrics*, 28(2), pp. 155-169.

Shrimpton, H., Skinner, G. and Hall, S. (2017) *The millennial bug: Public attitudes on the living standards of different generations*. Foundation, R. [Online]. Available at: https://www. resolutionfoundation. org/app/uploads/2017/09/The-Millennial-Bug. pdf (Accessed: 12th August 2017).

Silverman, D. (2005) 'Instances or sequences? Improving the state of the art of qualitative research', *Forum: Qualitative Social Research*, 6(3) 30.

Silverstein, M. and Bengtson, V.L. (2019) 'Longitudinal Study of Generations, California, 1971, 1985, 1988, 1991, 1994, 1997, 2000, 2005'. Inter-university Consortium for Political and Social Research [distributor]. Available at: https://www.icpsr.umich.edu/icpsrweb/NACDA/studies/22100 (Accessed: 21st April 2019).

Silverstein, M., Gans, D. and Yang, F.M. (2006) 'Intergenerational support to aging parents: The role of norms and needs', *Journal of family Issues*, 27(8), pp. 1068-1084.

Silverstein, M. and Long, J.D. (1998) 'Trajectories of Grandparents' Perceived Solidarity with Adult Grandchildren: A Growth Curve Analysis over 23 Years', *Journal of Marriage and the Family*, 60(4), pp. 912-923.

Silverstein, M. and Marenco, A. (2001) 'How Americans enact the grandparent role across the family life course', *Journal of Family Issues*, 22(4), pp. 493-522.

Simonoff, E. (2012) 'Autism spectrum disorder: prevalence and cause may be bound together', *The British Journal of Psychiatry*, 201(2), pp. 88-89.

Sims, M. and Rofail, M. (2013) 'The experiences of grandparents who have limited or no contact with their grandchildren', *Journal of Aging Studies*, 27(4), pp. 377-386.

Sloper, T. and Beresford, B. (2006) 'Families with disabled children', *British Medical Journal*, 333(7575), pp. 928-929.

Smith, B. and Sparkes, A.C. (2006) 'Narrative inquiry in psychology: exploring the tensions within', *Qualitative Research in Psychology*, 3(3), pp. 169-192.

Smith, F.L. and Dougherty, D.S. (2012) 'Revealing a master narrative: Discourses of retirement throughout the working life cycle', *Management Communication Quarterly*, 26(3), pp. 453-478.

Smith, J.A., Braunack-Mayer, A., Wittert, G. and Warin, M. (2007) '"I've been independent for so damn long!": Independence, masculinity and aging in a help seeking context', *Journal of Aging Studies*, 21(4), pp. 325-335.

Smith, T.B., Oliver, M.N. and Innocenti, M.S. (2001) 'Parenting stress in families of children with disabilities', *American Journal of Orthopsychiatry*, 71(2), pp. 257-261.

Social Community Planning Research (2006) 'British Social Attitudes Survey, 1998'. Inter-university Consortium for Political and Social Research [distributor], UK Data Archive [distributor].

Somary, K. and Strieker, G. (1998) 'Becoming a grandparent: A longitudinal study of expectations and early experiences as a function of sex and lineage', *The Gerontologist*, 38(1), pp. 53-61.

Sorensen, P. and Cooper, N.J. (2010) 'Reshaping the family man: A grounded theory study of the meaning of grandfatherhood', *The Journal of Men's Studies*, 18(2), pp. 117-136.

Spalding, R. and Carpenter, B. (2018) 'Examining the Intergenerational Stake Hypothesis in Grandparent–Grandchild Dyads', *The International Journal of Aging and Human Development,* 89(2), pp. 172-186.

Stephens, M.A.P., Townsend, A.L., Martire, L.M. and Druley, J.A. (2001) 'Balancing parent care with other roles: Interrole conflict of adult daughter caregivers', *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences,* 56(1), pp. 24-34.

Stinson, H. (2019) 'Supporting people? Universal Credit, conditionality and the recalibration of vulnerability', in Dwyer, P. (ed.) *Dealing with welfare conditionality: Implementation and effects*. Bristol, UK: Policy Press, pp. 15-40.

Stolz, E., Mayerl, H., Waxenegger, A., Rásky, É. and Freidl, W. (2017) 'Impact of socioeconomic position on frailty trajectories in 10 European countries: evidence from the Survey of Health, Ageing and Retirement in Europe (2004–2013)', *Journal of Epidemiological Community Health,* 71(1), pp. 73-80.

Strauss, A. and Corbin, J. (1998) *Basics of qualitative research techniques*. Thousand Oaks, CA: SAGE Publications

Strauss, A.L. (1987) *Qualitative analysis for social scientists*. Cambridge, England: Cambridge University Press.

Strazdins, L. (2002) 'Emotional Work And Emotional Contagion', in Ashkanasy, N.M., Zerbe, W.J. and Charmine, E.J.H. (eds.) *Managing emotions in the workplace*. Armonk, New York: M.E. Sharpe.

Strazdins, L. and Broom, D.H. (2004) 'Acts of love (and work) gender imbalance in emotional work and women's psychological distress', *Journal of Family Issues,* 25(3), pp. 356-378.

Sullivan, A., Winograd, G., Verkuilen, J. and Fish, M.C. (2012) 'Children on the Autism Spectrum: Grandmother Involvement and Family Functioning', *Journal of Applied Research in Intellectual Disabilities,* 25(5), pp. 484-494.

Szydlik, M. (2012) 'Generations: Connections across the life course', *Advances in Life Course Research,* 17(3), pp. 100-111.

Tarrant, A. (2010) 'Constructing a social geography of grandparenthood: A new focus for intergenerationality', *Area,* 42(2), pp. 190-197.

Tarrant, A. (2012) 'Grandfathering: the construction of new identities and masculinites', in Arber, S. and Timonen, V. (eds.) *Contemporary grandparenting*. Bristol: The Policy Press.

Tarrant, A. (2016) 'The spatial and gendered politics of displaying family: exploring material cultures in grandfathers' homes', *Gender, Place & Culture,* 23(7), pp. 969-982.

Tasker, S.L. and Stonebridge, G.G.S. (2016) 'Siblings, You Matter: Exploring the Needs of Adolescent Siblings of Children and Youth With Cancer', *Journal of Pediatric Nursing*, 31(6), pp. 712-722.

Taubman-Ben-Ari, O. (2012) 'Becoming and developing: Personal growth in the wake of parenthood and grandparenthood', in Shaver, P.R. and Mikulincer, M. (eds.) *Meaning, mortality, and choice: The social psychology of existential concerns.* Washington, DC, US: American Psychological Association, pp. 163-181.

Taylor, A.C., Robila, M. and Lee, H.S. (2005) 'Distance, contact, and intergenerational relationships: Grandparents and adult grandchildren from an international perspective', *Journal of Adult Development*, 12(1), pp. 33-41.

Taylor, M.F., Marquis, R., Batten, R. and Coall, D. (2016) 'Understanding the mental health travails of custodial grandparents', *Occupational Therapy in Mental Health*, 32(3), pp. 259-280.

Tennant, P.W.G., Gibson, G.J. and Pearce, M.S. (2008) 'Lifecourse predictors of adult respiratory function: results from the Newcastle Thousand Families Study', *Thorax*, 63(9), pp. 823-830.

The Children's Society (2012) *Holes in the safety net: The impact of Universal Credit on disabled people and their families*. The Children's Society. [Online]. Available at: https://www.citizensadvice.org.uk/Global/Migrated_Documents/corporate/holes-in-the-safety-net-final-copy.pdf (Accessed: 20th August 2019).

Thiele, D.M. and Whelan, T.A. (2006) 'The nature and dimensions of the grandparent role', *Marriage & Family Review*, 40(1), pp. 93-108.

Thiele, D.M. and Whelan, T.A. (2008) 'The relationship between grandparent satisfaction, meaning, and generativity', *International Journal of Aging and Human Development*, 66(1), pp. 21-48.

Thijssen, P. (2016) 'Intergenerational solidarity: the paradox of reciprocity imbalance in ageing welfare states', *The British Journal of Sociology*, 67(4), pp. 592-612.

Thomas, C. (2007) *Sociologies of disability and illness : contested ideas in disability studies and medical sociology*. New York, US: Palgrave Macmillan.

Thomas, S., Reddy, N.K. and Sagar, K.J.V. (2016) 'Review on Psychosocial Interventions for Siblings of Children with Autism Spectrum Disorder (ASD)', *Journal of Psychosocial Rehabilitation and Mental Health*, 3(2), pp. 101-107.

Tiffin, P.A., Pearce, M.S. and Parker, L. (2005) 'Social Mobility over the Lifecourse and Self Reported Mental Health at Age 50: Prospective Cohort Study', *Journal of Epidemiology and Community Health*, 59(10), pp. 870-872.

Timonen, V. (2016) *Beyond successful and active ageing: A theory of model ageing*. Bristol, UK: The Policy Press.

Timonen, V. (2019) *Grandparenting practices around the world: Reshaping family*. Bristol, UK: The Policy Press.

Timonen, V. and Arber, S. (2012) 'A new look at grandparenting', in *Contemporary grandparenting*. Bristol: The Policy Press.

Timonen, V., Conlon, C., Scharf, T. and Carney, G. (2013) 'Family, state, class and solidarity: re-conceptualising intergenerational solidarity through the grounded theory approach', *European Journal of Ageing*, 10(3), pp. 171-179.

Timonen, V. and Doyle, M. (2012) 'Grandparental agency after adult children's divorce', in Arber, S. and Timonen, V. (eds.) *Contemporary grandparenting: Changing family relationships in global contexts*. Bristol, UK: The Policy Press, pp. 159-180.

Tourjeman, K., Doron, I. and Cohen, M. (2015) 'Losing a grandchild: The mourning experience of grandparents in Israel', *Death studies*, 39(8), pp. 491-499.

Trute, B., Hiebert-Murphy, D. and Levine, K. (2007) 'Parental appraisal of the family impact of childhood developmental disability: Times of sadness and times of joy', *Journal of Intellectual and Developmental Disability*, 32(1), pp. 1-9.

Twigg, J. (2000) 'Carework as a form of bodywork', *Ageing & Society*, 20(4), pp. 389-411.

Uhlenberg, P. (2005) 'Demography of aging', in Poston, D.J. and Micklin, M. (eds.) *Handbook of population*. New York, US: Springer, pp. 143-167.

Uhlenberg, P. and Hammill, B.G. (1998) 'Frequency of Grandparent Contact With Grandchild Sets: Six Factors That Make a Difference', *The Gerontologist*, 38(3), pp. 276-285.

Vadasy, P.F. (1987) 'Grandparents of Children with Special Needs: Supports Especially for Grandparents', *Children's Health Care*, 16(1), pp. 21-23.

Van Bavel, J. and De Winter, T. (2013) 'Becoming a Grandparent and Early Retirement in Europe', *European Sociological Review*, 29(6), pp. 1295-1308.

Van der Geest, S. (2004) 'Grandparents and grandchildren in Kwahu, Ghana: the performance of respect', *Africa*, 74(1), pp. 47-61.

Van Riper, M., Ryff, C. and Pridham, K. (1992) 'Parental and family well-being in families of children with down syndrome: A comparative study', *Research in Nursing and Health*, 15(3), pp. 227-235.

Vickerstaff, S. (2010) 'Older workers: the 'unavoidable obligation'of extending our working lives?', *Sociology Compass*, 4(10), pp. 869-879.

Villar, F., Carme, T., Pinazo-Hernandis, S., Celdrán, M. and Solé, C. (2010) 'Grandparents and their adolescent grandchildren: Generational stake or generational complaint? A study with dyads in Spain', *Journal of Intergenerational Relationships*, 8(3), pp. 281-297.

Villar, F., Celdrán, M. and Triadó, C. (2012) 'Grandmothers Offering Regular Auxiliary Care for Their Grandchildren: An Expression of Generativity in Later Life?', *Journal of Women & Aging*, 24(4), pp. 292-312.

Villar, F. and Serrat, R. (2014) 'A Field in Search of Concepts: The Relevance of Generativity to Understanding Intergenerational Relationships', *Journal of Intergenerational Relationships*, 12(4), pp. 381-397.

Walker, A., Alfonso, M.L., Colquitt, G., Weeks, K. and Telfair, J. (2016) '"When everything changes:" Parent perspectives on the challenges of accessing care for a child with a disability', *Disability and Health Journal*, 9(1), pp. 157-161.

Walker, R. and Hutchinson, C. (2018) 'Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability', *Ageing and Society*, 39(7), pp. 1512-1527.

Wallander, J.L. and Varni, J.W. (1998) 'Effects of pediatric chronic physical disorders on child and family adjustment', *Journal of Child Psychology and Psychiatry*, 39(1), pp. 29-46.

Wang, M., Turnbull, A.P., Summers, J.A., Little, T.D., Poston, D.J., Mannan, H. and Turnbull, R. (2004) 'Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years', *Research and Practice for Persons with Severe Disabilities*, 29(2), pp. 82-94.

Warin, J., Solomon, Y. and Lewis, C. (2007) 'Swapping Stories: Comparing Plots: Triangulating Individual Narratives within Families', *International Journal of Social Research Methodology*, 10(2), pp. 121-134.

Watson, B. (2019) *Regional labour market statistics in the UK: January 2019*. Office for National Statistics, [Online]. Available at: file:///H:/Downloads/Regional%20labour%20market%20statistics%20in%20the%20UK%20September%202019.pdf (Accessed: 29th September 2019).

Great Britain. *Welfare Reform Act Elizabeth II*. (2012) London: The Stationery Office.

Wellard, S. (2011) *Doing it all? Grandparents, childcare and employment: An analysis of British Social Attitudes Survey Data from*. Plus, G. [Online]. Available at: http://www.grandparentsplus.org.uk/wp-content/uploads/2011/03/Doing-it-all__Online.pdf (Accessed: 24th April 2017).

Wengraf, T. (2001) *Qualitative research interviewing : biographic narrative and semi-structured methods*. London: SAGE Publications.

Werner, P. and Lowenstein, A. (2001) 'Grandparenthood and Dementia', *Clinical Gerontologist*, 23(1-2), pp. 115-129.

Wheelock, J. and Jones, K. (2002) '‘Grandparents Are the Next Best Thing’: Informal Childcare for Working Parents in Urban Britain', *Journal of Social Policy*, 31(3), pp. 441-463.

Whittingham, K., Wee, D., Sanders, M.R. and Boyd, R. (2013) 'Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences', *Disability and Rehabilitation*, 35(17), pp. 1447-1452.

Wiese, B.S., Burk, C.L. and Jaeckel, D. (2016) 'Transition to Grandparenthood and Job-Related Attitudes: Do Grandparental Sex and Lineage Matter?', *Journal of Marriage and Family*, 78(3), pp. 830-847.

Willig, C. (2013) *Introducing qualitative research in psychology*. 3rd ed.. edn. Maidenhead, UK: McGraw-Hill Education.

Winefield, H.R. (2000) 'Stress Reduction for Family Caregivers in Chronic Mental Illness: Implications of a Work Stress Management Perspective', *International Journal of Stress Management*, 7(3), pp. 193-207.

Wiscott, R. and Kopera-Frye, K. (2000) 'Sharing of culture: Adult grandchildren's perceptions of intergenerational relations', *The International Journal of Aging and Human Development*, 51(3), pp. 199-215.

Wise, B.V. (2002) 'In their Own Words: The Lived Experience of Pediatric Liver Transplantation', *Qualitative Health Research*, 12(1), pp. 74-90.

Wofford, J.R. and Carlson, R.G. (2017) 'A literature review and case study on the strengths and struggles of typically developing siblings of persons with disabilities', *The Family Journal*, 25(4), pp. 398-406.

Women's Royal Voluntary Service (2011) *Gold age pensioners. Valuing the socio-economic contribution of older people in the UK*. Royal Voluntary Service. [Online]. Available at: https://www.royalvoluntaryservice.org.uk/Uploads/Documents/gold_age_report_2011.pdf.

Women Against State Pension Age Increase (2019). Available at: https://www.waspi.co.uk/ (Accessed: 9th October 2019).

Woodbridge, S., Buys, L. and Miller, E. (2009) 'Grandparenting a child with a disability: An emotional rollercoaster', *Australasian Journal on Ageing*, 28(1), pp. 37-40.

Woodbridge, S., Buys, L. and Miller, E. (2011) '‘My grandchild has a disability’: Impact on grandparenting identity, roles and relationships', *Journal of Aging Studies*, 25(4), pp. 355-363.

World Health Organization (2002) *Active Ageing: A Policy Framework. A contribtuion of the World Health Organization to the Second United Nations World Assembly on Ageing.* Madrid: Organisation, W.H. [Online]. Available at: http://whqlibdoc.who.int/hq/2002/who_nmh_nph_02.8.pdf (Accessed: 3rd May 2017).

World Health Organization (2016) *The Global strategy and action plan on ageing and health*. Available at: http://who.int/ageing/global-strategy/en/index1.html (Accessed: 3rd May 2017).

Yamashiro, J.A. and Matsukura, T.S. (2014) 'Intergenerational support for families of children with disabilities', *Psicologia em Estudo*, 19(4), pp. 705-715.

Yau, M.K.-s. and Li-Tsang, C.W. (1999) 'Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes', *The British Journal of Development Disabilities*, 45(88), pp. 38-51.

Zaidi, A. (2015) 'Active ageing index: A legacy of the European year 2012 for active ageing and solidarity between generations', *Policy Brief, April 2015*. Vienna: European Centre for Social Welfare Policy and Research

Zaidi, A., Gasior, K., Hofmarcher, M.M., Lelkes, O., Marin, B., Rodrigues, R., Schmidt, A., Vanhuysse, P. and Zolyomi, E. (2013) 'Active ageing index 2012 concept, methodology and final results'. European Centre Vienna.

Zaidi, A. and Howse, K. (2017) 'The Policy Discourse of Active Ageing: Some Reflections', *Journal of Population Ageing*, 10(1), pp. 1-10.

Zelezná, L. (2018) 'Care-giving to grandchildren and elderly parents: Role conflict or family solidarity?', *Ageing and Society*, 38(5), pp. 974-994.

Zhang, M. and Li, Y. (2019) 'Family fortunes: The persisting grandparents' effects in contemporary British society', *Social science research*, 77(1), pp. 179-192.

Appendix A. Advert for Recruitment

Grandparent of a grandchild with a disability?

Interested in taking part in some research?

Researchers at Newcastle University are working in collaboration with Contact a Family to explore the role and experiences of grandparents of grandchildren with a disability.

Grandparents provide a lot of support to families, especially families of children with a disability, however little research has been done around this topic.

It is hoped this research will have an influence on services and support for grandparents and families of children with a disability.

The researcher would like to hear the views of grandparents, parents and grandchildren to understand more about grandparents' role.

They are currently looking for **grandparents** who would be interested in taking part who:

✓ Have a grandchild with a disability or special needs. For example: physical disability, intellectual difficulties, behavioural issues, emotional problems, or neurodevelopmental disorders

✓ Grandparents with grandchildren of any age

✓ Grandparents who provide **any amount of informal care** for their grandchild with a disability.
Unfortunately, the scope of this research cannot include grandparents who are legal sole carers and guardians of their grandchildren

✓ Speak and understand English language

The research would involve taking part in a 1-1 interview (about 60-90 minutes). If you would be interested in hearing more you can contact Jacqui Adams or Sarah Lewis at Contact a Family, or you can contact the researcher directly, Hannah Merrick (PhD Student), on the details below.

Hannah Merrick: Email- h.merrick2@ncl.ac.uk, **Telephone:** 0191 282 1381**; Mobile**: 07580097423

Newcastle University

Institute of Health & Society

Appendix B. Poster/Flyer for Recruitment

Grandparents of a grandchild with a disability

Interested in taking part in some research?

Researchers at Newcastle University would like to hear the views of grandparents, parents and grandchildren to understand more about grandparents' role.

They are currently looking for **grandparents** who would be interested in taking part who:

- ✓ Have a grandchild with a disability or special needs of any age
- ✓ Provide **any amount of informal care** for their grandchild with a disability
- ✓ Speak and understand English language

Newcastle University
Institute of Health & Society

contact For families with disabled children

Appendix C. Grandparent Information Sheet

contact For families with disabled children

Newcastle University
Institute of Health & Society

Exploring Grandparenthood in the Context of Disability

Grandparent Information Sheet

Researchers from Newcastle University are working with Contact to study the relationship between grandparents and grandchildren with a disability. This is part of a PhD project funded by the Economic and Social Research Council (ESRC).

Please take your time to read all the information below and decide if you would like to take part.

Why this research is being done?

There has been very little research about grandparents of children with a disability in the UK. We know that grandparents provide a lot of support to families, especially to families with children with a disability. We are talking to grandparents, parents and grandchildren to learn more about what it is like being a grandparent to a grandchild with a disability. We want to hear from grandparents about their role in the family. We would like to know about the kind of activities they do together and how grandparents help look after children and young people.

We understand that there are many family influences on the experience of being a grandparent. Therefore, if you choose to take part in the study we would also like to approach the parent (your adult child) and your grandchild in order to hear their perspective. If you think this would be appropriate, we would discuss this with you at the end of your interview.

What we hope to achieve with this research?

This research will help inform policymakers, service providers and other organisations such as Contact a Family, about the contribution grandparents make to the lives of children with a disability. This information will then hopefully be used to influence services that support families of children with a disability.

What will taking part involve?

We would like to hear about your experience of having a grandchild with a disability. This will involve taking part in an interview about your experience. We will contact you to arrange a convenient time and place for the interview. The interviews can take place in your own home, or another location that would suit you. It is expected the interview will take approximately 60-90 minutes. We may invite you to take part in a second interview to follow-up on topics raised in the first interview.

During the interview, we will ask you some questions about your experience of being a grandparent to a child who has a disability. If you agree the researcher will audio-record the interview and make some notes during the discussion. During the interview you can choose not to answer any of the questions, take a break, and you can stop the interview at any point if you do not wish to continue.

At the end of the interview you will receive a £10 shopping voucher as a thank you for taking part in the research.

Confidentiality

All information will be kept strictly confidential. Your personal details (e.g. name, address) will be stored in a locked filing cabinet, only accessed by the researcher. All the interviews will be transcribed (typed up in detail) and all identifiable information (e.g. names, address) will be removed. The recording of your interview will be destroyed after it has been typed up and

v1.1_Grandparent_infosheet_22062017

checked. These transcripts from interviews will be stored on a university computer with password protection, and the only information about you will be a unique number which links the computer file to the personal details in the locked filing cabinet.

Your personal details and replies will be kept safe and secure. We will keep your personal details for a maximum of 1 year after the end of the research and keep the interview transcripts for up to 10 years. No personal identification information such as names of people or places will be used in any reports of the research. We may use quotes from the interviews, but no individual will be identifiable in any publication arising from this study.

The only person that will hear the recording will be the researcher. No one in your family will hear or see what you have told the researcher.

Very occasionally people tell the researcher that someone may be at risk of, or has experienced harm or abuse. In these situations the researcher has an obligation to tell this information to the appropriate authority in order to make sure the person at risk is safe.

What will happen if I don't want to take part?

We hope you will be interested in helping us with this study, but you do not have to. A decision not to take part in this study will not affect the support you get from Contact or anyone else.

You are free to change your mind and leave this study at any time and you do not need to give us any reasons.

Taking Part

If you are interested in taking part please complete the expression of interest form enclosed and return to the research team in the stamped addressed envelope.

Alternatively, you can contact the researcher, Hannah Merrick (PhD Student) on the contact details below via telephone, email or text:

Telephone: 0191 282 1381
Email: h.merrick2@ncl.ac.uk

Address:
Newcastle University, Baddiley Clark Building, Richardson Road, Newcastle upon Tyne, NE2 4AX

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interest.

What if I have any concerns or complaints?
If you have any concerns about this research and would like to discuss them further, please contact:

Dr Suzanne Moffatt	**Dr Lindsay Pennington**	**Professor Janice McLaughlin**
Tel: 0191 208 5005	Tel: 0191 282 1360	Tel: 0191 208 7511
Email: Suzanne.moffatt@ncl.ac.uk	Email: Lindsay.pennington@ncl.ac.uk	Email: janice.mclaughlin@ncl.ac.uk

Appendix D. Parent Information Sheet

contact For families with disabled children

Newcastle University
Institute of Health & Society

Exploring Grandparenthood in the Context of Disability

Parent Information Sheet

Researchers from Newcastle University are collaborating with Contact to conduct a study to explore the relationship between grandparents and grandchildren with a disability. This is part of a PhD project funded by the Economic and Social Research Council (ESRC).

Please take your time to read all the information below and decide if you would like to take part.

Why this research is being done?

There has been very little research on grandparents of children with a disability in the UK, especially from the grandparent's perspective. Grandparents offer a great amount of support in many ways, especially for families of children with a disability.

The main focus of this research is on the grandparents' experience and perspective. However, we understand that there are many family influences on the experience of being a grandparent. Therefore, we are also approaching parents of children with a disability and, if appropriate, the grandchild, in order to hear their perspective. You have been approached as your parent/parent-in-law thought you would be interested in taking part in this research.

What we hope to achieve with this research?

It is intended that this research will help inform policymakers, service providers and other organisations such as Contact, about the contribution grandparents make to the lives of children with a disability. This information can then be used to influence services and support for families of children with a disability.

What will taking part involve?

We would like to hear about your perspective on the role of grandparents in your life and the life of your child with a disability. This will involve taking part in an interview about your experiences. We will contact you to arrange a convenient time and place for the interview. The interviews can take place in your own home, or another location that would suit you. It is expected the interview will take approximately 60-90 minutes. We may invite you to take part in a second interview to follow-up on topics raised in the first interview.

During the interview, we would like to ask you some questions about the roles your child's grandparents play in your life with a child with a disability and about the kind of support you receive from grandparents. The questions will be open-ended to allow you to share your stories and experiences. If you agree the researcher will audio-record the interview and make some notes during the discussion. During the interview you can choose not to answer any of the questions, take a break, and you can stop the interview at any point if you do not wish to continue.

At the end of the interview you will receive a £10 shopping voucher as a thank you for taking part in the research.

Involvement of Grandchildren

One area where there has been very little research is understanding the grandchild's perspective on their relationship with their grandparents. We would like to invite some grandchildren to be interviewed about the research. We understand in some cases this will not be appropriate, but the researcher will discuss this with you at the end of the interview.

v1.1_Parent_infosheet_22062017

The researcher will have received training in interviewing children and young people from experienced researchers at Newcastle University. If you would be happy for your child to be interviewed as well, the researcher will discuss this in more detail with you and provide you with information to go through with your child.

Confidentiality

All information will be kept strictly confidential. Your personal details (e.g. name, address, contact details) will be stored in a locked filing cabinet, only accessed by the researcher. All the interviews will be transcribed (typed up in detail) and all identifiable information (e.g. names, address) will be removed. The recording of your interview will be destroyed after it has been typed up and checked. The transcripts from interviews will be stored on a university computer with password protection, and the only information about you will be a unique number which links the computer file to the personal details in the locked filing cabinet.

Your personal details and replies will be kept safe and secure. We will keep your personal details for a maximum of 1 year after the end of the research and your interview transcripts for up to 10 years. No personal identification information such as names will be used in any reports of the research. We may use quotes from the interviews, but no individual will be identifiable in any publication arising from this study.

The only person who will hear the recording will be the researcher. No one in your family will hear or see what you have told the researcher.

Very occasionally people tell the researcher that someone may be at risk of, or has experienced harm or abuse. In these situations the researcher has an obligation to tell this information to the appropriate authority in order to make sure the person at risk is safe.

What will happen if I don't want to take part?

We hope you will be interested in helping us with this study, but you do not have to. A decision not to take part in this study will not affect the support you get from Contact.

You are free to change your mind and leave this study at any time and you do not need to give us any reasons.

Taking Part

If you are interested in taking part please complete the expression of interest form enclosed and return to the research team in the stamped addressed envelope. Alternatively, you can contact the researcher, Hannah Merrick (PhD Student) on the contact details below;

Telephone: 0191 282 1381
Mobile 07580097423
Email h.merrick2@ncl.ac.uk

Address:
Newcastle University, Baddiley Clark Building, Richardson Road, Newcastle upon Tyne, NE2 4AX

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interest.

What if I have any concerns or complaints?

If you have any concerns about this research and would like to discuss them further, please contact:

Dr Suzanne Moffatt	Dr Lindsay Pennington	Professor Janice McLaughlin
Tel: 0191 208 5005	Tel: 0191 282 1360	Tel: 0191 208 7511
Email: Suzanne.moffatt@ncl.ac.uk	Email: Lindsay.pennington@ncl.ac.uk	Email: janice.mclaughlin@ncl.ac.uk

Appendix E: Grandchild Information Sheets

contact For families with disabled children

Newcastle University
Institute of Health & Society

Learning more about grandparents of children with a disability

Children's Information Sheet (8-13 years)

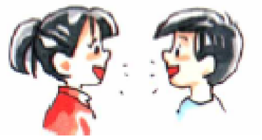
You are invited to take part in some research looking at children with a disability and their grandparents. The research is being carried out by a student at Newcastle University, with Contact a Family.

What is the study about?

We want to hear from children about what they think about their relationship with their grandparent. We would like to know about the kind of things children do with their grandparents and how grandparents help look after children with a disability.

What would I have to do?

If you want to take part, and your parents agree, a researcher (called Hannah) will visit you to talk to you about your grandparents. The talk would be recorded. We can talk at your house or anywhere else you feel comfortable.



You can choose someone to help you with the talk. This can be a parent, carer or friend. If you use a communication aid, then you can plan the talk with the researcher to help you feel more comfortable, and to show the researcher how you use your communication aid.

What if I do not want to take part?

You do not have to take part. It is totally up to you. If you do not want to take part, or if you want to stop at any time you do not need to give a reason.

What happens to the information from the talk?

We will type up the talk and the researcher will read it carefully to understand what you have said. It will be kept strictly private. Only the researcher knows who you are.

Sometimes, but not often, someone says something to the researcher that suggests that they or someone else is at risk of harm (being hurt), if that happens the researcher must tell the people who can then protect you or the person who might be hurt.

Who are the researchers?

Hannah Merrick
Hannah is a PhD student at Newcastle University. She will be the person who will interview you. She is a trained researcher who has experience of carrying out research with children and young people.

Hannah is being supervised by Dr Suzanne Moffatt, Dr Lindsay Pennington and Professor Janice McLaughlin at Newcastle University.

What if I have more questions or do not understand something?

Please contact the researcher, Hannah at Newcastle University:

Hannah Merrick
Newcastle University,
Baddiley Clark Building,
Richardson Road,
Newcastle upon Tyne,
NE2 4AX
Telephone: 0191 282 1379, Mobile: XXXXX
Email: h.merrick2@ncl.ac.uk

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interest.

What if I have worries or I'm not happy with the research?

If you have any concerns about this research and would like to discuss them further, please contact:

Dr Suzanne Moffatt	**Dr Lindsay Pennington**	**Professor Janice McLaughlin**
Tel: 0191 208 5005	Tel: 0191 282 1360	Tel: 0191 208 7511
Email: Suzanne.moffatt@ncl.ac.uk	Email: Lindsay.pennington@ncl.ac.uk	Email: janice.mclaughlin@ncl.ac.uk

Learning more about grandparents of children with a disability

Young Person Information Sheet (14 years +)

You are invited to take part in a research project looking at the relationship between children and young people with a disability and their grandparents. The research is being carried out by a student at Newcastle University, with the help of Contact a Family.

Please take your time to read all the information below and decide if you would like to take part.

What is the study about?

We know that grandparents provide a lot of support to families, especially to families with children with a disability. But, there has not been much research about it in the UK. We are talking to grandparents, parents and grandchildren to learn more about being a grandparent to a grandchild with a disability. We want to hear from young people about what they think about their relationship with their grandparent. We want to find out about the kind of activities they do together and how grandparents help look after young people.

Why have you been asked to take part?

We have talked to your grandparent and parent. They thought you might also like to take part in the research to talk about how you feel about the things you do with your grandparents and how your grandparents help you.

What would I have to do?

If you agree to take part, and your parent agrees, a researcher (called Hannah) will visit you to talk to you about the role of grandparents. The talk would be recorded. The talk can take place either at your home or anywhere you feel comfortable.

We will ask you about what kind of things you do with your grandparents, how often you see them and how they support you. It will be like a chat rather than lots of questions.

You can choose someone to help you with the talk if you like- this can be a parent, carer, or friend. If you use a communication aid, then you can plan the talk with the researcher to help you feel more comfortable, and to show the researcher how you use your communication aid.

In the talk you do not have to answer all of the questions. You can have a break and you can stop the talk at any point if you want to.

Why is this research useful?

We hope that by talking to grandparents, parents and grandchildren we will be able to help advise services and organisations such as Contact a Family, how best to support families like yours.

What if I do not want to take part?

You do not have to take part. It is totally up to you. If you do not want to take part, or if you want to stop at any time you do not have to tell us why.

What happens to the information from the talk?

The recording will be typed up and the researcher will read it carefully to understand what you have said. It will be kept strictly private. The recording will be destroyed once it has been typed up. Your name will not be used when we type up the recording. We will give each person a number and only the researcher will know which number is yours. The researcher will make sure all information is kept private.

We will keep your personal details for a maximum of 1 year after the research has finished. We will keep the typed up talk for up to 10 years. Your name or other personal details will not be used in any reports of the research. We may use some of your words from the talk, but no-one will be able to tell who said this.

The only people that will hear the recording will be the researchers. No one in your family who is not at the visit will hear or see what you have told the researcher.

Very occasionally young people tell the researcher that someone may be at risk of, or has experienced harm or abuse. In these situations the researcher has an obligation to tell this information to the appropriate authority in order to make sure the person at risk is safe.

Knowing more about the researchers:

Hannah will be the researcher interviewing you. Hannah is a PhD student at Newcastle University. She is a trained researcher who has experience of carrying out research with children and young people.

Hannah is being supervised by Dr Suzanne Moffatt, Dr Lindsay Pennington and Professor Janice McLaughlin from Newcastle University. All of whom are experienced researchers.

What if I have more questions or do not understand something?

Please contact the researcher, Hannah at Newcastle University:

Hannah Merrick
Newcastle University,
Baddiley Clark Building,
Richardson Road,
Newcastle upon Tyne,
NE2 4AX
Telephone: 0191 282 1379, Mobile: XXXXX
Email: h.merrick2@ncl.ac.uk

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interest.

What if I have concerns or a complaint?
If you have any concerns about this research and would like to discuss them further, please contact:

Dr Suzanne Moffatt	**Dr Lindsay Pennington**	**Professor Janice McLaughlin**
Tel: 0191 208 5005	Tel: 0191 282 1360	Tel: 0191 208 7511
Email: Suzanne.moffatt@ncl.ac.uk	Email: Lindsay.pennington@ncl.ac.uk	Email: janice.mclaughlin@ncl.ac.uk

V1.1_YPInfosheet_22062017

Appendix F. Ethics Approval Letter

Newcastle University

Faculty of Medical Sciences

Newcastle University
The Medical School
Framlington Place
Newcastle upon Tyne
NE2 4HH United Kingdom

Hannah Merrick
Institute of Health & Society (IH&S)

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Hannah,

Title: Exploring grandparenthood in the context of grandchild disability
Application No: 1288/9395/2017
Start date to end date: 31/07/2017 to 30/03/2019

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: **1288/9395/2017**. If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During the course of your research project you may find it necessary to revise your protocol. Substantial changes in methodology, or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation.*

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee.*

Best wishes,

Yours sincerely

K. Sutherland

Kimberley Sutherland
On behalf of Faculty Ethics Committee

cc.
Professor Daniel Nettle, Chair of FMS Ethics Committee
Mrs Kay Howes, Research Manager

*Please refer to the latest guidance available on the internal Newcastle web-site.

tel: +44 (0) 191 208 6000
fax: +44 (0) 191 208 6521

www.ncl.ac.uk

The Queen's
Anniversary Prizes
2013

Appendix G. Grandparent and Parent Interview Agendas

Grandparent Interview Agenda

Pre-recording information

We are collaborating with Contact a Family to conduct some research on the experience of being a grandparent to a grandchild with a disability. Very little is known about this, especially from the grandparent perspective. We hope that the findings from this research will help us inform organisations like Contact how best to support grandparents and families of children with a disability.

- Everything you say will be confidential.
- The conversation will be audio-recorded with your permission.
- You can stop the interview at any time and choose not to answer any of the questions or discuss anything you do not want to.
- Structure of the interview: There are some topics I am interested in covering around your experience of being a grandparent of a grandchild with a disability. However, we want to hear your story so I will be asking quite open questions to begin with to allow you to tell your story and what is important to you. I'll keep quiet during this and you'll see me taking a few notes- the notes will just be little prompts for me to ask you about after you have finished telling your story. I'll ask some more focussed questions towards the end of the interview to follow-up on topics you mention and other topics we think are of relevance to the research. You'll also have time at the end to add anything else you think is important.
- Any questions?

Part 1: Start recording

1) Sociodemographic Questionnaire

Filled in with a discussion about the grandparent and their current situation e.g. working, retired, family etc.

2) Opening Question:

"Can you tell me about your experience of being a grandparent, describing events or experiences that are important to you? Maybe you could start with a bit about your grandchild with a disability, [your other grandchildren], and your family, then onto how you support your grandchild and their parent, then maybe how things have changed as you have all gotten older, or what your thoughts are about the future for you all. Please take all the time you need. I'll listen first, I won't interrupt. I'll just take some notes for after you've finished telling me about your experiences."

****No interrupting, make notes of points of interest to go back to later. Encouraging non-verbal gestures to continue storytelling.**

3) Structure and prompts on other page if needed.

Topic	**Prompts**	
1. **About yourself** (can be guided by sociodemographic questionnaire as well)	Can you tell me a little bit about yourself? Can you tell me about your experience of being a grandparent? What do you enjoy or not enjoy about it?	Age, living circumstances, working/retired, family members, what do you do when not being a grandparent? Is being a grandparent as you imagined? Role as expected? What does being a grandparent mean to you? [Couples: Do you approach the grandparenting individually with your own roles or is it undertaken jointly?]
2. **About the grandchild and parent**	Can you tell me about your grandchild with a disability? What condition do they have? How does it affect them? Can you remember what happened around [child's] diagnosis? What was the experience like for you? For the parents? Can you tell me about your child [parent], their circumstances and how you support them?	Age, siblings, type of help they need, personality, likes and dislikes How do they cope with the difficulties their condition brings? Age, marital status/living circumstances. Types of support- financial, emotional, practical….
3. **Involvement in care**	Can you tell me how you are involved in the care of your grandchild? Are you involved in caring for other grandchildren as well? Is your involvement similar with all your grandchildren?	Number of hours, type of care, how it was initiated, what kind of activities do you do together, involved in decision making? What aspects do you enjoy, what do you find harder? How their involvement is worked out/established with the parent?
4. **Impact on other areas of life**	How do you feel about your involvement with [grandchild name]? Does it impact on other areas of your life? For example your hobbies, health, work?	Other grandparents or family members involved? Prefer more or less involvement? Retired early? Different plans for retirement? Opened up opportunities not expected? Health impacts?
5. **Impact of ageing and thinking about the future**	Has the relationship changed with your grandchild as you have both gotten older? Do you have any concerns for the future? For you, your child, your grandchild?	Changing activities together, less or more involved, experience of child leaving school Are there ways the grandchild cares for them – now or in the future? Everyone's care needs change as you are all getting older, health limitations to continue helping with care,

Part 2: Chance to follow-up on topics discussed during the narrative. Follow-up in order that they were mentioned in the narrative.

Use prompts in table to get more detail if not already used.

Can you tell me more about….? How was [event/experience] for you?

Closing

- Is there anything else you would like to share about your experience of being a grandparent that we have not covered?
- Do you have any questions you would like to ask me?

Parent Interview Agenda

Pre-recording Information:

We are collaborating with Contact to conduct some research on the experience of being a grandparent to a grandchild with a disability. We are interested in hearing about experiences from a range of perspectives including the grandparents, parents and grandchildren. We hope that the findings from this research will help us inform organisations like Contact about how best to support families of children with a disability.

- Everything you say will be confidential.
- The conversation will be audio-recorded with your permission.
- You can stop the interview at any time and choose not to answer any of the questions you do not want to.
- I will not be disclosing anything the grandparent said in their interview and likewise I will not disclose anything you say to them.
- *Structure of the interview*:
  I have previously interviewed [NAME] about their involvement in the care of [NAME]. I would now like to hear your views. There are some topics I am interested in covering around the involvement of your parent(s) in the care of your child or the support they give you. However, we want to hear your story so I will be asking quite open questions to begin with to allow you to tell your story and what is important to you. I'll keep quiet during this and you'll see me taking a few notes- the notes will just be little prompts for me to ask you about after you have finished telling your story. I'll ask some more focussed questions towards the end of the interview to follow-up on topics you mention and other topics we think are of relevance to the research. You'll also have time at the end to add anything else you think is important.
- Any questions?

Part 1: Start recording:

1) Can you tell me a bit about yourself? For example, do you work? Do you have a partner?
   (Can be done with sociodemographic questionnaire as well)
   Can you tell me about your family? Who do you have nearby? Do any family members live further away?

2) *Open Question*:
   Can you tell me about the involvement of grandparents in supporting you and your child? You can start where you like, with any stories or events that you think are particularly relevant.

   **No interrupting, make notes of points of interest to go back to later. Encouraging non-verbal gestures to continue storytelling.

3) Structure and prompts on other page if needed.

Topic	**Prompts**	
1. About yourself	Can you tell me a little bit about yourself? Can you tell me about your family? Who do you have nearby? Do any family members live further away?	Age, living circumstances, working, family members What is the involvement of family/other grandparents that live further away?
2. Current support	Can you tell me about the support you currently receive from grandparent(s)? Can you tell me how this support has developed/been negotiated? (since the child was born) Did you have any expectations of grandparent care? Has it met your expectations? How do you feel about their level of involvement? How does the support from the grandparent impact on you? Does it allow you to do things you wouldn't otherwise be able to do? Do you have any other support networks? Family, friends?	Number of hours, type of care, what kind of activities do they do with you and/or your children, involved in decision making with school or hospital appointments? Differences between sets of grandparents? Is the type of support/involvement different for different grandchildren? What access to other support or services do you have? E.g. respite, childcare.
3. Change over time, thinking about the future	How has the involvement/support changed from when your child(ren) were younger to now? Was the support different in the early days compared to now? How do you think the involvement will change as everyone gets older? Are there ways you now care for/support your parent(s)–or may need to in the future? Do you have any concerns for the future? For you, your child or the grandparents?	Changing activities together, less or more involved, experience of child starting school or leaving school. Everyone's care needs change as you all get older, are there health limitations to grandparents continuing to help with care?

Part 2: Chance to follow-up on topics discussed during the narrative. Follow-up in order that they were mentioned in the narrative.

Use prompts in table to get more detail if not already used.

Can you tell me more about….? How was [event/experience] for you?

Closing

- Is there anything else you would like to share about your experience that we have not covered?
- Do you have any questions you would like to ask me?

Appendix H. Sociodemographic Questionnaires

Sociodemographic Questionnaire – Grandparent

Your DOB: ____
(dd/mm/yyyy)

Your gender: (Please tick appropriate box)

☐ Female ☐ Male

Your relationship to your grandchild: (Please tick appropriate box)

☐ My daughter's child ☐ My son's child

Your ethnic origin is: (Please tick appropriate box)

☐ White/European
☐ Black African
☐ Black Caribbean
☐ Pakistani
☐ Indian
☐ Bangladeshi
☐ Chinese
☐ Black other
☐ Asian other

Mixed (please specify) __________________________________

Other (please specify) __________________________________

Your marital status: (Please tick appropriate box)

☐ Married/Civil Partnership/co-habiting with long term partner
☐ Divorced/separated
☐ Widowed
☐ Single

Your employment status: (Please tick appropriate box)

☐ Retired from paid work Age of retirement: …………………..
☐ Full time carer
☐ Paid work part time Number of hours: ………………………
☐ Paid work full time
☐ Other (please specify): ---

What is/was your current/previous occupation?

……………………………………………………………………………………

What is/was your partner’s current/previous occupation?

…………………………………………………………………………………..

How many grandchildren do you have?

…………………………………………………

How many grandchildren do you provide childcare for and for how many hours per week on average?

……………………………….........................

Do you have any health conditions?

☐ Yes ☐ No

Does your partner have any health conditions?

☐ Yes ☐ No

Do you provide care for anyone else?

☐ Yes ☐ No

If yes, who for and for how many hours a week?

……………………………………………………………………………………………………..

Some details about your grandchild with a disability:

How old is your grandchild?

…………………………………………………………………

What disability/diagnosis does your grandchild have?

………………………………………………………………………………………………

How many hours of care do you provide on average a week?

………………………………………………………………………………………………

Sociodemographic questionnaire – parent/carer

Your DOB: (dd/mm/yyyy) ______________________________

Your gender: (Please tick appropriate box)

☐ Male ☐ Female

Postcode: ______________________________

Your marital status:

☐ Married/Civil Partnership/co-habiting with long term partner

☐ Divorced/separated

☐ Single

☐ Widowed

Your ethnic origin is: (Please tick appropriate box)

☐ White/European

☐ Black African

☐ Black Caribbean

☐ Pakistani

☐ Indian

☐ Bangladeshi

☐ Chinese

☐ Black other

☐ Asian other

Mixed (please specify) ______________________________

Other (please specify) ______________________________

How many children do you have?

____

Your employment status (please tick appropriate box)

☐ Employed full-time

☐ Employed part-time

☐ Full-time homemaker

☐ Full-time carer

☐ Unemployed and looking for work

☐ Other (please specify) ______________________________

☐ Unemployed and not looking for work

☐ Retired

☐ Doing voluntary work

☐ Full-time student

***For co-habiting couples only:**

Partner's employment status (please tick appropriate box)

☐ Employed full-time

☐ Employed part-time

☐ Full-time homemaker

☐ Full-time carer

☐ Unemployed and looking for work

☐ Other (please specify) ______________________________

☐ Unemployed and not looking for work

☐ Retired

☐ Doing voluntary work

☐ Full-time student

Appendix I. Grandchild Topic Guide

Topic Guide: Grandchild Interview

Introductory information

I am a researcher from Newcastle University. I'm doing some research on grandparents. We would really like to hear about the kind of things you do with your grandparent and if they help you with things.

- Everything you say will be kept private
- The conversation will be audio-recorded with your permission
- You can stop the interview at any time and choose not to answer any of the questions you do not want to
- Very occasionally people tell the researcher that someone may be at risk of, or has experienced harm or abuse. In these situations the researcher has an obligation to tell this information to the appropriate authority in order to make sure the person at risk is safe.
- Any questions?

Main questions

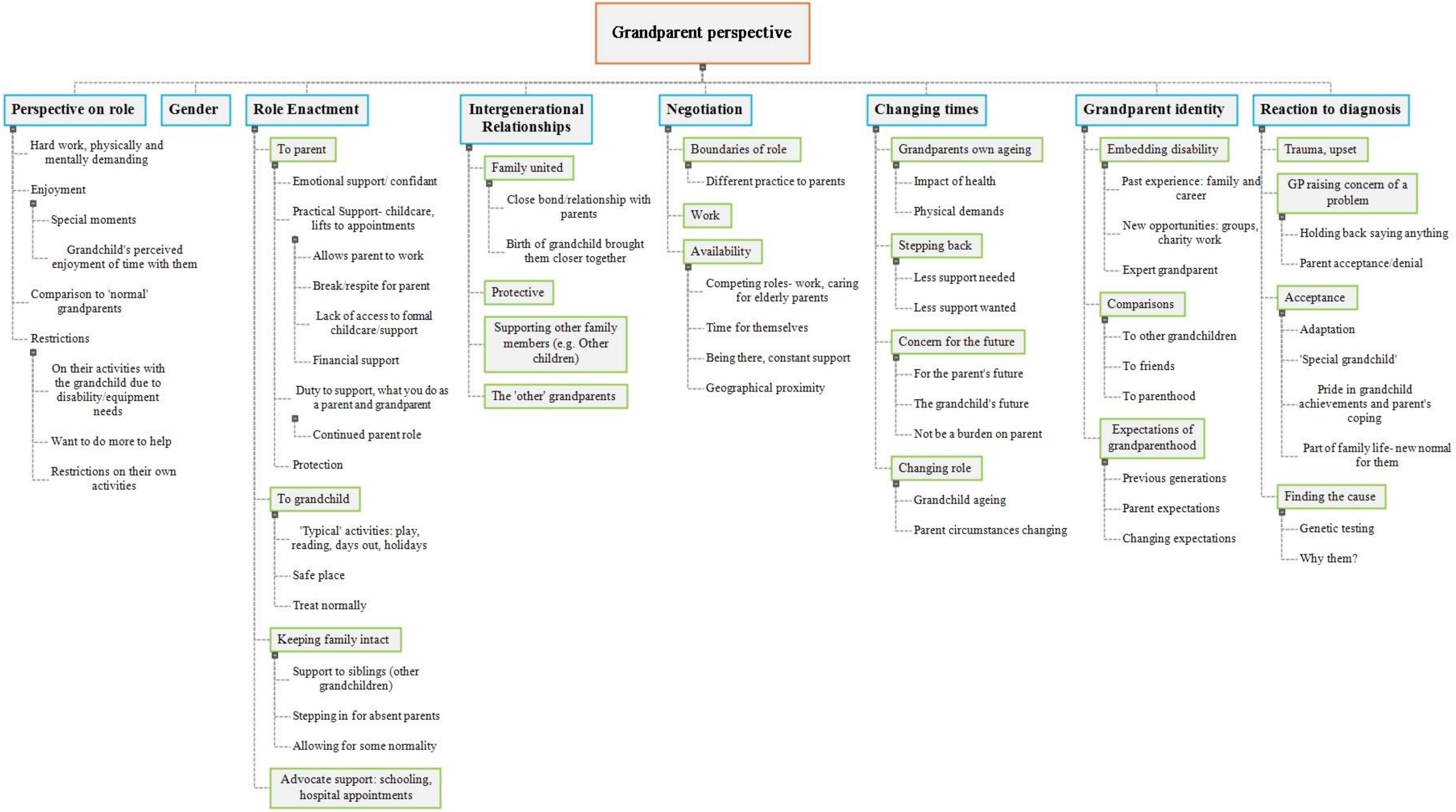
- Can you tell me a little bit about yourself? How old you are? What are you favourite things to do?
- Can you tell me about your grandparents? How often do you see each other? What kind of things you do together? Do they help you with things? How do they help you?
- What do you enjoy doing with your grandparents? Is there anything you do not like doing with your grandparents? What is your favourite thing to do with your grandparents?
- Who else helps/supports/looks after you?
- What is your grandma/grandad good at doing?
- What do you like best about your grandma/grandad/grandparents?
- What is your favourite memory/time/story with your grandparents?
- *[Depending on age of grandchild]*- How has your relationship with your grandparent changed as you have grown up?

Closing

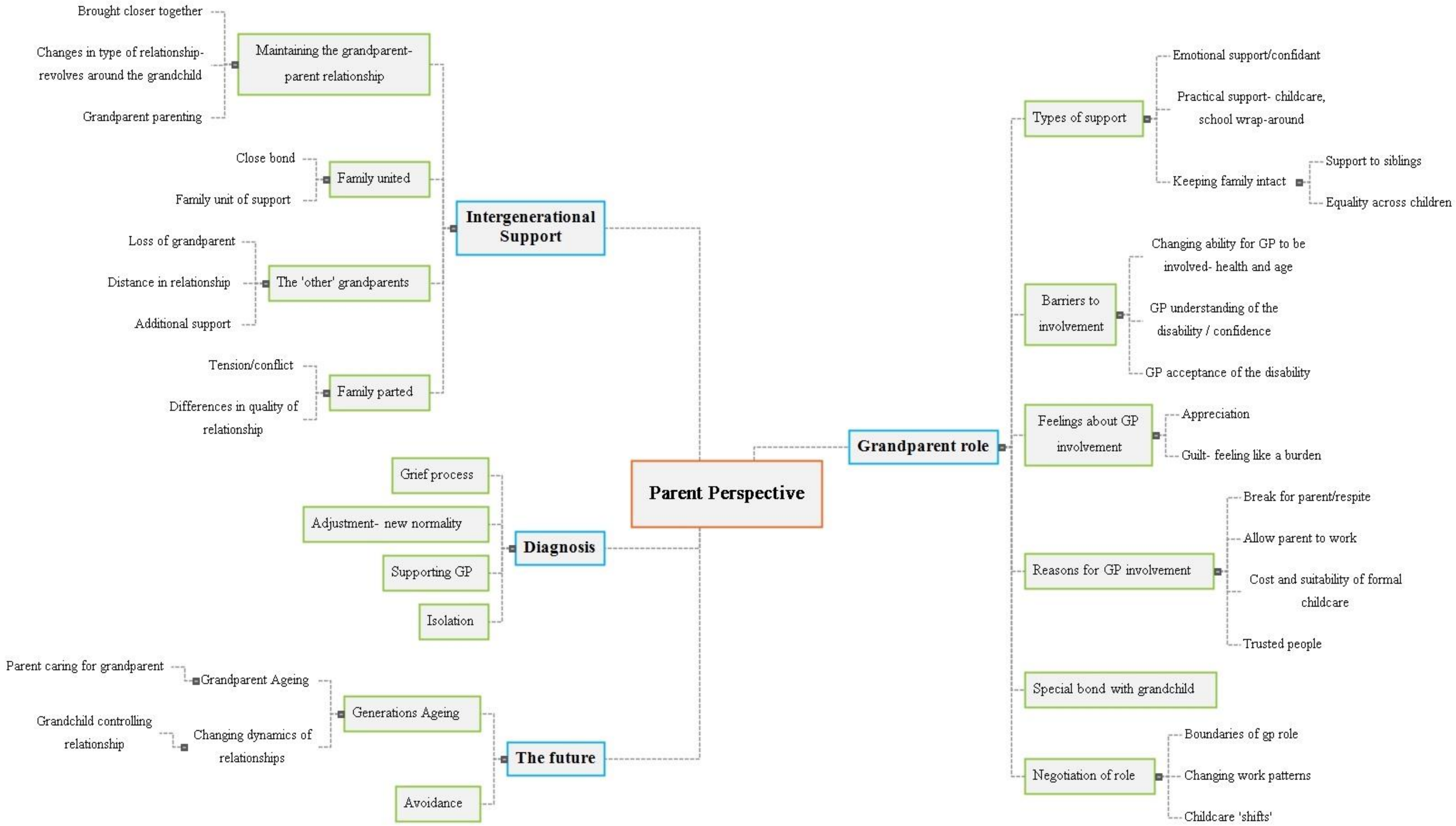
- Is there anything else about your grandparents you would like to talk about?
- Do you have any questions you would like to ask me?

Thank you for taking part.

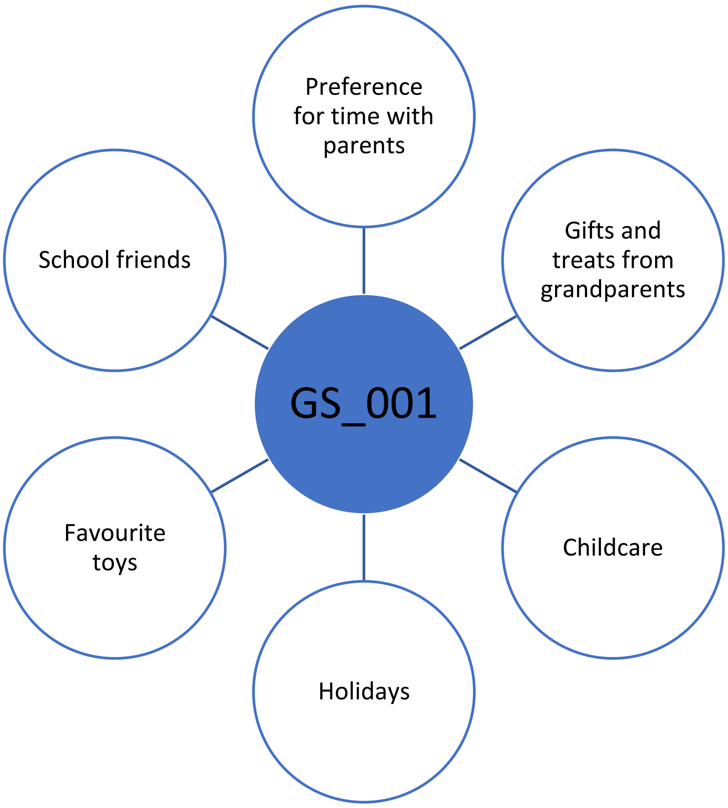
Appendix J. Mind Map of Grandparent Interview Codes

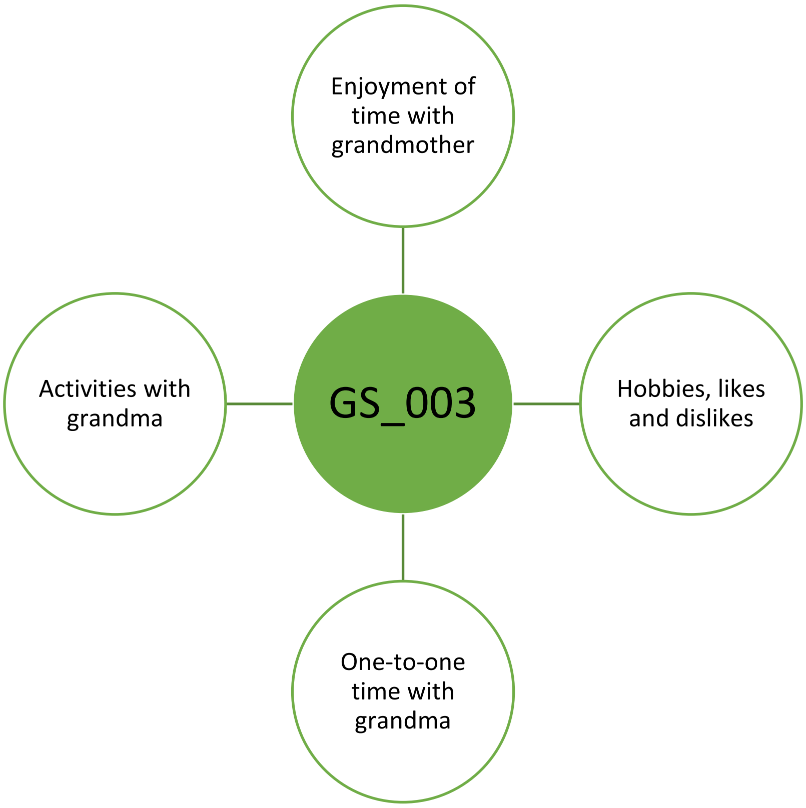


Appendix K. Mind Map of Parent Interview Codes



Appendix L. Grandchild Interview Codes




Enjoyment of time with grandmother
Activities with grandma
GS_003
Hobbies, likes and dislikes
One-to-one time with grandma

For the girl who believed she could not

The young woman who wanted to try

And the woman who will now always believe she can