'I want to have children, but I've got a learning disability': Understanding the reproductive and parenting imaginaries and experiences of people with learning disabilities from their perspectives and that of family members and support workers.

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Abstract

Today, social policies recognise that people with learning disabilities have the same rights as anyone else to family life, but many still face challenges to fulfilling these rights in practice. This thesis explores why, by prioritising the perspectives of people with learning disabilities alongside the perspectives of family members and support workers as important actors in their lives. Online and phone interviews were conducted during the Covid-19 pandemic with 21 people with learning disabilities, 10 siblings and three parents of someone with a learning disability, and three support workers. Interviews examined the possibilities for and experiences of people with learning disabilities having children. Key themes included: family roles and care dynamics, lack of accessible sexual and reproductive health education and information, barriers to intimacy, and issues of child removal.

I use disability studies, reproductive justice, and stratified reproduction as conceptual frameworks to illustrate how oppressive reproductive controls associated with previous institutionalisation and sterilisation practices still exist today through more subtle 'newgenic' ways. I argue that people with learning disabilities can be both supported and constrained when family members try to balance their rights with protectionism. People with learning disabilities continue to be restricted in their reproductive decision making by support workers that monitor and surveil their intimate lives and reproductive opportunities. Even when individual staff are supportive of the reproductive rights of people with learning disabilities, the wider organisational contexts they work within shape whether and how they engage with the topics of sexuality, reproduction, and parenthood. Social contexts of 'risk', especially around child removal, are also limiting the reproductive choices of people with learning disabilities as judgements about the capabilities and appropriacy of them having children is questioned. I end the thesis by considering changes in practice and attitudes that could enhance the reproductive rights of people with learning disabilities.

Accessible summary

About the research

- This work describes what people with learning disabilities think about having children.

- People with learning disabilities, family members of people with learning disabilities, and support workers took part in interviews.

Findings from the research

- People with learning disabilities should be able to make their own choices about having children.

- Parents and support staff can stop people with learning disabilities from having children. Sometimes this is to protect them, but it can also go against what people with learning disabilities want.

- People with learning disabilities need to be given information about sex, pregnancy, and parenthood so they can make their own choices.

- Some people with learning disabilities might need help with parenting. They should be able to get this help if they want it.

- Having information could help some people with learning disabilities look after their children and avoid having their children taken away by social services.

- More needs to be done to help people with learning disabilities make their own choices about having children and becoming parents.

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Chapter 1. Introduction

1.1 Introduction

Social norms present parenthood as a choice and part of ordinary adulthood that confirms adult status and shapes self-image and identity (May & Simpson 2001; Booth & Booth 1993). However, whilst there is growing acknowledgement that people with learning disabilities should be recognised as sexual actors, parenthood status remains out of reach for most people with learning disabilities (May & Simpson 2003: 36). This research was conducted with three participant groups: participants with learning disabilities, family members, and paid learning disability support workers. It aims to find out what people with learning disabilities think about the possibilities of having children and to explore the experiences of those already parenting with a learning disability. This research further aims to understand how family members, support workers and wider social contexts may influence the parenthood imaginaries and experiences of people with learning disabilities.

People with learning disabilities have long endured discriminatory obstacles in their social participation and social inclusion, particularly with regards to sexual and reproductive citizenship (Wright 2011). Historical myths have framed people with learning disabilities as either asexual and child-like, or sexually deviant and oversexed (Spencer et al. 2001). These social ideas influenced the negative treatment and general disregard for people with learning disabilities in society as large numbers of individuals were incarcerated in institutions for much of the nineteenth and twentieth centuries. The disability rights movement emerged in the UK during the 1960s and 1970s advocating for the equal rights and opportunities of disabled people to participate fully in society. Influenced by the disability rights movement, many people with learning disabilities today are living in the community instead of institutions and have greater visibility in society, yet the notion of people with learning disabilities having children and becoming parents remains an area that they still have little choice and autonomy over.

The Human Rights Act (1998) details the right to marry and have children and the right to respect for a private and family life but many people with learning disabilities continue to face barriers to intimate relationships and parenthood possibilities (Harflett & Turner 2016: 4). There are long-standing concerns about people with learning disabilities becoming parents as Shewan et al. (2014) notes; when people with a learning disability become parents, it is often viewed with concern and disapproval from others. More specifically, an individual's ability to manage the complexities of parenting is questioned and assumptions of incompetency are made as it is often assumed that parents with learning disabilities will be found ‘lacking’ (Murphy & Feldman 2002). As well as social attitudes, the policies and practices of social care organisations and services are shaping the parenting possibilities of people with learning disabilities. Opportunities for intimacy and privacy for people with learning disabilities are limited by staff surveillance and organisational care contexts (Hollomotz 2009a). Furthermore, services do not necessarily look beyond the label of ‘learning disability’ and thus tend to neglect the complex factors that influence parental competence in their approach to providing support to parents with learning disabilities (Baum et al. 2011; Edmonds 2000; Booth & Booth 1993). There is concern around the high rates of child protection proceedings initiated against parents with learning disabilities that often leads to children permanently being removed from their care (Booth & Booth 2005, Booth et al. 2005). It is therefore important that the beliefs underpinning negative attitudes towards the reproductive rights and choices of people with learning disabilities be examined.

This research uses concepts of disability studies, reproductive justice and stratified reproduction to explore how the reproductive and parenthood choices of people with learning disabilities can be shaped by structural and interpersonal relationships, especially family members and support workers. Within existing feminist and disability studies literature, these concepts have rarely been applied to discussions about the reproductive and parenthood possibilities of people with learning disabilities. By drawing from these conceptual frameworks, I will show how the reproduction of people with learning disabilities is controlled by power inequalities that reinforce social ideas that people with learning disabilities having children is still seen as something to be avoided. I will argue that often, despite good intentions of protection, family members can both support and constrain the reproductive and parenthood opportunities of people with learning disabilities. I will also argue that the monitoring and surveillance from support workers and the organisational contexts they are embedded within can further restrict the reproductive possibilities of people with learning disabilities. By centring the views of participants with learning disabilities in this study, I suggest that what people with learning disabilities think about having children is often shaped by broader social contexts of risk that questions the appropriacy and adequacy of their reproduction and parenting. By gaining insights from people with learning disabilities, family members and support workers, this research will contribute to broader discussions surrounding the issues of disability, reproductive justice, and parenthood. It will also highlight ways people with learning disabilities could be supported to reflect on parenthood and make informed choices in the future.

This introductory chapter will situate the context of this research, define and establish the use of the term learning disability, and it will explain the focus on people with learning disabilities, family members and support staff as participants. The research questions and the structure of the thesis will also be presented in this chapter.

1.2 Situating the research

People with learning disabilities have long experienced widespread social discrimination with a specific disregard for their recognition as sexual and reproductive citizens (Wright 2011). This section provides a brief historical overview regarding the lives of people with learning disabilities with a focus on the topic of reproduction. Historical myths and fears have framed people with learning disabilities as sexually deviant and dangerous and a threat to society (Gill 2015; Spencer et al. 2001). These negative understandings about people with learning disabilities informed social ideas and policies that led to many being incarcerated in institutions. From the mid-late nineteenth century in Britain, large groups of people with learning disabilities were incarcerated in institutions that segregated them from the rest of society. Within these institutions, people with learning disabilities were restricted from having intimate relationships as men and women were segregated to stop them from reproducing (Collins & Cozens, 1999; Shakespeare et al. 1996; Kempton & Kahn 1991). The sequestration of people with learning disabilities within institutions stemmed from the eugenic belief that mental deficiency would be passed on through inappropriate breeding and they would ‘‘pollute’ societies with ‘tainted’ offspring’ (Malacrida 2012: 391). In addition to being segregated within institutions, the coerced sterilisation of many women with learning disabilities became an integral part of the Eugenics movement in Western Europe and the US during the mid-twentieth century (Malacrida 2012). Sterilisation was often justified by concerns about social degeneration and the idea that women with learning disabilities were ‘unfit’ and unable to cope with the demands of pregnancy and motherhood (Saxton 2013).

Following the Second World War, new ideologies about normalisation (Nirje 1972; Wolfensberger 1972); the idea that people with learning disabilities should have opportunities to experience ‘normal’ life, and a series of scandals[1] about the inhumane treatment of people with learning disabilities within institutions influenced deinstitutionalisation and care in the community polices. Towards the end of the twentieth century, people with learning disabilities were gradually moved out of long-stay institutions into the community (see National Health Service and Community Care Act 1990). That it took a long time for community-based practices to emerge is important to acknowledge as it points to the deep-seated nature of the institutionalised mindset that still limits how community work occurs. Today, it is estimated that there are 1.1 million adults with a learning disability in the UK, that is approximately two per cent of the adult population. Many people with learning disabilities either live with friends and family, in a registered care home or in supported accommodation (Mencap 2023a). A smaller number of people with learning disabilities live in local authority housing and privately rented accommodation (Mencap 2017: 5). However, despite deinstitutionalisation and changes in policy disability activists argue that people with learning disabilities continue to be denied full and equal participation in society (Shakespeare 2017), especially with regards to their opportunities for parenthood.

On the topic of parenthood, Article 8 of the Human Rights Act (1998) is significant as it states that: ‘everyone has the right to respect for his private and family life’. The 2006 UN Convention on the Rights of Persons with Disabilities, ratified by the UK in 2009, also details the rights of disabled people to be parents and their right to choose when, and how many children to have (Article 23, para 1). Yet despite these rights entrenched in legislation, it is important to state that people with learning disabilities are far less likely to be in intimate relationships and be parents compared with the general population (Bates et al. 2017; O'Reilly

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[1] For example, the Ely hospital in Cardiff scandal that emerged in the 1960s detailed the inhumane treatment and abuse that people with learning disabilities endured in institutional settings (Fyson and Kitson 2007).

et al. 2009; Shackelford et al. 2005). For instance, earlier UK research by Emerson et al. (2005) found only four per cent of participants with a learning disability in their study had a partner, and only three per cent of people with learning disabilities in a relationship lived with their partner compared with 70 per cent of the general population (Emerson et al. 2005; Brown 1994).

The Working Together with Parents Network (2008) provides UK-wide support for professionals working with parents with learning disabilities and it estimates that there are over 53,000 parents with learning disabilities in England alone, although the actual number is likely to be much higher than this. Factors such as poor records, inconsistencies in assessment procedures, and the invisibility of many parents to formal services means the precise number is probably unknowable (Booth 2003: 203). It is also important to consider why such information is gathered at all; the way that this information is collected reinforces wider social ideas that frame parents with learning disabilities as different, problematic and a group in need of monitoring.

There remain long-standing social concerns within formal provision services about people with learning disabilities becoming parents as a study in England suggests nearly 50 per cent of parents interviewed had their children removed from them (Emerson et al. 2005[2]). This figure echoes international studies that estimates that somewhere between 40 – 60 per cent of parents with learning disabilities have their children removed from their care (McConnell et al. 2002). Shewan et al. (2014) note that when people with learning disabilities become parents, it is often viewed with concern and disapproval from others. More specifically, an individual's ability to manage the complexities of parenting is questioned and assumptions of incompetency are made. For example, it is often assumed that parents with learning disabilities are unfit to fulfil parenting roles and will be found ‘lacking’ (Murphy & Feldman 2002). Parents with learning disabilities are often let down as these negative attitudes are often present within services that makes it harder for them to access help, like other non-disabled parents can benefit from, to successfully raise their children (O’Hara & Martin 2003).

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[2] I recognise the date of this reference is quite old now but due to the lack of recording about parents with learning disabilities in the care system, it is difficult to find more recent figures (see Working Together with Parents Network (WTPN) 2021).

This research will consider how these dominant assumptions of inadequacy and services guarding against the 'risk' of parenthood shapes how people with learning disabilities think about and experience parenthood. By hearing from parents with learning disabilities who have experienced child removal, this research will explore the impact social service involvement can have on individuals and how this can influence parenting possibilities of people with learning disabilities who do not yet have children. The findings from this research will be used to identify ways family members, support workers and care organisations can uphold the rights of people with learning disabilities to make their own informed decisions about reproduction and parenthood. The findings will also make recommendations for how social services can better support parents with learning disabilities to fulfil parenting roles.

1.3 My experiences as a support worker

Prior to starting this research, I worked as a paid support worker for children and adults with learning disabilities and it was from these work experiences that I took the decision to return to higher education to explore the topic of disability further. In my role as support worker, I was often struck by the barriers to inclusion and equal opportunities people with learning disabilities experienced, particularly around leaving the family home, having intimate relationships, and making reproductive choices. For instance, I regularly supported a woman with learning disabilities in her early thirties to a special education needs (SEND) college where she would learn 'life skills' such as cooking, how to take public transport, and counting money but discussions about relationships, intimacy and reproduction were non-existent. With family members and support staff closely involved with most aspects of her life, it also seemed unfair to me that she did not have the same opportunities as people without learning disabilities to experience these life markers, especially when her sister (without learning disabilities) and other staff around her were enjoying relationships and having children.

While I have witnessed some of the barriers to social inclusion that people with learning disabilities can face, I make no claim to *know* what it is like to have a learning disability nor to know how it *feels* to experience the stigma and barriers attributed to having a learning disability that some participants described. I am sensitive to the wider oppression and marginalisation that people with learning disabilities often experience, and I have tried to challenge this by centring their views and voices within this research. I consider participants that took part in this research as experts, and I wanted to learn as much from their experiences as possible. This approach has also been influenced by my previous support worker experiences and my own moral position that is firmly grounded in person-centred practice.

These experiences have helped inform: my reading of the literature, the design of the research questions, and how I conducted and analysed the data in this research. Throughout this research I have stayed mindful of how my background as a non-learning-disabled student in higher education without a sibling with a learning disability differs from most of the participants I interviewed. My own positionality and how this has shaped the research will be explored further in Chapter 3.

1.4 Defining and establishing uses of the term 'learning disability'

Use of the term learning disability is complex and the term can mean different things to different people. As a term, learning disability is closely linked with negative historical and social discourses and previous terms used to describe people with learning disabilities have included: feebleminded, idiot, imbecile, mentally defected, mentally handicapped, and mentally retarded (see Digby & Wright 2002). Today, the Department of Health and Social Care (DHSC 2001 cited in Public Health England 2023) defines a learning disability as:

> *"a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood."*

Medical diagnostics categorise learning disability as either mild, moderate, severe or profound (Mencap 2023b). However, it is important to state that not everyone who self-identifies as having a learning disability will have a medical diagnosis, and not everyone who has a medical diagnosis will identify with the label of learning disability. Positioned within social constructivism, this research is less concerned with medical diagnoses of impairment, rather it is focused on complex social interactions that shape the views and lived experiences of people who self-identify with, or are close to someone with the label of a learning disability.

The term learning disability is often replaced or interchanged with terms such as learning difficulty, intellectual disability, cognitive impairment, and developmental delay (McCarthy 2009a). Public Health England (2023) states that a learning disability is different to a learning difficulty as learning difficulty refers to a specific form of learning and conditions such as dyslexia, dyspraxia, and attention deficit hyperactivity disorder (ADHD). There are debates about whether Autism is considered a learning disability but like all inclusion criteria for this study, Autistic people were included if they self-identified with the term learning disability (see Chapter 3). It also is important to acknowledge some of the ongoing discussions within the disability community about the terminology, for example some people and self-advocacy groups prefer to use the term people with learning difficulties as it suggests that people can learn once disabling barriers, such as inaccessible language, are overcome (Hollomotz 2009a: 92). This position links with a social model of disability perspective as it suggests that it is the environment that disables people and not their individual impairment (see Oliver 1990 and Chapter 2).

There are also debates about the language used to talk about individuals as ‘disabled people’ or ‘people with disabilities’, and ‘learning disabled people’ or ‘people with learning disabilities’. The term ‘disabled people’ is influenced by social understandings of disability that argues social barriers and environments oppress and disable people. Others prefer to use the term ‘people with disabilities’ which is also referred to as ‘people first’ language. Those who use this term argue that they want to be recognised as people first and not to be called by their impairment first (Llewellyn et al. 2010: 7). It is argued that using people first language asserts their human status and citizenship that has often been undermined through social histories of in-humane treatment, oppression, and marginalisation (Llewellyn et al. 2010). Influenced by this context, I have chosen to use the people first term ‘people with learning disabilities’ throughout this thesis. Most participants in this research were happy using the terms learning disability and people with learning disabilities and while the term learning disability is predominantly used throughout this thesis, I do use learning difficulty when directly quoting participants or authors who used this term. When talking about (not directly quoting) existing research that uses the terms people with learning difficulties or intellectual disabilities, I have replaced this with the term learning disability for consistency.

Learning disability can be understood as an embodied reality *and* a social construct that shapes the lives of people who are labelled or self-identify with the term (see Reaume 2014: 1248 – 1249). It is important to acknowledge that disability is *part* of an individual's identity, like class, ethnicity, gender, race and sexuality, that intersects with other identity markers (see Liddiard 2017). Using intersectionality, Shelly (2006) states that the relationship between identity and disability is more complicated than the binary categories of disabled or non-disabled and people will differ in the identities they prioritise (cited in Goodley 2011: 30). Identifying as disabled might be more significant in the lives of some people more than others, as 'who is to say that disability is the 'master signifier' of one's identity?' (Shakespeare 2006 cited in Goodley 2011: 30). The diversity and heterogeneity of people who self-identify with the term 'learning disability' means the views and experiences of participants in this research cannot be generalised nor assumed to be true of other people who identify with the label. This notion of intersectionality is present throughout the discussions in this thesis.

1.5 Introducing the participant groups

This research consists of three participant groups: people with learning disabilities, family members of someone with a learning disability, and paid learning disability support workers. In this section I will explain why I chose to focus in on these participant groups and highlight the contribution that the inclusion of these participants will make to disability literature and the field of disability studies. A focused discussion about how my research design and participant inclusion criteria changed in response to the Covid-19 pandemic is set out in Chapter 3.

People with learning disabilities

Doubts about the credibility and reliability of the accounts of people with learning disabilities has often denied them opportunities to share their perspectives and be included in social research (Atkinson 1997; Goodley 1996). As well as people with learning disabilities being treated as objects and subjects of research, this also extends to them being considered as 'vulnerable' by wider society. While this categorisation of people with learning disabilities as vulnerable may have had seemingly good intentions of protection, it often limited and restricted their participation in research thus reinforcing their powerlessness and marginalisation (Northway 2014). Furthermore, concerns about the ability of people with learning disabilities to talk about sensitive topics and complications with gaining ethical approval have traditionally limited the voices of people with learning disabilities in these spaces (Hollomotz 2018; Hays et al. 2003) (also see Chapter 3).

More recently, the exclusion of people with learning disabilities has waned as the social model of disability, empowerment philosophies and inclusive practices have influenced a shift towards more research *with* and *for* people with learning disabilities (Mirfin-Veitch et al. 2018). Through newer research paradigms people with learning disabilities are more than subjects of research. For example, within the field of disability studies terms such as ‘emancipatory’, ‘inclusive’ and ‘participatory’ research refer to the ways people with learning disabilities are increasingly involved in initiating, doing, writing, and disseminating research. By positioning my research within disability studies and drawing from the values of inclusive research, I centre the voices of people with learning disabilities and recognise them as agents and meaning makers of their own lives and experiences (Santinele Martino 2022); this will also be discussed in Chapter 3.

Much of the recent disability research around the topic of learning disability and parenthood focuses on the experiences of women and mothers with learning disabilities (see Gould & Dodd 2014; Baum & Burns 2007). This reflects wider social phenomena and traditional gender roles in which women are often the main caregivers (Sharma et al. 2016; Malacrida 2012). By including the imaginaries and experiences of women *and* men with learning disabilities, this research will explore the influence that social ideas about gender can have on parenting possibilities and opportunities. Furthermore, much of the research on the topic of parenthood tends to hear from the views of parents with learning disabilities. As well as parents with learning disabilities, this current study hears from people with learning disabilities who do not (yet) have children, thus contributing to a gap within disability studies parenting literature.

Family members

In this research the use of the term family member participants refers to a parent of a person with learning disabilities or a sibling of someone with learning disabilities. Families play an instrumental part in shaping personal identity, relationships with others and how we experience and relate to the world around us (Chambers 2012). Family members are significant in the lives of most people, but parents can be particularly involved in the care, support, and decision making of people with learning disabilities often well into adulthood. Due to this influential role many parents of people with learning disabilities can have, their views and opinions are included in this research to give further insights into the relational family dynamics that can shape ideas and decisions about reproduction for people with learning disabilities.

The bond between siblings is built on shared genetic and cultural heritage that develops throughout the life-course (Dew et al. 2014). In the lives of many people, the sibling relationship is associated with notions of companionship and caretaking roles. For some siblings of people with learning disabilities these caretaking roles can feel like a familial responsibility and obligation, especially as parents grow older (Travers et al. 2020). The inclusion – a change that developed while adapting to the Covid-19 pandemic (see Chapter 3) – of sibling participants broadens the family focus beyond parents of people with learning disabilities and provides scope for more nuanced discussions around kinship relations, learning disability and parenthood. It also addresses the gap in existing disability research, as the perspectives of adult siblings of people with learning disabilities about the topics of reproduction and parenthood have rarely been considered (Travers et al. 2020; Atkin & Tozer 2014). The ways siblings can shape what people with learning disabilities know about sexual and reproductive health information is discussed throughout this research.

It is important to state here that while I am including family members in this research, their views do not act as proxy for the perspectives of participants with learning disabilities. Instead, the decision to hear from family members was taken with the aim of gaining insights into some of the complex interpersonal relationships that shape the lives of people with learning disabilities. Furthermore, none of the family participants in this research were related to the participants with learning disabilities.

Support workers

Throughout this research the term ‘support worker’ is used to refer to non-familial paid staff that work closely with people with learning disabilities. Support workers can be employed in a range of learning disability services that can include residential homes, supported living, day centres, education (such as SEND schools and colleges) and community services. They play an integral role supporting the day to day living of many people with learning disabilities by providing support with everyday tasks such as shopping, cooking, trips out and personal care. The role can also include supporting people with learning disabilities to develop intimate relationships, access sexual and reproductive health information, contraception, and parenting support that will be explored in this research.

The decision to include the voices of support worker participants in this research was shaped by my own experiences in the role and an awareness of how closely they can be intertwined in the lives of people with learning disabilities. The inclusion of support worker participants was also influenced by the lack of support worker views in wider disability research and social discussions. Despite support workers often having substantial influence in the lives of people with learning disabilities, there seem to be few studies in which support workers are recognised as knowledge-holders (Hayes 2017). Existing research has largely focused on the perspectives of parents of people with learning disabilities, medical and social work professionals. Demographically, support workers can be broadly characterised as working-class women[3] with low levels of education and low pay, and as Hayes (2017: 12) suggests, this low socio-economic status has so far denied support workers' views from being heard and valued within research. By including support worker participants in this research, I hope to provide new insights that contribute to the discussions around learning disability and parenthood.

As will be described in Chapter 3, the support workers interviewed in this research did not support any of the participants with learning disabilities. As above, the accounts of support worker participants in this study are reflections of their own experiences and are not proxy to what participants with learning disabilities said. Thus, the inclusion of non-learning-disabled family members and support workers is not to undermine what participants with learning disabilities have said, but to instead acknowledge their significance as important

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[3] Within adult social care in England, it is estimated that between 85-95 per cent of care and support providing roles are carried out by women (Skills for Care 2010 cited in The King's Fund 2018).

actors in the relational networks that inform the lives and decision-making of people with learning disabilities (McLaughlin et al. 2016). This research is therefore a reflection of my interpretation of a small sample of people with learning disabilities, family members and support workers, it does not claim any objective truths about the topics of learning disability, reproduction, and parenthood.

1.6 Research questions

By speaking with people with learning disabilities, family members and support staff, this research aims to respond to four main questions concerned with how people with learning disabilities think about and experience parenthood:

1. What imaginaries and experiences do people with learning disabilities have towards reproduction and parenthood?

2. How are parenting imaginaries and experiences shaped by family members, staff and other professionals in their lives?

3. How are social ideas and assumptions about people with learning disabilities shaping parenting possibilities and experiences?

4. How can people with learning disabilities be supported to reflect on the topics of reproduction and parenthood and be empowered to make their own active choices?

1.7 Thesis structure

This thesis consists of seven chapters. Following this first introductory chapter, the literature review in Chapter 2 situates the work and presents findings from previous research that include topics about sexuality, sex education, parenthood and disability. The findings from the literature have been instrumental in developing the research questions as well as informing the theoretical framework and analytical themes for this thesis. The theoretical frameworks used to analyse the data are also presented in this chapter.

The third chapter details the methodology used and some of the methodological issues experienced conducting this research. The chapter presents the research plans pre-Covid-19 and describes how the study was carefully re-designed to respond to the disruptions caused by the pandemic. It details how the pandemic led me to extend my planned research focus from exploring the parenthood imaginaries of young people with learning disabilities under the age of 35 without children, to also include the views and parenting experiences of older people with learning disabilities. The methodology chapter also talks through the decision to include the voices of siblings of someone with a learning disability and outlines the methods of analysis and ethical considerations that have shaped this research.

The next three chapters present the research findings (Chapters 4, 5 and 6). Chapter 4 details how family relational networks can influence the parenthood imaginaries and experiences of people with learning disabilities. I argue that family members, especially mothers, can both support and constrain the parenting possibilities of people with learning disabilities. I highlight some of the challenges family members can face trying to balance protection whilst also supporting people with learning disabilities to make their own reproductive choices. While much of the focus is on how family members can oppress the reproductive possibilities of people with learning disabilities, this chapter also illustrates some ways family members can support individuals to successfully fulfil parenting roles.

Chapter 5 considers how the parenthood imaginaries and experiences of people with learning disabilities can be influenced by support staff as organisational actors. Despite the closure of long-stay institutions, I argue that people with learning disabilities are still restricted in their parenthood decision-making as staff continue to monitor and surveil their intimate lives and reproductive possibilities. This chapter illustrates whether and how staff engage with people with learning disabilities about the topics of reproduction and parenthood can be shaped by the organisational contexts they work within.

Chapter 6 considers the ways ideas of ‘risk’ are informing how people with learning disabilities think about and experience parenthood. The first part of the chapter focuses on risk in relation to child removal practices as parents with learning disabilities describe feeling judged by stricter criteria than non-learning-disabled parents. This section also explores how the risk of child removal and precarious parenting is shaping the reproductive imaginaries of people with learning disabilities who do not have children. The second part of the chapter considers how ideas about genetic risk are influencing what people with learning disabilities think about having children. I argue that a lack of accessible information about genetic screening and reproductive technologies is restricting the decision making of people with learning disabilities.

The final chapter presents the conclusions from this research and sets out recommendations for enabling people with learning disabilities to access information and make their own choices around the topics of reproduction and parenthood. I also detail suggestions for how this research could be extended and developed in future.

Chapter 2. Literature review

2.1 Introduction

This chapter presents some of the existing literature around the topics of learning disability, reproduction and parenthood and identifies gaps in this literature that my research will address and contribute towards. I describe the socio-historical contexts of eugenics and institutionalisation that has disempowered and restricted the reproductive imaginaries of people with learning disabilities before introducing the contemporary contexts of 'newgenics' and reproductive control. This chapter will also highlight literature regarding the sexual and intimate lives of people with learning disabilities as well as exploring access to sex education. It will consider some of the ways women with learning disabilities can experience contraceptive control from family members, support staff, and professionals that influences their reproductive decision-making. A review of existing literature about parenting, child removal, and genetic risk is looked at before setting out the theoretical frameworks that are used in this thesis. As well as UK contexts, I also discuss some international research; especially from countries such as Australia, Canada, Iceland, Sweden and the US. These countries are significant in leading researching about the topics of sexuality, reproduction and parenthood with people with learning disabilities. The service provision, or rather lack of, in some of these countries also shares similarities with the UK which makes them useful to consider in these discussions. By drawing from this international literature, this chapter details some of the widespread challenges that people with learning disabilities can endure when it comes to thinking meaningfully and making informed choices about parenthood in the UK and elsewhere.

Until the mid-late twentieth century, most research had been done *on* people with learning disabilities and focused on individual pathology that perceived disability as a personal tragedy that people needed to be cured and prevented from (see Paterson & Hughes 2000; Oliver 1990). During this time there was a dearth of sociological research about learning disability, instead research was dominated by medical disciplines such as psychology and psychiatry (Mladenov 2015). In addition, much of this earlier research focused on physical disability and it is only more recently that learning disability has become a topic of exploration. The highly medicalised research that was carried out on the topics of learning disability often included the perspectives of family members, staff and professionals (see Gillberg & Geijer-Karlsson 1983; Brandon 1957). Significant to this research, dominant contrasting ideas about people with learning disabilities as either asexual and child-like or oversexed 'monstrous perverts' meant sexuality and reproduction was a topic that had previously been under-explored in social research. However, this began to change in the late 1980s when researchers started using social and human-rights based approaches and more recently this has extended to exploring topics of sexuality *with* people with learning disabilities. There is now a growing body of literature that explores the views and lived experiences of people with learning disabilities on the topics of sexuality, reproduction and parenthood that my research will contribute to. As suggested earlier, while existing research often centralises the experiences of women, fewer studies have considered the role of fatherhood for men with learning disabilities (Theodore et al. 2018; Dugdale & Symonds 2017; Shewan et al., 2014; Mayes & Sigurjónsdóttir 2010 are some exceptions to this). By including men with learning disabilities and fathers with learning disabilities, my research will address some of these gaps in the literature.

2.2 Eugenics to Newgenics

The term 'eugenics' is an extension of Darwin's theory of Evolution that refers to a set of social ideas and practices concerned with improving humanity through selective breeding (Kempton and Kahn 1991). Popular across much of Europe during the late nineteenth and early twentieth century, the eugenics movement advocated for the mass sterilisation of people (mainly women) with learning disabilities that was influenced by the belief and fear that they might reproduce excessively and pass on their mental defects to their children (Dotson et al. 2003). This history of reproductive control and eugenic sterilisation is shared by other marginalised groups of women, including black women and poor women (Gill 2015: 19). While sterilisation practices were not compulsory in the UK, people with learning disabilities were segregated in institutions to control and restrict their reproductivity. Characterised by locked doors, high walls, and barbed wire, these large-scale institutions segregated large groups of people with learning disabilities from the rest of society (Goffman 1961 cited in Hollomotz 2011, also see Thomas 2017). Within these institutions people with learning disabilities often lived in harsh conditions that were over-crowded and unhygienic (Johnson & Traustadóttir 2005: 15). In addition, people with learning disabilities often experienced inhumane treatment and abuse from staff working in the institutions (Hollomotz 2011). Malacrida (2012) has suggested that being hidden from the public eye within these institutions helped to reinforce a common understanding of people with learning disabilities as unfit and incapable of fulfilling intimate relationships and parenthood roles. My research considers how this history has shaped the parenthood imaginaries of older people with learning disabilities who experienced living in these institutions, but also if, and how, the past influences what younger people with learning disabilities think about their opportunities for parenthood today.

It was not until the 1980s that the UK government made a series of policy reforms devolving responsibility to local authorities and began advocating for care in people's own homes instead of institutions. These reforms were set out in the National Health Service and Community Care Act (1990) that introduced the requirement for local authorities in the UK to plan and assess people's long-term care needs to enable them to live in the community, either in their own home with support or in residential housing, rather than being admitted into institutional settings. While the Act recognises the importance of living within the community as a way of promoting independence and avoiding social isolation, the extent to which this can be considered a success is still widely debated.

Arguing from a disability's studies perspective, Malacrida (2012) claims that the eugenic beliefs rife during the late nineteenth and early twentieth century have not necessarily died off with changed political and social sensibilities, but rather she asserts that disabled people, and especially women with learning disabilities, continue to have their reproductivity restricted and controlled. She uses the term 'newgenics' to refer to the more subtle ways people with learning disabilities continue to experience reproductive control. Newgenics extends beyond medical sterilisation practices to include systematic barriers to accessing sexual and reproductive health information and parenting support services (Malacrida 2020). Newgenics can be overt, such as care home policies and regulations that prohibit people with learning disabilities from having sexual partners, and covert, for example social stigmas and prejudice that assume people with learning disabilities are unfit and incapable of fulfilling parenting roles (Malacrida 2020). The impact these contemporary newgenic practices are having on the reproductive and parenthood possibilities of people with learning disabilities are described throughout this thesis.

2.3 Sexual and intimate relationships

Many people with learning disabilities value companionship, affection, love, and support and want opportunities to form relationships with a partner (Rushbrooke et al. 2014), but the literature suggests people with learning disabilities are far less likely to experience being in an intimate relationship compared with the general population (Bates et al. 2017; O'Reilly et al. 2009; Shackelford et al. 2005). This section presents four key discussion points describing some of the ways intimate opportunities for people with learning disabilities can be influenced by stigma and restricted by: stereotypical ideas of asexuality and infantilisation, protection and overprotection, surveillance, and institutionalised and segregated contexts. An exploration of literature on parenting will be considered later in the chapter. People with learning disabilities are a group that still experience stigma despite the disability rights movement and recent social policy initiatives trying to increase social inclusion, independence, and empowerment (Scoir 2011 cited in Franklin et al. 2022). Stigma can be understood as the ways certain groups of people are devalued, marginalised and 'othered' because they differ from dominant social norms (Ali at el. 2012). Stigmatised people experience labelling, stereotyping and prejudice that leads to a loss of status and discrimination (Link & Phelan 2001). In this vein, 'normal' becomes a prized social status which excludes people with learning disabilities (McLaughlin 2017: 244). Franklin et al. (2022: 936) highlight the link between stigma and power; they state that the subjugation of people with learning disabilities is maintained by the disempowerment they experience when the access to rights, resources and opportunities are determined by 'powerful others', such as family members, support staff and professionals.

2.3.1 Asexual and child-like stereotypes

Today, people with learning disabilities have the same rights as anyone else to experience intimate relationships and start a family but many face challenges to fulfilling these rights in reality because of the negative views and ableist assumptions society holds towards them (Harflett & Turner 2016: 4; Rojas et al. 2016). A review of existing disability literature finds that parents of people with learning disabilities and support workers can perceive people with learning disabilities as child-like and asexual and assume people with learning disabilities either do not want to have, or are incapable of having, ‘adult’ desires and sexual relationships (Santinele Martino & Perreault-Laird 2019). This is echoed more recently in work by Callus et al. (2019) who find that the intimate lives of people with learning disabilities are often not taken seriously by those closest to them, for example, they describe how intimate relationship experiences of people with learning disabilities are perceived as ‘sweet’ and ‘cute’ which reinforces the discourse of infantilisation (Callus et al. 2019: 355).

This notion that parents and support workers can perceive people with learning disabilities as child-like is also described in research by Corr McEvoy and Keenan (2014). Their study was conducted in Ireland by a researcher with a learning disability to find out how adults with learning disabilities feel they get treated in everyday life. Over 40 participants with learning disabilities took part in focus groups to share their views and experiences. Some participants with learning disabilities said they had experiences of being treated like a child and that they were not allowed to make their own decisions, especially about relationships. Participants added that the decisions were often made by their parents, staff and social workers. This notion that people with learning disabilities are restricted in decision-making by powerful others because of child-like stereotypes is a theme that is widely reported in international literature with similar contexts to the UK. It also is an area that I explore in this thesis to see how this perception impacts the reproductive choices and parenting experiences of people with learning disabilities.

Widely held stereotypes of people with learning disabilities as child-like and asexual marks them as incapable of having sexual wants and desires (Liddiard 2017; Chan et al. 2009; Shakespeare et al. 1996). These dominant negative stereotypes deny people with learning disabilities opportunities for equal intimate citizenship that further impacts on the possibilities for intimate relationships and parenthood (Wiseman and Ferrie 2020). Stereotypical assumptions of infantilisation and asexuality also means that people with learning disabilities are not afforded opportunities to access sexual and reproductive health information (Rushbrooke et al. 2014). It is assumed that sex, reproduction and parenthood are topics people with learning disabilities are either not interested in or incapable of learning.

The issues surrounding stereotypes and the appropriacy of sex education is an area that is detailed further later in this chapter.

2.3.2 Protection and overprotection

Feely (2016: 728) tells us that there has been a shift from prohibiting intimate relationships of people with learning disabilities because it was seen as inherently immoral, to concerns that it is inherently abusive. Even when some parents and staff support the rights of people with learning disabilities to have intimate relationships, in practice, concerns about risk and potential harm dominate and continue to restrict the intimate relationship possibilities of people with learning disabilities (Evans et al. 2009). The topic of sexuality is an area that sees family members, staff and professionals balancing the rights of people with learning disabilities to have romantic and intimate relationships, if that is what they desire, whilst simultaneously protecting them from potential harm (Jahoda & Pownall 2014). The literature suggests overprotection and a culture of risk aversion is a barrier that restricts people with learning disabilities from intimate relationship opportunities (McConnell & Phelan 2022; Callus et al. 2019; Bates et al. 2017; Grieve et al. 2009). Hollomotz (2011: 44) has given a useful description of overprotection as being 'characterised by excessive physical and social contact, prolonged infantilisation, active prevention of independent behaviour and social maturity and excessive parental control'. She continues to note that overprotection is not limited to parents, but further adds staff and care institutions can also restrict the intimate lives of people with learning disabilities by overprotection.

In Malta, Callus et al. (2019) conducted focus group research with people with learning disabilities, parents, and staff to explore how overprotection is impacting the lives of people with learning disabilities. Findings from their study describe that while some parents and staff actively support people with learning disabilities to have and maintain intimate relationships, other parents and staff have less liberal views on the topic. Callus et al. confirm a recurring theme throughout the literature which suggests people with learning disabilities frequently encounter barriers to going out, socialising and opportunities to develop intimate relationships as these are often blocked by parents. It is important to recognise what Callus et al. describe as 'a tug of war' between what people with learning disabilities want to do and the often-legitimate concerns of their parents (Callus et al. 2019: 363). Both perspectives need to be recognised and the literature suggests there needs to be more support to enable people with learning disabilities to make their own decisions as well as more support for parents to help people with learning disabilities with their decision making. Importantly, Callus et al. (2019: 347) explain that overprotection is not all or nothing, instead overprotection can be understood as a continuum as some people with learning disabilities can be totally overprotected, some not at all, and others somewhere in between. This notion of protection and overprotection is an area my research explores, with a particular focus on how siblings describe the tensions between protection and overprotection from their parents and how this influences parenthood imaginaries of people with learning disabilities. To my knowledge, this exploration of sibling understandings of protection and overprotection and how it shapes parenting possibilities of people with learning disabilities has not been considered by existing literature.

2.3.3 Surveillance

Disability literature has highlighted how surveillance can be another barrier to people with learning disabilities thinking about and forming intimate relationships that restricts them from becoming parents. Surveillance is often used to prevent and protect people from harm, but it can also be used as a means of controlling the behaviour of others (Mortenson et al. 2016). Foucault (1991) describes the ways knowledge and power are intertwined with one another and this is evident in surveillance as the more an individual or group are surveilled, the more is known about them as subjects (Mortenson et al. 2016). Foucault argues this surveillance creates a normalising gaze that positions individuals as subjects that are monitored, examined and judged by powerful others. People with learning disabilities are subjected to the scrutiny and surveillance by family members, staff and other professionals reporting and documenting their daily lives in minute detail (Feely 2016; McIntosh 2002). This surveillance further highlights the unequal power dynamics between people with learning disabilities and those watching them. Löfgren-Mårtenson (2004: 204) finds people with learning disabilities live in what she calls a 'protected world' because of the high level of surveillance and oversight they receive from family members and support staff. Löfgren-Mårtenson further suggests instead of old institutional barriers, this surveillance and monitoring means family members and support staff can act as the 'new institutional walls' that continue to restrict relationship and parenthood opportunities for people with learning disabilities (Löfgren-Mårtenson 2004: 204).

The intimate lives of people with learning disabilities are often under constant supervision and surveillance from family members and staff that makes it difficult to form and experience relationships (Bates et al. 2017; Winges-Yanez 2014). Gill (2015: 17) has described how some people are able to be sexual and reproduce without oversight and intervention, but others have been marked as being in apparent need of regulation and restriction. Gill (2015: 17) writes that learning disability disrupts normative assumptions about embodiment as people with learning disabilities are perceived and marked as different and therefore not fit for sexuality and reproductive possibilities (Gill 2015: 41). This notion of normative sexual embodiment can also be found in much earlier work by Saxton (1984: 303) who describes how sex is regarded as 'a rare commodity… reserved for highly-valued, able-bodied people'. This judgement made about the appropriacy of people with learning disabilities to experience intimacy is used to justify the surveillance many of them experience throughout their lives.

In formal care settings the minute detail of the lives of people with learning disabilities are observed, logged, and scrutinised by staff which creates a normalising gaze that positions staff as powerful observers and people with learning disabilities as subjects of observation (McIntosh 2002). Feely (2016: 727-728) similarly comments on how in these settings staff, as well as other service users, are surveilling and policing the sexuality of people with learning disabilities as they are trained to watch each other and report on behaviour deemed 'inappropriate'. For people with learning disabilities, their intimacy is often supervised and restricted to acceptable forms of affection such as hugging, handholding, and kissing (Grieve et al., 2009; Abbott & Howarth 2007; Löfgren-Mårtenson 2004). These restricted forms of intimacy further reinforce dominant societal views of people with learning disabilities as vulnerable and unfit for sexual intimacy (Gill 2015).

2.3.4 Institutionalised and segregated contexts

People with learning disabilities experience institutional barriers that make it difficult for them to fulfil their ambitions for relationships and intimacy (Rushbrooke et al. 2014). For example, existing literature details how a lack of opportunities for people with learning disabilities to meet new people can restrict their relationship possibilities (National Development for Inclusion 2019). Löfgren-Mårtenson's (2004) research in Sweden shows that while there are some social clubs and events organised by and for people with learning disabilities, many rely on the support of family members and staff to attend these groups. In practical terms, some people with learning disabilities may miss out on opportunities to attend social events because poor staffing levels that means there is a lack of staff available to provide support.

Knight (2017: 75) says group homes and similar care settings purposefully destroy opportunities for people with learning disabilities to engage in intimate relationships and sexual activity that make it difficult for them to think meaningfully and realistically about having children. For example, UK research by Rushbrooke et al. (2014) highlight how a ban on over-night stays and open-door policies restrict the intimate opportunities of people with learning disabilities and reinforce social ideas that sexual relationships and reproduction is not something they should be engaging in. By using participatory research methods and focus groups with people with learning disabilities, Hollomotz (2009a) also explores some of the barriers to intimate relationship opportunities and privacy people with learning disabilities can experience living in residential group settings in the UK. Her work finds staff and care organisations rules and regulations can restrict people with learning disabilities from intimate relationships as they are often prevented from inviting other people into their bedrooms. Hollomotz illustrates how single beds in residential living settings can also limit people with learning disabilities from experiencing intimate relationships. Her findings further suggest participants with learning disabilities do not feel they have the same rights and choices as other people without learning disabilities because staff are blocking their decision making opportunities. Hollomotz (2009a: 96) asserts that access to privacy should be a norm and not a privilege, she calls for a change in policy so people with learning disabilities living in residential settings can be supported to make their own choices about intimate relationships and privacy. The lack of privacy described in the literature reinstates the ways sexual citizenship for many people with learning disabilities is still denied and unrecognised; thus, further disenfranchising them from thinking and making meaningful decisions about intimacy and parenthood.

It is significant that currently in England, there is no mandatory training for social care staff about supporting people with learning disabilities with the issues of relationships and sexuality. The organisation Skills for Care sets out the standards and qualifications for social care workers in England and some of the core and mandatory training they identify includes basic life support and first aid; communication; dignity equality and diversity; food hygiene; health and safety awareness; infection prevention and control; nutrition and hydration; safeguarding children and adults (the full list of topics and learning outcomes can be found on the Skills for Care website). Noticeably absent from this list is any reference to intimate relationships and sexual reproductive health. Despite a Care Quality Commission (2020) report recommending that 'promoting sexual safety through empowerment' should be one of the topics social care staff should be given training on, it is up to individual care organisations to decide whether this specialist training is provided.

Findings from an annual review by Skills for Care (2021) reports that because of a lack of guidance and resources from their organisations, social care staff feel fearful about engaging with people with learning disabilities about the topics of relationships and sexuality[4]. This is also echoed in existing studies that show a lack of formal training and guidance about intimate relationships and sexuality by care providers means staff are apprehensive and reluctant to engage in discussions with people with learning disabilities about the topics (Santinele Martino & Perrault-Laird 2019; Hamilton 2009; Abbott & Howarth, 2007; Cuskelly & Bryde 2004). Echoing UK contexts, Santinele Martino and Perrault-Laird (2019) conducted in-depth interviews with six frontline staff in Canada; they report staff participants lacked education and training about the topics and found staff had been told by care organisations to avoid talking to people with learning disabilities about sex and intimacy. Staff in their study said they worried about getting into trouble if they talked about these issues with people with learning disabilities and feared the reaction of family members. This issue is highlighted in earlier work by Brown (1994) who claims that sexual and intimate behaviour can cause

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[4] Skills for Care and Supported Loving have recently developed a range of training materials to help social care organisations to educate staff about how to support people with learning disabilities with relationships. These materials can be accessed here: https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Supporting-personal-relationships/Supporting-personal-relationships.aspx

conflict between parents and staff as parents often hold less liberal views on the topic than staff (Brown 1994).

Santinele Martino and Perreault-Laird (2019) argue institutional care settings engender a culture of silence and fear among staff around discussing sexuality and intimate relationships as staff worry about getting into trouble if they talk about these issues. This silence serves as a form of regulation and oppression that reinforces the idea that intimate relationships are not something people with learning disabilities should be engaging in. Formal care organisations often avoid the issues of intimate relationships and sexuality because they are deemed too risky; in these instances, concerns about potential harm seem to override the rights and choices of people with learning disabilities to experience intimate relationships (National Development for Inclusion 2019: 6).

In England, Maguire et al. (2019) interviewed support workers to find out what they thought about supporting people with learning disabilities with the issue of sexuality. Participants viewed their role as a 'juggling act' as they talked about the challenges of managing facilitation with protecting the welfare of people with learning disabilities. Their study also highlights how support workers felt supporting people with learning disabilities with issue of sexuality was very much a minor part in their role as it was something rarely raised by people with learning disabilities. However, Maguire et al. suggest in their findings that the absence of 'seeing' sexuality as an area to support individuals with could be influenced by support workers' ambivalence towards the issue. This highlights some of the complexities surrounding support staff as institutional actors and whether information about sexuality is shared with people with learning disabilities. This is an area my research extends by focusing on whether support workers engage with disseminating sexual and reproductive health information and what impact this has on the parenthood imaginaries and experiences of people with learning disabilities.

Informed by existing disability literature, this section has detailed some of the ways dominant narratives of protection and overprotection, surveillance and regulation mean it is difficult for people with learning disabilities to be recognised as competent sexual agents capable of making their own choices about intimate relationships, reproduction, and parenthood (Gill

2015: 19). The attitudinal and institutional contexts preventing people with learning disabilities from having intimate relationships is indicative of newgenic practices that deem people with learning disabilities as unfit for sexual expression, reproduction, and parenthood opportunities (Santinele Martino & Perreault-Laird 2019). Existing studies have focused on how protection, regulation and surveillance impacts opportunities for intimate relationships, but less has been said about how these practice influence parenting possibilities of people with learning disabilities. This a gap in the literature that my research will address by extending the focus of protection, regulation and surveillance specifically to the topic of parenthood.

2.4 Sex education and information

Existing disability literature suggests there remains a sense of reluctancy and confusion about providing people with learning disabilities with sexual and reproductive health education and information (McDaniels & Fleming 2016; McCabe 1993). Without opportunities to access sex education and information, people with learning disabilities are restricted from making their own informed choices about sexuality, reproduction, and parenthood (McConnell & Phelan 2022). Wheatley (2005) tells us learning about sex, sexuality, and relationships is considered important for all people and access to good information is pertinent for this. However, people with learning disabilities have historically been denied access to sex education to shield them from information and activities deemed inappropriate for them because of their perceived vulnerability and embodied difference (Daly et al. 2019). A review of literature suggests access to sex education is an international problem that is rooted in eugenic schema and institutions that sought to prevent and limit sexual and reproductive opportunities of people with learning disabilities (Björnsdóttir & Stefánsdóttir 2020). It is significant that the struggles of accessing sex education continue to impact the lives and decision making of people with learning disabilities today as this section will illustrate. Not having opportunities to access sexual and reproductive health information impinges on the rights of people with learning disabilities to make their own informed and autonomous decisions about intimate relations, sexuality and parenthood. This section will consider the literature about how people with learning disabilities access, and struggle to access, sex education information from 'formal' sources, such as schools and social care institutions, and 'informal' sources, like family members and social networks. I will then present findings from existing studies that illustrate the impact this is having on the opportunities of people with learning disabilities to make informed choices about the topics.

The provision of sex education has historically been patchy and inconsistent across many schools in England (Setty & Dobson 2023; Emmerson 2018). While the topics of sex and reproduction were taught in some schools, it was not until the 1980s that legislation to regulate the provision of sex education in schools was introduced in England and Wales (Education (No. 2) Act 1986). Much of this education was centred around the issues of the prevention of HIV, sexually transmitted infections (STI's) and avoiding teenage pregnancy. In the late 1990s and into the 2000s, schools began extending this focus to include educating pupils about relationships as well as the topics of sex and reproduction. As of September 2020[5], the Children and Social Work Act (2017) made it compulsory for all schools in England to provide Relationships Education to pupils in primary schools and Sex Education to secondary school pupils. The new guidance states that these subjects must be accessible for all pupils, including those with learning disabilities[6] (Commons Library Research Briefing 2023).

As previous studies on this issue have documented, pupils with learning disabilities often struggle to access any formal information because the assumption has been that they are child-like and asexual and therefore do not want, or are incapable of having, sexual desires and intimate relationships (Kulick & Rydström 2015: 6). Research conducted in Canada shows that in contrast to assumptions of asexuality, people with learning disabilities have also been denied opportunities to learn about sex education because of the fear that access to this information will somehow awaken their sexual curiosity and encourage people with learning disabilities to engage in 'risky' sexual behaviour (McConnell & Phelan 2022). This notion of safety is also illustrated in Swedish research by Löfgren-Mårtenson (2012) who similarly found that sexuality and relationship education for people with learning disabilities centred on

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[5] 'Schools' includes special education needs (SEND) schools. Schools were allowed to delay the introduction of these new requirements because of the disruption cause by the Covid-19 pandemic (Commons Library Research Briefing 2023).

[6] In this research, the age of participants with learning disabilities and the legislative contexts when they were in school means it is unlikely that many would have received much meaningful sex education, particularly around relationships and parenting. This issue will be unpacked further in the data analysis chapters.

safety and teaching them how to say no (cited in McConnell & Phelan 2022). This reinforces the long-standing discourse that perceives the sexuality of people with learning disabilities as 'risky' and something that should be avoided (Craft 1987 cited in McConkey & Ryan 2001: 86).

When sex education is provided to people with learning disabilities, it has been critiqued for being inaccessible. For example, McDaniels and Fleming (2016: 220) suggest that many people with learning disabilities cannot understand sex education because the information provided is too 'vague, euphemistic and overly technical'. Other research finds that school staff can struggle to provide young people with learning disabilities information about sex education as they only have access to outdated resources, and staff feel they do not have the time or confidence to deliver lessons about the topics (Simpson et al. 2010; Wright 2011). This echoes earlier comments about support staff lacking the time, training, and confidence to engage with people with learning disabilities about sex education. Thus, these barriers to access to information reinforces the social idea that disability is incompatible with sexuality and reproduction.

As well as struggles with accessing formal sex education, the literature also suggests people with learning disabilities experience barriers to gaining this information from informal sources, such as family members, peers and online. While conversations about sex education can be something many parents are reluctant to talk about (Hall 2009), for parents of people with learning disabilities it can be a particularly challenging topic to engage with. Work by Daly et al. (2019) in the UK highlights that parents of people with learning disabilities worry about the appropriateness of sex education more than parents of people without learning disabilities. The opportunities for people with learning disabilities to experience intimate relationships and access sex education varies depending on the personal views and attitudes of family members and staff. For instance, those with liberal views on the issue are more likely to provide people with learning disabilities with more information than family members and staff who hold more conservative views (Scotti et al. 1996). Research by Pownall et al. (2012) found mothers of young people with learning disabilities spoke less about the topics of sexuality with their children and focused more on emphasising issues around safety than mothers of young people without learning disabilities.

As people with learning disabilities often have fewer social networks than people without learning disabilities this can further impact their opportunities to gain information on the topic. Borawska-Charko et al. (2017) highlight how the exclusion of people with learning disabilities from online and digital spaces is limiting their opportunities to access sex education information. Jahoda and Pownall (2014) compared the sexual understanding of young people with and without learning disabilities in the UK; their results show that people without learning disabilities had more knowledge about the topic as well as more sources to access this information. Consistent with other literature in the field (Pownall et al. 2012: 140; Cole and Cole 1993), their study also found people with learning disabilities had smaller and fewer social networks to interact with and exchange information with friends, compared with young people without learning disabilities (Jahoda & Pownall 2014: 438).

Some existing literature says non-disabled women tend to know more about the topics of sex and contraception than men perhaps because they directly face the consequences of pregnancy (Hansen & Skjeldestad 2003). However, this was not the case in Jahoda and Pownall’s (2014) study as they found men with learning disabilities seemed to know more about the topics than the women with learning disabilities. The researchers suggest this is because of the dominant discourse about vulnerability as family members may think they are protecting women with learning disabilities from harm and the risk of pregnancy by limiting their access to sex education. Although, as other research suggests, restricting their access to information about sex and reproduction is likely to make women with learning disabilities more vulnerable to harm (Hollomotz 2011).

Concerns about the appropriateness of people with learning disabilities knowing about and engaging in sexual relationships can mean any information they do receive is watered down (Shah 2017) and it is perhaps not surprising that the literature finds people with learning disabilities have limited knowledge about the topics or that the knowledge they do have is not always accurate (Wright 2011; Isler et al. 2009). This is illustrated in research carried out by the organisation CHANGE (2010) as findings from their study show that some people with learning disabilities have serious misunderstandings about sexuality; for instance, some people with learning disabilities think gay sex is illegal in the UK (CHANGE 2010 cited in Wright 2011).

Scholars have detailed how inaccurate sexual and reproductive health information provision is problematic as it restricts people with learning disabilities from making informed choices about the topics (McConnell & Phelan 2022; Daly et al. 2019; Frawley & Wilson 2016). Recent research by Wiseman and Ferrie (2020) in Scotland describes how women with learning disabilities experience distress when their periods start because of the lack of education they receive about the topic. Women with learning disabilities in their study were aged between 18 and late 70s and many described how periods had not been part of their education and many did not understand the reproductive purpose of their periods (more will be said about periods and menstrual control later in this chapter).

Furthermore, accessible sex education is important for shaping how people with learning disabilities make decisions about having children and responding to pregnancy. Some people may not want to have children, but they will need access to information about fertility, reproduction and contraception in order to make this choice. Conder et al. (2011) explore the experiences of six parents with learning disabilities in New Zealand about how they made pregnancy and parenthood choices. They found decision making opportunities of people with learning disabilities can be restricted by inaccessible information; for example, participants they interviewed said they only understood part of the formal sex education they had received in school (Conder et al. 2011). In their study they found the reproductive choices of some women with learning disabilities were limited by the lack of information they had about how they became pregnant and the options that could have enabled them to prevent pregnancy. Conder et al. argue that for people with learning disabilities to make their own choices about having or not having children, they must receive information about fertility and contraception at a level they can understand. This should include information about how to respond to unprotected and unplanned sexual intercourse in a timeframe that allows them to choose whether to access emergency contraception and abortion services (Conder et al. 2011). As mentioned earlier, this international context highlights that these issues are widespread.

As well as restricting autonomous decision making, disability advocates are concerned that the lack of sex education and information is putting people, especially women, with learning disabilities at increased risk of 'bad sex' (Shakespeare et al. 1996), that can include sexual abuse, sexually transmitted infections (STI's) (Aderemi et al. 2013), and unplanned pregnancies (Cheng & Udry 2005). McKenzie and Swartz (2011) for example suggest the lack of sex education may mean people with learning disabilities are unable to recognise sexual violence and abuse committed against them and instances go unreported.

Some of the challenges of accessing sexual and reproductive health information described in this section will be explored further in this thesis. I will specifically consider how interpersonal relationships and institutional contexts are impacting what information is disseminated to people with learning disabilities. I aim to contribute to this existing literature by looking at the role siblings can have in sharing sexual and reproductive health information and how they balance this with their parents' wishes.

2.5 Contraceptive control

The contraceptive choices of women with learning disabilities can be shaped and controlled by family members, staff and professionals that can restrict their reproductive decision making. Evidence in UK and international literature states that hormonal contraception is disproportionately prescribed to women with learning disabilities to manage their menstruation and avoid the risk of pregnancy (see Björnsdóttir & Stefánsdóttir 2020; Hollomotz 2011; McCarthy 2009a, 2009b). McCarthy (2009a) suggests that contraception is also being used in response to fears around sexual abuse and rape as women with learning disabilities who are not sexually active are being prescribed contraception 'just in case' they become pregnant. Wiseman and Ferrie (2020) remark that these efforts to avoid pregnancy reinforce dominant eugenic ideas about the suitability and capability of women with learning disabilities to successfully fulfil parenting roles.

McCarthy (2009b) states while the contraceptive pill is often used by women with and without learning disabilities, existing disability research shows other contraceptive use of women with learning disabilities does not match the contraception used by women without learning disabilities of child-bearing age (McCarthy 2009b: 363). McCarthy's work in the UK also finds that contraception is often started at an earlier age for women with learning disabilities and they continue to use it later than other women (McCarthy 2009a, 2009b). Women with learning disabilities are using hormonal contraceptives even after they have gone through the menopause (Wiseman & Ferrie 2020). These patterns of contraceptive usage have been described by McCarthy (2009b: 204) as 'over-cautious at best and 'overkill' at worst'. This overuse of contraception reiterates social ideas that the reproductivity of people with learning disabilities is a 'threat' that needs to be regulated and prevented (McCarthy 2009a). In her work, McCarthy calls for supporters of women with learning disabilities to do more to question the likelihood of pregnancy and whether there is a need for them to be continually prescribed contraception. As well as being an oppressive form of reproductive control, McCarthy and other disability writers critique this routinisation of hormonal contraception by suggesting it could cause further harm to women with learning disabilities by concealing signs of sexual violence that could otherwise have been detected by unplanned pregnancy (also see Hollomotz 2011).

Servais et al. (2002: 110) further suggest that use of barrier contraceptives is uncommon and 'never advocated' among women with learning disabilities. Unlike contraceptive implants and injections that are controlled by medical professionals, barrier methods rely on what McCarthy (2009b) calls 'user compliance' and requires individuals to manage usage themselves. This notion that barrier methods are not advocated for women with learning disabilities also echoes research by Conder et al. (2011) who similarly found barrier methods were rarely mentioned to women with learning disabilities in their study, instead their contraceptive use was mostly limited to the contraceptive pill and injection. The lack of knowledge about barrier contraceptives is problematic as it can leave women with learning disabilities at greater risk of sexually transmitted infections (STI's) (Servias 2006).

The contraceptive decision making of women with learning disabilities can be constrained by other people making choices for them. Ledger et al. (2016) conducted a UK-based survey with 90 family members and professionals involved in supporting women with learning disabilities to explore who decides about contraception for women with learning disabilities. Ledger et al. found that many women with learning disabilities are not making active decisions about their contraception but instead have the decision made for them by family members, paid support staff and other professionals (Ledger et al. 2016: 714). This echoes earlier work by McCarthy (2009a and 2009b) as her findings suggest women with learning disabilities generally play passive roles in their contraceptive usage as decisions are often made by other people.

Agaronnik et al. (2020) conducted interviews and focus groups with practising physicians in the US and their results indicate that some medical professionals still hold negative views towards the reproductive rights of women with learning disabilities[7]. As a result, women with learning disabilities are denied opportunities to make their own choices about contraception because health care professionals often direct information and questions to family members and support staff (Wiseman & Ferrie 2020: 319). When women with learning disabilities do raise these topics for discussion, medical professionals are often ill-prepared to support them in their decision-making or may ignore their requests altogether (Agaronnik et al. 2020; Wiseman & Ferrie 2020).

Recent literature by scholars in Iceland also details how the contraception used by women with learning disabilities can be controlled by staff. Björnsdóttir and Stefánsdóttir (2020) describe the experiences of a woman with learning disabilities who received the contraceptive injection to limit her periods, despite not being sexually active, because staff were not willing to assist her to the toilet during that time of the month. Björnsdóttir and Stefánsdóttir assert this decision was made by staff and no efforts were made to include the woman with learning disabilities in the decision making. The use of hormonal contraception to suppress or stop women with learning disabilities from menstruating without their full understanding and consent prominently features in the existing literature. Feminist disability scholars argue that not involving women with learning disabilities in contraceptive choices is a form of newgenics that reflects historical examples of reproductive control and forced sterilisation that women with learning disabilities endured (Malacrida 2020).

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[7] While it is not an issue I discuss in this thesis, it is also important to acknowledge a 'double standard' of sexual and reproductive healthcare in England as women with learning disabilities are 45 per cent less likely to receive cervical cancer screening tests that non-disabled women (NHS England 2019). One reason for this is some medical professionals assume women with learning disabilities are not sexually active and screening is therefore not considered a priority for them (Agaronnik et al. 2020: 370, also see Sykes et al. 2022; Mencap 2019; Connolly 2013).

In addition to others making contraceptive choices for them, women with learning disabilities can be restricted in their reproductive decision making by the problems they have in gaining adequate information about the topic of menstruation and how this links in with their fertility (Rodgers et al. 2006). For example, Rodgers et al. (2006: 370) conducted questionnaire surveys with women with learning disabilities in the UK and they found a large number of women with learning disabilities aged 14-55 did not have periods, and many respondents did not know why.

McCarthy (2009b) has also detailed this lack of contraceptive knowledge in her UK-based study as she found many of the women with learning disabilities she interviewed had very limited knowledge of how their contraception worked and basic understandings about reproduction. McCarthy's work shows some women with learning disabilities did not understand the links between contraception, sexual intercourse, and pregnancy; for example, some women did not know sex was necessary to become pregnant. Many of the women in her study did not know about different methods of contraception and some thought they could get pregnant if they stopped using contraception even if they were not sexually active (McCarthy 2009b). While some women with learning disabilities in McCarthy's study said they received some leaflets about contraception, none of the women felt this information was accessible to them.

This issue of the accessibility of contraceptive information is also raised in recent work by Wiseman and Ferrie (2020) who suggest women with learning disabilities are still not given adequate time or easy-read resources to make informed decisions about their contraceptive care and reproductive health (also see McCarthy 2009a, 2009b). Rowlands (2011) have also called for easy read information and visual aids to support women with learning disabilities to be able to make informed choices about contraceptive decision making. This is an area that my research focuses on and towards the end of this thesis I will share recommendations for how the accessibility could be improved.

Considering existing literature on the topic, this section has highlighted how the contraceptive use of women with learning disabilities can be controlled by family members, support staff and medical professionals. Women with learning disabilities can lack knowledge and accessible information about the different methods of contraception; this dearth of information is a barrier to women with learning disabilities being able to make free and informed choices about their own bodies that restricts their reproductive decision making. On these issues about contraception, disability scholars call for a balance between protectionism and empowerment that enables women with learning disabilities to make their own choices about contraception, reproduction, and parenthood (Rowland 2011; McCarthy 2009b). They also urge supporters of women with learning disabilities to reflect on the likelihood of pregnancy and question whether there is a need for them to be taking contraceptives if they are not sexually active or post-menopause (McCarthy 2009b). As this section has illustrated, much of the existing literature around the topic of contraception and learning disability is focused on the views and experiences of women, little attention has been paid to the issue of contraception and men with learning disabilities. This is an area my study contributes towards as male participants with learning disabilities described their knowledge and experiences of contraception and how this informs their views about parenthood.

2.6 Parenting

To understand how people with learning disabilities think about and experience having children, it is helpful to consider some of the wider social contexts of parenting that can shape their understandings and experiences. Dominant social ideas and stereotypes about disability means that the capability and suitability of people with learning disabilities for parenthood is frequently called into question and they experience greater scrutiny and surveillance over their parenting than non-disabled parents. This section will focus specifically on the social assumptions about learning disability and parenthood and the ways these ideas impact the parenting possibilities of people with learning disabilities. It also illustrates some of the ways support networks can both facilitate and constrain the parenting experiences of people with learning disabilities before discussing the sensitive issue of child removal, something that disproportionately affects parents with learning disabilities.

Within the UK, and other western societies, parenthood, and more specifically motherhood, is a socially valued role that has been constructed as ‘a selfless, time-and-labour intensive project’ that requires mothers to be ‘all things at all times to their children’ (Hays 1996 cited in Francis 2012: 928). Echoing this, Arendell (2000) has also suggested that this idealised notion of ‘middle-class heterosexual, nuclear families… gives rise to discourses of maternal deviance that construct some mothers as unfit’ (cited in Francis 2012: 928). This discourse of deviance constructs and sustains the ‘bad mother/parent’ label that is often associated with mothers who are teenagers, single, poor, non-white, immigrant, homeless, lesbian, and/or disabled (Francis 2012: 928). People falling outside of normative white middle-class constructions of the parenting ideal are then likely to endure stigma and scrutiny over their capabilities (see Lawler 2002; Skeggs 1997).

For example, research by Tyler (2008) highlights how young teen mothers and ‘chav mums’ are regularly portrayed as breaching normative ideals of motherhood. Like disabled women, they are stigmatised because assumptions of ‘excessive sexuality and economic dependency’ mark them as an ‘embodiment of ‘failed’ femininity’ (Saunders 2021: 79). The introduction of the government’s Teenage Pregnancy Strategy (TPS) in 1997 to try and reduce the number of teenagers having children illustrates how certain kinds of parenthood are seen as ‘risky’, problematic and something that needs to be prevented (Saunders 2021). Lawler (2002) has also commented on some of the ways working-class women have been labelled as ‘Other’ for the ways they are presented as differing from and disrupting middle-class ideals of femininity, instead they are often presented as oversexualised ‘bad neglectful mothers’ (Lawler 2002: 109). Writing about reproduction and social class, Saunders (2021) highlights how the ‘family cap’ policy introduced in the UK in 2017 is affecting certain groups of people. She argues that by restricting means-tested benefit support to two-children, the policy disproportionately limits the reproductive choices of many lone parents and poor and disabled families. This context further informs broader social ideas that poor, teen, non-white and non-middle-class women are not capable of ‘good enough’ mothering and should be restricted from reproducing.

Despite this, existing literature on stigma and parenthood states that for many stigmatised groups, the identity of being a mother or father is a socially valued role that enables them - to some extent - to ‘pass as normal’ (Goffman 1968). This has been shown through studies examining stigma amongst young and teenage mums, victims/survivors of domestic abuse, refugees and so on (see Skeggs 1997). Some of the existing disability studies literature surrounding parents with learning disabilities has also highlighted how motherhood is seen as an opportunity to be 'normal' - for many mothers their 'disabled identity' no longer defines them. As suggested, becoming a parent is a positive 'master status' for many people (Edmonds 2000), but as Frederick et al. (2019: 174) found from interviewing mothers with sensory and physical disabilities in the US, motherhood can often be experienced 'as a double-edged form of legitimacy'. On one hand, being a mother confirms their femininity regularly denied to disabled women, but on the other their suitability to parent is met with concern and disapproval from others. Their ability to manage the complexities of parenting is questioned and assumptions of incompetency are made; for example, it is often assumed that disabled parents will a priori be found 'lacking' and assumed incompetent in their parenting capabilities (Frederick et al. 2019: 174; Shewan et al. 2014; Murphy & Feldman 2002). The stigma of disability and dominant normative ideals of motherhood therefore reinforce social views that women with learning disabilities are unfit and unsuited for the role (Malacrida 2020).

Furthermore, disabled parents often experience scrutiny and surveillance over their parenting roles (Parchomiuk 2014); and they are judged by stricter criteria about what constitutes 'good enough' parenting, compared with non-disabled parents (Gould & Dodd 2014: 36; Booth 2003). For example, research by Thomas (1997) in the UK finds mothers with sensory and physical disabilities can go to great lengths to 'present' themselves and prove they can fulfil their parenting roles successfully. One disabled mother in their study said she found dressing and undressing her baby difficult, but Thomas describes how the woman struggled on with the dressing routine to 'present' and prove herself to professionals as being a good enough mother (Thomas 1997: 635). Another woman in Thomas' study said she found it difficult to relax into motherhood because of the constant surveillance and scrutiny she was under, she said she wished she could have that time again to enjoy time with her baby instead of worrying about visits from social services (Thomas 1997: 635). This notion of disabled parents feeling they must prove their parenting capabilities is similarly described in recent research by Theodore et al. (2018). Their UK study illustrates how some parents with learning disabilities feel they need to prove they are capable of being more than good enough parents. For example, the study describes how some people with learning disabilities chose to undertake courses in childcare prior to getting pregnant to try and prove their parenting capabilities. The researchers argue that this sense of needing to prove their parenting abilities is influenced by eugenic movement ideology about who is considered worthy to reproduce (Theodore et al. 2018: 192).

Existing studies about learning disability and parenting have also described how opinions and understandings about what makes a ‘good mother’ are subjective and ideas can vary. For example, in their UK study, Kaspar and Kroese (2017) interviewed eight older women with learning disabilities, aged 44-56, who did not have children to explore their ideas of what being a ‘good mother’ meant and whether this was a role they felt women with learning disabilities could fulfil. Findings from their study found that views on whether women with learning disabilities could make good mothers were split, with strong opinions on both sides. The researchers describe how some women seemed to think having a learning disability was compatible with being a good mother suggesting that loving the child was more important than being competent in specific skills (Kaspar & Kroese 2017: 113). In contrast, some other women said that women with learning disabilities can lack the cognitive skills, such as reading and writing, that they felt were required to make a good mother.

Dominant social ideas and stereotypes of dependency make it difficult for others to imagine that disabled women can ever be capable of successfully fulfilling parenting roles when they are seen as being reliant on care and support themselves (Vaidya 2015; Parchomiuk 2014). For people with learning disabilities, social perceptions of them as child-like can further restrict their opportunities for thinking about and experiencing parenthood as too frequently it is asked how these people can cope with the demands of parenting when they are seen as children themselves (Booth & Booth 2005). Research suggests women with learning disabilities internalise this discourse and despite their own desire to have children, many do not see parenthood as a role that is realistically available to them (Johnson et al. 2001: 211).

The parenting possibilities of people with learning disabilities can also be restricted by family members and staff, particularly if they hold negative views about their capabilities to fulfil parenting roles. For example, Aull Davies and Jenkins (1997) used qualitative research methods to explore the transition of young people with learning disabilities to adulthood in Wales during the 1990s; their results describe the control parents and support staff can have over the reproductive imaginaries and choices of people with learning disabilities. In their study, some women with learning disabilities described how they had been persuaded by family members not to have children because of the work entailed in looking after them (Aull Davies & Jenkins 1997: 106). Some women with learning disabilities in their study said they had also been discouraged from having children as family members told them that any children they do have will probably also be disabled (Aull Davies & Jenkins 1997) – this notion of genetic risk will be explored further later in this chapter.

Aull Davies and Jenkins (1997: 106) also found that young men with learning disabilities seemed to experience fewer restrictions from family members and staff regarding parenting possibilities. This important insight into the gendered difference in parenthood choices for women and men with learning disabilities is also presented in a recent UK study by Theodore et al. (2018). Four fathers with learning disabilities were interviewed in their study and spoke about how they have felt ''pushed out' or even 'cheated' in their role as a father, both by professionals and others in their social networks' as mothers tended to be the focus (Theodore et al. 2018: 191). This view of fathers with learning disabilities feeling neglected is also echoed in recent work from Symonds et al. (2021). By including the perspectives of both men and women with learning disabilities in my research, I consider whether, and how, gender shapes parenting opportunities and experiences of people with learning disabilities.

As well as concerns about parental competency, mothers with learning disabilities and disabled mothers more broadly, are often judged as not 'good enough' parents because of the assumption that they will come to depend on their children for care and support. Present in broader professional literature, this notion of 'upside-down' families is concerned that children will be exploited and robbed of their childhoods by taking on 'young carer' roles (Malacrida 2020: 470; Lanci 2018; Sigurjónsdóttir & Rice 2018; Rivera Drew 2009; Booth & Booth 1998). This sits in opposition with contemporary ideas that childhood should be lived away from the difficulties and hardship of adulthood (Hays 1996). It is important here to acknowledge and position this understanding of upside-down families within the context of Western culture, as in many Indian and Asian cultures, children are often expected to play vital roles in supporting and caring for their parents and other family members (Frederick et al. 2019: 167). Understanding the social context of parenthood is important for considering how widely held ideas and assumptions can shape the reproductive choices and experiences of people with learning disabilities that is central to my research.

For many disabled and non-disabled people, parenting is not an individual task, rather it is a role that often relies on support from different social networks, including family members and formal support services (McKenzie et al. 2010). Family support networks have been found in existing research to be instrumental in helping people with learning disabilities fulfil parenting roles and keep custody of their children (Sigurjónsdóttir & Traustadóttir 2010). The literature also tells us people with learning disabilities prefer seeking parenting help and support from family members close to them instead of accessing formal support services Llewellyn & McConnell 2002). However, as mentioned earlier in this chapter, it is also important to consider that many people with learning disabilities have small networks of family and friends that can put them at a disadvantage when it comes to accessing informal help and support with parenting and child rearing duties.

While the support from family helps some parents with learning disabilities to fulfil their parenting roles, other studies have described how parents with learning disabilities can feel oppressed and undermined by family members interfering in their parenting roles (Llewellyn et al. 1999). Much earlier research by Tucker and Johnson (1989) found family members of parents with learning disabilities often intervened 'for the good of the child' but this meant parents often felt 'belittled' and undermined by family members not consulting them about parenting issues first (also see Kitson & Wilson 2019). It is possible that family members who intervene in this way may think they are doing what is right to 'help', but as Tucker and Johnson found, this oppression and control reinforces the power that family members can have over the reproductive and parenting possibilities of people with learning disabilities.

Research has shown that parents with learning disabilities are able to learn and can benefit from formal parenting training and support (Feldman 1994; Tymchuk & Feldman 1991), but many find it difficult asking for help in case it marks them as struggling and being unable to cope (Thomas 1997). For those that do come forward seeking support, Gould and Dodd (2014: 36) say that many are being let down by inadequate support services that ultimately set them up to fail. McKenzie et al. (2010: 30) also acknowledges the importance of formal support and suggests more needs to be done to ensure parents with learning disabilities can access these training opportunities to help them succeed in their parenting roles. The importance of having access to adequate support services is also found in the literature regarding child removal experiences, as is discussed next.

2.7 Child removal

The issue of child removal is significant to this research. Becoming a parent is an important identity marker that challenges the stigmatised label of learning disability, but this identity can be threatened by the intervention of social services and child removal processes (Franklin et al. 2022). This section presents some of the wider context about child protection and child removal proceedings before focusing on how this disproportionately impacts parents with learning disabilities. It is helpful to first describe some of the child protection legislation and child removal processes in the England. Currently child protection in England is directed by the Children Act 1989 that states the importance of parental responsibility, child welfare and that children should be raised in their families. The Act also sets out how local authority services should respond when they suspect a child's needs are not being met or they suspect a child is suffering, or likely to suffer, significant harm. Under The Children Act 1989, social services have a duty to promote and safeguard the welfare of children. Following the murder of Victoria Climbié by her family in 2000, the Children Act 2004 strengthens the previous Act to prioritise child welfare and protection. In urgent cases where there is immediate risk of harm to a child, social services can apply to the courts for an emergency protection order to remove the child from the parents. If the case is not considered urgent, social services may engage and try to support parents before child removal processes are initiated. In these instances, a 'child in need plan' or 'child protection plan' will often be made. If a child is still considered to be at risk of harm despite the support from social services, then the case will be passed by the local authority to the courts for a decision (Family Rights Group 2023).

Of course, the protection of children is important, but a dominant culture of risk aversion in the child welfare system in England today means some parents with learning disabilities are denied the chance to parent their children (Tarleton & Ward 2007, also see Masson & Parton 2020; Webb 2006). This issue of discriminatory child removal is something McConnell and Llewellyn (2002: 297) talk about as they suggest removing a child in need of care and protection is not the issue here, rather the concern is with the 'unnecessary, unwarranted and all-too-frequent removal' of children from parents with learning disabilities. Parents with learning disabilities have been identified as the social group most at risk of enduring child protection investigations and having their children removed from them (Sigurjónsdóttir & Traustadóttir 2010; Booth et al. 2005). As mentioned previously in this thesis, UK and international research estimates that between 40 – 60 per cent of parents with learning disabilities have their children removed from their care (Emerson et al. 2005). Due to the lack of recording about parents with learning disabilities in the care system I have been unable to find more recent figures for England, but research in Wales in 2019 reports that children of parents with learning disabilities were twice as likely to be removed from their parents instead of being supported to stay with them at home (Hodges & Brigstow 2019 cited in Working Together with Parents Network 2021: 47).

Widely held social views that parents with learning disabilities will abuse or neglect their children influences the excessive willingness of child welfare agencies to remove children from custody of parents with learning disabilities (Crossley 2020; Feely 2016). Contrary to these social myths and assumptions however, Booth (2003) states that abuse by parents with learning disabilities is rare and issues that do arise are more likely to be about neglect, rather than abuse, that can be indicative of their own childhood experiences (James 2010: 14; McGaha 2002). International court case reviews in America (Tymchuk & Andron 1990) and Australia (Glaun & Brown 1999) also find that mothers with learning disabilities who had allegedly maltreated their children had also experienced abuse or neglect themselves.

On the issue of child removal, Hewitt (2007: 34) says it is also important to consider how more mothers than fathers with learning disabilities seem to be referred to child protection services which may reflect the negative views and prejudices held by society, or it could be because mothers are often more involved in caring duties. As mentioned earlier in this chapter, my research also aims to contribute to this discussion about the role gender has in shaping the parenthood imaginaries and outcomes for women and men with learning disabilities, an area relatively under-explored within existing disability literature.

Research by Sigurjónsdóttir and Rice (2018) states that the prejudice, ignorance, and negative attitudes of some professionals towards parents with learning disabilities explains the often-discriminatory intervention of social services. Sigurjónsdóttir and Rice analysed publicly available court reports and documentation regarding custody deprivation cases in Iceland between 2012-2017. They found the label of 'intellectual disability' featured prominently in case reports, but this was often made without a clear connection as to how this was linked to the allegations of abuse or neglect. From their research Sigurjónsdóttir and Rice call into question some of the 'evidence' provided by professionals conducting parenting assessments as 'odd' and 'absurd'. For example, they highlight a case that describes a cat sitting on the bed in the parents' house and another that says there were fingerprint smudges on a window, both with no further explanation about how this was negatively impacting their parenting abilities or its broader relevance to the investigations (Sigurjónsdóttir & Rice 2018: 68). Crucially, the researchers go on to say this odd and absurd evidence is not recorded in cases where parents do not have learning disabilities. These findings tie in with wider literature mentioned earlier that highlights the increased judgement and scrutiny that parents with disability status are often subjected to because their impairment is deemed incompatible with being able to parent successfully.

The high rates of child removal from parents with learning disabilities is further exacerbated by the lack of formal support service provision and investment (Booth et al. 2006); they are let down by patchy and inadequate services that makes it harder for them to access the help some of them need to raise their children and fulfil parenting roles (O'Hara & Martin 2003). Booth (2003: 205 - 206) says that the inadequate services and discriminatory child removal practices are exempla of the systematic abuse that continues to oppress parents with learning disabilities and prevents them being able to raise their children. Valuing People Now (2009) outlines the UK government's three-year commitment plan to improve the lives of people with learning disabilities. Within the document it suggests that parents with learning disabilities need the same level of information, advice and support available for all parents to enable them to successfully raise their children (also see Working Together to Safeguard Children 2018). Despite the government commitments, this thesis will look at what more could be done to be done to support people with learning disabilities to fulfil their parenting roles and keep custody of their children.

Much of the literature described in this chapter relates to parents with learning disabilities that were known to social services. Thomas (1997) is one of the few studies I found that talks about the issue of child removal undertaken by family members. For instance, one disabled woman in Thomas' study described how her own mother assumed she would not be able to cope with parenting because of her disability and wanted to 'keep' the baby (Thomas 1997: 633). This is another example of how concerns about protecting the child from the risk of potential harm seem to override the parenting rights of the mother; a theme that is consistent throughout the literature. This discourse further overlaps with what was highlighted earlier about family members intervening in an attempt to 'help', but this overprotection can be acting as a form of reproductive control that denies people with learning disabilities opportunities to perform parenting duties (see Tucker and Johnson 1989; Kitson and Wilson 2019).

Research suggests people with learning disabilities find child removal processes confusing and they do not always understand why their children have been taken away from their care. For example, Gould and Dodd (2014: 35) interviewed nine women with learning disabilities who had had their children removed from their care in the UK, their study found that most mothers were unaware of the reasons why their children had been removed from them. Earlier UK research by Baum and Burns (2007: 3) that interviewed eight mothers with learning disabilities who had lost custody of their children also found some mothers did not understand why they had lost custody. Others said the stigma of their learning disability was the reason why their children had been removed and blamed social workers for what happened to them suggesting they were bullied and victimised. Mothers in Baum and Burns' study also described how they received no parenting training which echoes broader findings on the topic that suggest people with learning disabilities are set up to fail in their parenting roles because of the dearth of formal support. Participants in Theodore et al. (2018) similarly detailed the ongoing scrutiny that people with learning disabilities face compared to other parents. This further highlights the double-standards that exist between parents with learning disabilities and those without, it also points towards the on-going stigmatisation and discrimination that people with learning disabilities experience.

Even before they have their children, people with learning disabilities are worried and concerned about the realities of them being able to keep custody and go on to raise their children. From interviewing parents with learning disabilities, Theodore et al. (2018) found that whilst most parents seemed to follow and enjoy the 'typical' experiences of preparing for a baby by buying equipment and thinking about baby names, for some however, this was tinged with uncertainty and doubts that after the birth they might not be allowed to bring their children home with them.

Moreover, future parenthood decision making can be influenced by child removal experiences as parents feel threatened by social services and fear if they have more children that they will also be taken from them (Malacrida 2020). Conder et al. (2011) for example, interviewed parents with learning disabilities in New Zealand and found experiences of child removal shaped participants' decisions not to have any more children. As research explored in this chapter has shown, this fear and threat of child removal is not without grounds as the label of learning disability is often used by social services against people to deny them custody of their children (Malacrida 2020). The impact of child removal experiences on future parenthood imaginaries is an area my research considers as I explore what impact these stories can have on the parenthood imaginaries of people with learning disabilities who do not yet have children.

This section has detailed how people with learning disabilities continue to be excluded from parenting roles because of the entrenched stigma and negative assumptions held against them (Sigurjónsdóttir & Rice 2018: 66). These widely held views mean that learning disability is often 'treated as *prima facie* evidence of parental inadequacy' that warrants child protection proceedings (McConnell & Llewellyn 2000: 886). These discriminatory child removal processes parents with learning disabilities often experience can be understood as a form of newgenics that continue to deny people with learning disabilities parenting possibilities. This issue of child removal is a theme my research explores in more detail as I consider what impact this context of risk aversion has on the reproductive decision making of people with learning disabilities. My study will also contribute to this field by looking at whether parents with learning disabilities feel there are ways they can avoid the distress of child removal.

2.8 Reproductive and genetic risk

I argue throughout this thesis that the reproduction of people with learning disabilities is inextricably linked to eugenic ideas of 'risk' largely influenced by the fear that their impairment will be 'passed on' to their children. This section will highlight the ways negative social views and the general disregard of disabled people is influencing the assumption that disabled women should not be having children, and babies that might be born with an impairment should be avoided through prenatal testing and genetic screening technologies (Kallianes & Rubenfeld 1997: 212). Despite the dominant social discourses of reproductive risk, the literature suggests that disabled people have different views about their own reproductive possibilities. My research will build on existing disability studies literature to see how people with learning disabilities think about social perceptions of reproductive and genetic risk and whether these views impact how people with learning disabilities think about their own reproductive possibilities.

Several possible and complex causes can be linked to learning disability that can include, but are not limited to, chromosomal abnormalities, exposure to harmful substances or infection during pregnancy, premature birth, complications during birth and illness (NHS 2022). The literature states most children born to parents of people with learning disabilities will not have a disability, but it acknowledges there is a higher chance or 'risk' (McGaw & Candy 2010: 143). Disabled women's reproduction and parenting is bound in discourses of 'risk' and social judgements that the notion of them having children is generally considered irresponsible and unfair on their child and society. The literature on women's reproductive rights tells us that the idea of disabled women having children is viewed negatively because of the overwhelming fear that they will pass on their impairment to their children (Vaidya 2015). For example, Thomas (1997) interviewed 17 disabled women in the UK who were either mothers or who were thinking about having children. Most of the women she spoke to had faced issues surrounding reproductive risk; either about themselves or their babies. Some of the women in her study talked about the challenges of deciding whether to have a child if there was a chance their disability was hereditary or could be 'passed on'. The women also spoke about feelings of 'guilt' from the way they felt their decision to have a child was considered by others as both irresponsible and 'unfair' to the child (Thomas 1997: 631).

Knight (2017) describes how some disabled women are accused of ignoring cultural messages advising them not to have children. Knight suggests women who do go on to have children despite society strongly urging them not to, are often seen as irresponsible or selfish (Knight 2017: 76, also see Frederick et al. 2019).

Contrary to this, there is literature that suggests some people with learning disabilities are less concerned than non-disabled people about the potential ‘risk’ of passing on their disability to any children they might go on to have (McGaw & Candy 2010). My research will further add to this diverse literature as I explore whether and how dynamics of genetic risk shape the parenting possibilities of people with learning disabilities.

2.8.1 Prenatal testing and genetic screening technologies

When considering how social contexts can shape reproductive decision making, it is helpful to acknowledge some of the wider debates around prenatal testing and genetic screening technologies that have emerged in recent years with the development of genomic medicine. These technologies are embedded in general reproductive spaces and how people engage with them is influenced by societal ideas and perceptions of disability. Boardman and Hale (2018) suggest advances in scientific understandings of genomic medicine is rapidly changing how society thinks about and engages with reproduction. The literature currently identifies prenatal testing (e.g., non-invasive prenatal testing (NIPT)), and genetic screening (e.g., whole genome sequencing (WGS)) as the most recent advances in the field. At this point in time prenatal testing is routinely available free on the NHS, whereas WGS is only currently available through the NHS to individuals who have been referred for genetic testing by a doctor or hospital specialist (NHS 2023). The literature states that social attitudes towards testing and screening technologies are diverse and complex with feelings of support, resistance and ambivalence towards these technologies (Boardman & Hale 2018).

Supporters of these technologies have suggested that it enables society to move away from dependency on nature and instead it allows prospective parents to have more choice and control over their future families (Leefmann et al. 2017). For example, some have said that testing and screening offers prospective parents the opportunity to decide whether they are financially or emotionally in a position to raise a disabled child (Parens & Asch 1999). Other supporters of these technologies have said that some disabled people may not want to pass their impairment on to their child and this technology enables them to make decisions informed by the test results (Parens & Asch 1999). The literature also raises the question about with access to such technologies whether we have a moral obligation to use it to reduce congenital impairment from society (Leefmann et al. 2017).

Advances in genetic and testing technologies have also been critiqued by disability rights advocates as problematic for the way they discriminate against impairment and disabled people. Recent developments in screening and testing technologies have exacerbated social categories of ‘normal’ and ‘abnormal’ embodiment that marks disabled people as ‘Other’ and less than (Lupton 2013). Regarding prenatal testing in particular, the literature has highlighted issues around the medical and social pressures encouraging pregnant women to use these tests as part of their prenatal care (McLaughlin 2003). Saxton (2017: 78) for example describes how pregnant women are increasingly pressurised to have prenatal tests under the guise that it is socially and morally the responsible thing to do. There is both an assumption and an expectation that pregnant women will use the tests and act on them by terminating the pregnancy if the results indicate a high chance of having a disabled child (Thomas 2017).

In addition to the routinisation of testing technologies, the literature has also highlighted how decision making can be influenced by dominant medical discourses of ‘risk’ (Kerr & Shakespeare 2002). Within prenatal counselling sessions existing literature states that there is a lack of balanced information about conditions such as Down’s syndrome and that there is an overly pessimistic view of disability that is influencing the decision making of women to terminate their pregnancy (Thomas 2017). A combination of the routinisation of testing technologies and dominant discourses that construct disability as a ‘risk’ reinforce the social stigma that perceives ‘disability as a tragic mistake that could and should have been avoided’ (Saxton 2000: 150, also see Thomas 2017). A disability rights approach claims that testing and screening technologies therefore send a hurtful message to disabled people that marks them as flawed and less than. The literature suggests that new reproductive testing and screening technologies echo earlier eugenic ideology as some disability activists are concerned that these reproductive technologies exist within wider social contexts that are controlling what kind of people are allowed to exist (Jarman 2015). Saxton (2010 cited in Jarman 2015: 49) argues that these reproductive testing and screening technologies are serving as ‘quality controls’ and ‘admission standards’ for what type of people are born into the world.

As this section has indicated, the issue of genetics is a complex area of discussion. While dominant social discourse seems to be concerned with preventing disability and the ‘risk’ of disability being passed on, the literature describes how some disabled women have resisted this narrative and instead have asserted their agency to choose to have children with disabilities. Jarman (2020: 139) for example tells us how the Deaf community and people with dwarfism often embrace passing on these traits to their children, and in some instances, people have advocated for genetically selecting for these traits (O’Toole 2015 cited in Jarman 2020: 139; Kafer 2013). My research will contribute to this existing disability literature by exploring what people with learning disabilities think about genetics and how these understandings are shaping their reproductive and parenthood imaginaries.

2.9 Theoretical frameworks

This research draws from disability rights and feminist reproductive rights movements to explore the reproductive and parenthood imaginaries of people with learning disabilities and to understand how these can be shaped by other people and the social contexts they are embedded within. Both the women’s and disability rights movements have been critiqued for failing to respond to disabled women’s concerns regarding reproduction and motherhood. Disability rights advocates have critiqued feminist literature for failing to engage with discussions about disability. At the same time, feminist literature has been called out for not going far enough to include the perspectives and experiences of disabled people around the issues of reproduction and parenthood. This section will explore some of these discussions in more detail before outlining how the concepts of reproductive justice and stratified reproduction will also be used in this research to understand more about the reproductive and parenting decision making of people with learning disabilities.

2.9.1 Disability rights movement

Historically, disability has been associated with negative discourses that perceive disabled people as 'victims' and 'burdens' on their family and society. The disability rights movement emerged internationally in the 1960s and 1970s and has been instrumental in challenging widely held negative and tragic understandings of disability and campaigning for the citizenship rights of disabled people (Oliver 2013; Barnes & Mercer 2003; Campbell & Oliver 1996). In the UK, a particular focus of the disability rights movement has been distinguishing between the medical and social models of disability which has been influential to how political activism and thinking about disability has emerged. The medical model generally portrays disability as an individual tragedy and depicts disabled people as dependant and awaiting care, cure, or charity (Paterson & Hughes 2000), whereas the social model focuses on the social and environmental barriers that disable people (Barnes & Mercer 2010). A social model perspective identifies the institutional structures and social oppression as the cause of disabled people's oppression that denies them full and equal access to society (Shakespeare 2017; Barnes & Mercer 2010). For this research, the social model offers a useful standpoint from which to critique the institutional structures and barriers to education and information as I tease out some of the difficulties that people with learning disabilities have in accessing sexual and reproductive health education and parenting information. The social model is also useful as it allows for an exploration of some of the barriers disabled people experience when it comes to forming and maintaining intimate relationships that is important to this research (Shakespeare at el. 1996: 3).

However, it is important to acknowledge that the social model's focus on structural disablism has been critiqued, initially by disabled feminists, for ignoring the private and intimate lives of disabled people (Liddiard 2017). Disabled feminists, such as Fine and Asch (1988), Garland-Thomson (2005), Morris (1991) and Saxton (2017) argue that they have been marginalised by 'gender-blind' disability studies (Goodley 2011: 34). Disability activist Anne Finger (1992) further articulates this as she says sexuality is often the source of disabled women's deepest oppression (cited in Shakespeare 2010: 160). She continues to argue that public sphere issues of discrimination in employment, historically the remit of men, has taken privilege over private issues of the domestic sphere, sexuality and parenting, forcibly occupied by women (Goodley 2011: 34). In addition, as Waxman powerfully states: while *'many of us find sexuality* *to be the area of our greatest oppression… we are more concerned with being loved and finding sexual fulfilment than with getting on a bus'* (1991: 23 cited in Kallianes and Rubenfeld 1997: 207).

Of particular importance to my research, the social model has further been critiqued for neglecting the experiences of people with learning disabilities (Hollomotz 2009). Docherty et al. (2010: 438) for instance have argued that there is 'a hierarchy of impairments' that leaves people with learning disabilities at the bottom (cited in Stalker 2019: 161). Yet, whilst much of the existing disability studies literature on the social model focuses on physical impairment, other writers have suggested that the social model can also be used to include the experiences of people with learning disabilities (Watson et al. 2012). Stalker (2019) continues to highlight some of the similarities between the position of people with physical disabilities and those with learning disabilities that can be addressed by using the social model of disability. She suggests that oppression, exclusion and discrimination highlighted within the social model also affects the lives of people with learning disabilities and acknowledges that whilst people with learning disabilities are less likely to encounter the material barriers that people with physical or sensory impairment experience, people with learning disabilities are likely to face barriers in terms of accessing information (e.g., inaccessible formats, font, complicated language etc.).

Taking these critiques into account I argue that whilst there are flaws with social model, it does however provide a useful framework to explore the attitudinal barriers that people with learning disabilities face: '[as] they are not listened to, not respected, and subject to other people's judgements and decisions' (Stalker 2019: 160). These judgements and decisions will be a key area of interest within my research as I explore the tensions between the judgements made about the capabilities of people with learning disabilities to successfully fulfil parenting roles. My research will also use this framework to shed some light on whether people with learning disabilities understand these judgements and how these attitudes influence their imaginaries and experiences of parenthood.

2.9.2 Feminist reproductive rights and reproductive justice movements

The term 'reproductive rights' is widely used to equate women's right to control her own body and fertility; more specifically the right to decide *not* to have children and to be free from unwanted pregnancy by being able to access contraception and safe legal abortion (Vaidya 2015; Kallianes and Rubenfeld 1997). This is often described in the literature as a 'pro-choice' framework that centralises the woman's right to prevent or terminate their pregnancy (Knight 2017). Feminist literature about reproductive rights and the topic of parenting and mothering predominantly features the views and experiences of white, middle-class, heterosexual, non-disabled women; it often fails to engage with the voices of women who sit outside of these categories (Mayes et al. 2011).

While the feminist movement highlights the social pressures and expectations non-disabled women experience to become mothers, many disabled women are looking for the opposite as they are advocating for equal access to the normative female role of motherhood. Rothler (2017: 107) suggests that women with disabilities receive 'mixed messages' about their reproductivity: on one hand, as women, they are expected to have children and fulfil mothering duties, but on the other hand, negative perceptions about their impairment characterises them as incapable of performing 'normal' mothering roles.

Existing disability studies literature suggests that many disabled feminists support reproductive rights but are concerned that it does not consider the ways ableism and discrimination can shape reproductive decisions and experiences of parenthood. Where disability is mentioned in existing literature, it is largely concerned with debates about reproductive screening technologies and discourses of genetic risk. US scholar Amber Knight (2017: 68) argues that women with disabilities will continue to experience reproductive oppression until feminist discourses advocate women's right to bear and raise children to the same degree that it has previously championed the pro-choice right of women to choose not to have children.

Both the women's and disability rights movements have been critiqued for failing to respond to disabled women's concerns regarding sexuality, reproduction and motherhood. Jenny Morris (1995: 76) for example tells us:

> *"Having sexual relationships (whether they are heterosexual or lesbian relationships), family relationships, bearing and rearing children, making a home – all these are important human and civil rights which, if denied to nondisabled women, would be the subject of outrage."*

Disability writer Vaidya (2015: 518) argues that feminist and disability movements 'seem to talk past each other' as the feminist movement largely ignores perspectives of disabled women and the disability movement largely ignores experiences of women.

As this chapter has already described, disabled women's reproductive rights are often restricted by ableist myths and assumptions of asexuality or dangerous sexuality, lack of reproductive education, and social resistance to disabled women becoming mothers. Therefore, for disabled women, the term reproductive rights also includes the right to have intimate relationships, bear and raise their children (Vaidya 2015) and this is a central tenet of reproductive justice (Knight 2017).

Supporters of reproductive justice have critiqued the feminist reproductive rights movement for its focus on pro-life/pro-choice debates that are too individualistic as they fail to recognise the influence social contexts have on women's reproductive decision-making (Silliman & Bhattacharjee 2002 cited in Howard 2020: 348). Moving away from neoliberal ideas of individual choice, reproductive justice instead acknowledges how histories of oppression, social and cultural contexts, and family and community relationships can either support or restrict access to reproductive decision making (Saunders 2021). Reproductive justice critiques other feminist theory for treating all women the same; this overlaps with criticisms of feminist theory and the social model of disability that fail to recognise the nuanced role intersectionality has on reproductive possibilities. Reproductive justice is a useful concept to show that not all women have equal access to reproductive decision-making, and as Knight (2017: 67-68) suggests, some women's reproductive choices are made more freely than others.

In the lead up to the International Conference on Population Development in Cairo in 1994, a group of black women in the US gathered to lead a national movement to centre the reproductive rights of marginalised women in society. This group of women identified themselves as Women of African Descent for Reproductive Justice, where the term reproductive justice emerged (SisterSong). Reproductive justice has been defined as 'the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities' (SisterSong). These three core values highlight the shared histories of reproductive control and oppression experienced by marginalised groups of women. The reproductive justice movement emerged in response to black and other minority women experiencing economic barriers in seeking access to abortion. Even when abortion is a legal right, many marginalised women cannot afford it and often experience challenges travelling to access it (SisterSong).

In addition to abortion access, the reproductive justice movement also highlights that women cannot make reproductive decisions where they have no access to sex education, contraception, pregnancy care and parenthood support (Cadena et al. 2022; Saunders 2021; SisterSong). This theme of access is central to my research as I explore what access people with learning disabilities have to reproductive decision making opportunities and what roles structural and interpersonal relationships play in shaping their parenting possibilities.

A central tenet to reproductive justice is the belief that reproductive decision making and parenting experiences have always been influenced by systemic inequalities and negative views towards certain groups people based on their race or sexuality for instance (Ross 2017). Ross (2017: 184 cited in Morison 2023: 175) has commented on the usefulness of reproductive justice as a theoretical framework by saying:

> *"Reproductive justice theory is needed because many earlier theories about reproduction pay inadequate attention to the physical, social, economic, and emotional realities of Indigenous women, poor women, trans women and women of colour. Such theories fail to thoroughly analyze [sic] and critique the system of white supremacy that determines which bodies matter and which do not."*

Morison (2023: 175) further suggests that reproductive justice theory allows for 'more nuanced understandings of sexual and reproductive issues' than existing feminist and reproductive rights frameworks because of how it engages with concepts of intersectionality and human rights. Described as a 'novel, critical feminist theory' (Ross 2017: 287), reproductive justice enables researchers to consider how socio-political contexts and differing power dynamics across categories of difference, such as race, class, sexuality, and disability, influence reproductive decision making and parenthood experiences.

Reproductive justice highlights how certain kinds of women are expected and encouraged to reproduce, yet for some marginalised groups of women reproducing is seen as problematic and something to be avoided and guarded against. For instance, previously deemed as 'undesirable' mothers, black, poor, lesbian, and disabled women have historically experienced coercive sterilisation, abortion, and child removal to restrict their reproductive decision making (Saunders 2021; Sheldon 1999). The ways some groups of women endure oppression and regulation over their reproductive decision making and parenting experiences illustrates how different forms of personhood are more socially valued than others. Waxman points towards this notion of reproductive double standards as she asserts that 'while a non-disabled woman's pregnancy is considered a miracle, a disabled woman's pregnancy is considered a crime against society' (Waxman 1993 cited in Kallianes & Rubenfeld 1997: 211).

On this important point about valued and devalued reproduction, it is helpful to consider the concept of stratified reproduction (Colen 1995) that has been defined by Ginsburg and Rapp (1995) as 'the power relations by which some categories of people are empowered to nurture and reproduce, while others are disempowered' (cited in Saunders 2021: 78). This stratification has previously been visible through previous practices of institutionalisation and sterilisation that prevented people with learning disabilities from forming intimate relationships and reproducing. However, as this chapter has highlighted, this issue of stratified reproduction is still happening but in more subtle ways. For example, contraceptive control and the surveillance of people with learning disabilities by powerful others are just some ways that show how this group are still restricted and stratified in their reproductive decision making. These power dynamics reinforce social ideas that suggest the reproductive rights of people with learning disabilities are seen as less than the reproductive rights of non-disabled people (Kallianes & Rubenfeld 1997).

Morison (2023) contends that attention to power and oppression should be central to any research engaging with a reproductive justice framework. A reproductive justice lens centralises the views and experiences of marginalised groups and this is what I have done within both my methodology and analysis by focusing on the parenthood imaginaries and experiences of people with learning disabilities. My decision to also include family members and staff participants allows for further exploration into the social contexts and relational power dynamics that influence reproductive possibilities of people with learning disabilities. While the concepts of stratified reproduction and reproductive justice have been used in feminist literature about parenthood, these approaches have rarely been applied to explorations of the reproductive and parenthood decision making of people with learning disabilities. By addressing this gap, I will use these concepts to shed light on how people with learning disabilities continue to experience reproductive oppression and control as they endure barriers to intimacy and privacy, thus limiting their opportunities to thinking meaningfully about having children.

2.10 Conclusion

This chapter provides an overview of some of the relevant literature that helps situate my research and identify some of the gaps that this study will contribute towards. An understanding of the historical contexts of eugenic ideology illustrates how the reproductive decision making of people with learning disabilities was restricted in the past but it also raises the questions about how much has changed when it comes to people with learning disabilities making their own autonomous decisions about parenthood and having children today. My research will extend the existing discussions about eugenics to unpack some of the more subtle ways the reproductivity of people with learning disabilities is oppressed. This literature review has also highlighted issues regarding opportunities for people with learning disabilities to access sex education and information about reproduction and parenthood. My research will consider how interpersonal relationships of family members and support workers can impact what information people with learning disabilities have access to and how this shapes what people with learning disabilities think about and experience regarding parenthood. By calling upon the views and experiences of sibling participants, especially around discussions of contraception, this research also provides new insights into some of the familial relational networks that are influencing how people with learning disabilities imagine and experience parenthood. On the topic of parenthood, the decision to include the views and experiences of men and fathers with learning disabilities further responds to a gap within the literature outlined in this chapter. This research will also build on existing debates and discussion about reproductive testing and screening technologies to highlight whether and how this is shaping what people with learning disabilities think about having children. As well as presenting an overview of some of the existing literature, this chapter has highlighted some of the theoretical frameworks and concepts that will be used to analyse the findings of this research.

Chapter 3. Methodology

3.1 Introduction

This research aims to explore the reproductive and parenthood imaginaries of people with learning disabilities, it also considers how family members and support workers can shape the reproductive and parenting possibilities of people with learning disabilities. 21 participants with learning disabilities, 10 siblings and three parents of people with learning disabilities and three paid learning disability support workers were interviewed. In this chapter I set out the methodology used and some of the methodological issues experienced conducting this research. I also discuss the epistemological framework that guided why and how the research was conducted and highlight the importance of centring the views of people with learning disabilities. In this chapter I will describe how the Covid-19 pandemic disrupted the initial research focus of exploring the parenthood imaginaries of young people with learning disabilities and how this changed to also include the views of older participants with learning disabilities, some of whom are already parents. I talk in detail about how the pandemic also changed the planned methodologies of using face-to-face advisory groups, participant observations and interviews to rethinking how participants could take part online. This chapter presents a detailed account of the recruitment and interviews conducted with different participant groups before presenting the ethical considerations of this research.

3.2 Epistemology

Until the 1950s and 1960s people with learning disabilities were often excluded from participating in social research due to doubts about the reliability and credibility of what they said (Goodley 1996; Atkinson 1997). Booth (1996) also tells us how these negative assumptions and stereotypes previously held by researchers have been instrumental in restricting the views, voices and experiences of people with learning disabilities in social research. In cases where research did include people with learning disabilities, this was often fuelled by medical understandings of disability that treated individuals as objects of study instead of valuing them as people with credible views and experiences (Booth 1996: 238). The way that people with learning disabilities were largely absent from research has been shaped by their exclusion from mainstream society as many people with learning disabilities lived in institutions and residential homes that made them invisible (Atkinson 2001). Their absence from research was indicative of their marginalised position within society. It is important to recognise the ways people with learning disabilities have predominantly been considered incompetent, unreliable or untrustworthy is not about their impairment *per se,* rather these ideas are informed by wider social ideas and assumptions about learning disability (Welsby & Horsfall 2011). These stereotypes have also shaped the way research about people with learning disabilities has regularly relied on the perspectives of family members, professionals or advocates (Welsby & Horsfall 2011).

With the emergence of the disability rights movement and the influence of the social model of disability, since the 1980s there has been a shift towards more people with learning disabilities sharing their views and experiences on a range of social issues. Commenting on this shift, McCarthy (1998: 144) states that there is a growing understanding and appreciation that people with learning disabilities are not only valid sources of information about their lives, but they are often the best sources. The slogan of the disability rights movement ‘Nothing about us without us’ (Charlton 1998 cited in Santinele Martino 2022: 2) recognises the importance of including people with learning disabilities in social research and highlights the right and autonomy they have to speak on their own behalf (Santinele Martino & Fudge Schormans 2018).

Today, learning disability research is underpinned by ideas of inclusive research which broadly refers to ways people with learning disabilities are more than just subjects of research (Walmsley & Johnson 2013). Inclusive research, which also encompasses participatory and emancipatory approaches, is increasingly used to empower marginalised social groups like people with learning disabilities (see Smith-Merry 2019). Inclusive research aims to address the power dynamics between the researcher and researched as individuals take on active researcher roles by guiding research questions, collecting and analysing data and disseminating results and information. While participants with learning disabilities were not involved in the analysis or dissemination of this data, I had initially hoped to draw from some inclusive research approaches in my methodology.

Despite this increasing awareness and recognition of the rights of people with learning disabilities to have their views and voices represented in social research, some disability studies writers, such as Bigby et al. (2014), have highlighted ongoing issues with representation. For instance, people with learning disabilities who can speak tend have greater presence within research than others who do not speak. Ongoing discussions about spoken interviews as the gold standard in sociological research are documented throughout existing disability literature and, as Aldridge (2007) states, groups of people with learning disabilities will continue to be overlooked if researchers are not prepared to step outside the boundaries of conventional methodologies (see Fitzgerald & Withers 2013). These issues of inclusion and representation is something I spent time considering in the design and planning of this research and will be explored further in this chapter.

As well as issues with representation, Santinele Martino (2022: 2) states that people with learning disabilities are often silenced in research participation and knowledge creation because of persisting stereotypes and ideas of protection, risk and vulnerability. Existing literature also suggests that researchers can be cautious about the capacity of people with learning disabilities to consent. By including people with learning disabilities in this sensitive research I create a space for their voices to be heard and form part of the discussion. Drawing from inclusive research approaches and including people with learning disabilities in research enables people them to share their perspectives on issues that are important to them and presents possibilities for enacting positive change within these communities.

In this thesis I centre the voices of people with learning disabilities and recognise them as agents and meaning makers of their own lives and experiences (Santinele Martino 2022: 2). It is important to note that while the ways participants experience learning disability and the world around them is unique and individual to them, there are common and shared themes amongst their accounts that illustrate wider social contexts that are shaping their lived experiences. Positioned within social constructivism this research explores how the lives and experiences of people with learning disabilities are shaped through social contexts and interactions with others and how these interactions influence what people with learning disabilities think and experience about parenthood. As mentioned in Chapter 1, it is important to recognise that the lives of people with learning disabilities are often closely embedded with family members, support staff and other professionals. Throughout adulthood many people with learning disabilities stay living in the family home with their parents or live in residential and supported living accommodation (Mencap 2017). Family members and support workers can therefore play significant roles in the lives of people with learning disabilities and the decisions they make. As well as an interest in what impact these relational networks are having on the reproductive and parenthood possibilities of people with learning disabilities, I included family member and support worker participants to gain further insights into their perspectives on the topic.

3.3 Research design

3.3.1 Pre-Covid-19 pandemic

As detailed earlier, hearing the views of people with learning disabilities was central to this research. During the first year of my PhD, I spent time thinking through and reflecting on how I could make this research as inclusive as possible whilst also being realistic about the time and resources available to me as a PhD student. I was at the planning stage and about to start conducting fieldwork when the first Covid-19 lockdown happened. In this section I set out the initial research design and the progress made to achieve this by focusing on three key areas: the learning disability advisory steering group, ethnographic participant observations with people with learning disabilities, and interviews with people with learning disabilities and support workers.

- Advisory steering group:

In the initial research design, I had hoped to incorporate some aspects of inclusive research by using an advisory steering group made up of people with learning disabilities to help guide elements of the research (see Hollomotz 2018). The advisory steering group would ideally have been made up of approximately two to four people with learning disabilities, both males and females, that would offer multiple perspectives to help shape and inform interview topics and questions. The intention was that the advisory steering group would meet a couple of times to help design the interview questions and take part in a rehearsal of the interview questions to help identify questions and language that may have been difficult for some participants with learning disabilities to understand. It was hoped that the advisory steering group would also be involved in designing fictional vignettes and selecting visual materials about reproductive decision making and parenting scenarios that would have further supported the exploration of the topic with participants. In early 2020, I contacted a local learning disability organisation to introduce myself and explain my research. We met and spoke about the work they do with people with learning disabilities and how they could support my research advisory steering group. The next meeting for me to meet some of the members of the organisation had been arranged but then cancelled due to the beginning of the Covid-19 pandemic and lockdown restrictions.

- Ethnographic participant observations:

In addition to forming an advisory steering group, I had made plans to conduct observations with a learning disability organisation that uses life-size anatomically accurate cloth figures in sexual health workshops for people with learning disabilities. These participant observations could have been an interesting opportunity to understand more about how different people with learning disabilities interact with others and engage with sex education workshops, rather than just relying on the accounts of those who can speak and verbalise their views (see Johnson et al. 2011). Observing people with learning disabilities who may not talk, or feel comfortable talking, was one way of challenging some of the wider issues around inclusivity in research. In late 2019, I contacted and met with the CEO of the organisation, and he agreed I could observe three of the sexual health workshops they were due to run with women with learning disabilities in Spring 2020, however these were cancelled due to the start of the pandemic. The recruitment material prepared for these observation workshops is detailed in Appendix A.

- Interviews:

I had also planned face-to-face interviews with young people with learning disabilities, people with a close family member with a learning disability, and support workers. The hope was to speak with young people with learning disabilities between the ages of 18 and 35 who did not yet have children to focus on how they think about future opportunities to become parents. The plan was to have two ‘waves’ of interviews with each participant with learning disabilities. The first would act as an initial exploration of young people’s views, the second would help to clarify and probe more deeply into some of the points they made. Hollomotz (2018) has called for researchers to be aware of the diverse needs of people with learning disabilities to support their participation in social research, she suggests researchers should take time to get to know the communication styles and preferences of participants before interviewing them. Drawing on what Hollomotz says, I had hoped to be present in day service settings over several weeks getting to know people and find out who might be interested in taking part in the research. Participants with some verbal communication difficulties would have been given the choice of using communication aids such as Makaton[8] or Talking Mats[9] to further support their answers.

One limitation of this planned methodological approach was that both the advisory steering group and interviews would have excluded non-speaking people with learning disabilities as they privilege the spoken word (Welsby & Horsfall 2011). Despite plans to support people with communication difficulties, I found limiting the inclusion criteria to people that could speak difficult because I wanted this research to be as inclusive as possible. However, I needed to be realistic about what approach was feasible and practical for myself to carry out with the resources I had access to. This issue is something I talk about more in Chapter 7.

Whilst retaining a focus on the views of young people with learning disabilities, I also felt it was important to acknowledge the influence others close to people with learning disabilities can have on their parenthood imaginaries. Approximately 10 in-depth semi-structured interviews with family members and paid learning disability support workers had been mapped out in the initial research design. Unlike the two interview waves proposed with people with learning disabilities, I had planned to interview support workers and family members only once. Ethical documentation for this planned fieldwork was submitted in Spring 2020, but these plans were subsequently disrupted due to the pandemic as the next section will describe.

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[8] First developed in the 1970s by speech and language therapists, Makaton refers to a range of signs (gestures) and symbols (pictures) that can be used as an individual's main communication or to support their speech. Unlike British Sign Language, which is used by deaf communities, Makaton is used to support hearing children and adults with learning disabilities or communication difficulties. I attended a Makaton training course to help me learn some of the signs and symbols. See the Makaton website: https://makaton.org

[9] Talking Mats are a communication resource that is used to support and enable someone to communicate their opinions and preferences in the form of pictures (Whitehurst 2007, see Appendix B). Talking Mats can be used with people with learning disabilities to cover a range of different discussion topics and they can be accessed in both physical and digital formats. In preparation for potentially using Talking Mats in this research I attended a one-day training session with the organisation. More information can be found on the Talking Mats website: https://www.talkingmats.com

3.3.2 Research redesign

The pandemic caused significant disruption to the lives of people across the world and in March 2020, as the number of Covid-19 infections and deaths from the disease were rising, the UK went into lockdown and the public was instructed by the government to stop all non-essential contact and travel (Institute for Government 2022). On a personal note, my own health condition marked me as at increased risk of severe illness from Covid-19, so in line with NHS and government guidance at the time I left Newcastle and self-isolated with my parents in Nottingham for 12 weeks. In the wider social context, it must be recognised that disabled people have been significantly affected by the pandemic. In England, the risk of death from Covid-19 was over three times greater for disabled people than non-disabled people (Shakespeare et al. 2021: 1331). This risk was even higher for people with learning disabilities as according to Public Health England young people with learning disabilities aged 18 to 34 were 30 times more likely to die of Covid-19 than people without learning disabilities the same age. For people with learning disabilities living in congregate group care homes the risk of Covid-19 was also significant (Shakespeare et al. 2021).

Throughout the pandemic people with learning disabilities were marginalised and discriminated against in their access to healthcare. It is a scandal that in England people with learning disabilities were given Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices if they were to contract and become ill with Covid-19 (Tapper 2021). Despite DNACPR notices typically being used for people who are too poorly and frail to benefit from CPR, the learning disability charity Mencap said some notices had been issued for people because they had a learning disability (cited in Tapper 2021). As well as these health inequalities during the pandemic, many people with learning disabilities were impacted by their social care provisions being either cancelled, disrupted or put on hold which further exacerbated their social isolation and marginalisation (Shakespeare et al. 2021). These health inequalities and discrimination reinforce the ways the lives of people with learning disabilities are devalued and treated as less than people without learning disabilities.

As well as people with learning disabilities, crucial to this research is an awareness about how the pandemic impacted social care workers. In addition to the increased risk of contracting the disease, the pandemic has had a profound impact on the mental health and wellbeing of staff working with people with learning disabilities (see Care Quality Commission 2022). Alongside increased struggles with anxiety and trauma triggered by the pandemic, the 2021 report published by the Samaritans finds that healthcare workers' suicide risk was also exacerbated by the pandemic. It is helpful to highlight these wider social contexts of the pandemic because they have in some way or another influenced how I redesigned my research methodology and informed when I felt it was appropriate to reach out and engage with different participant groups.

Unaware of the extent to which the world would be disrupted and devastated by Covid-19, during March 2020 I continued to work on my planned methodology and ethics documentation (see Ethical considerations section). However, it soon became apparent that lockdown restrictions were not going to be lifted anytime soon. The pandemic forced me to stop the planned work with learning disability advisory steering groups, participant observations and interviews with people with learning disabilities, family members and support workers. I felt it was not possible to shift these planned interactions straight to online platforms because of the sensitivities around the research topic and the main participant group. There were several practical and ethical issues surrounding the use of online methods with people with learning disabilities that needed to be carefully considered before being able to go ahead with any form of data collection. I did briefly explore whether the use of online forums and chat rooms could be incorporated into the redesign of the research or if a shift to secondary data methods would be more feasible. During this uncertainty, my supervisors suggested not rushing to drastically redesign the research, but rather take the time to carefully think through different possibilities of adapting the plans I had already made.

Before the pandemic, researchers were starting to raise questions about the 'gold standard' of in person interviews (Deakin & Wakefield 2014). For example, Carr and Worth (2001) have suggested some participants may prefer phone interviews when talking about personal or sensitive topics. Seitz (2016) also says some people may feel more comfortable talking about certain issues in front of a screen rather than face-to-face (also see Lo Iacono et al. 2016). While Cater (2011 cited in Lo Iacono et al. 2016) has further argued that rapport building with participants can be challenging in online interviews, Lo Iacono et al. (2016) suggest rapport building, whether in person or online, is largely informed by the personalities of the participant and interviewer. Despite these comments, I still had concerns about how online and phone methodology might work with participants with learning disabilities. I worried whether people would feel comfortable talking to me, as someone they did not know, about their views on learning disability reproduction and parenthood. I was concerned about discussing what could be potentially sensitive topics that could cause upset or distress to some participants in online settings. These issues felt more significant because unlike in the initial research plans, I would not have had the opportunity to get to know or spend time with people with learning disabilities at their support services because of the pandemic and lockdown restrictions. Furthermore, on a more practical note, I did not know how familiar people with learning disabilities would be with using online video technologies such as Zoom or FaceTime.

However, after reading some of the existing disability literature and talking it through with my supervisors and some of my former support worker colleagues, I felt by *not* offering people with learning disabilities the opportunity to take part in the research and to share their views on the topic that I would then be maintaining the oppression that continues to marginalise and exclude them from social research spaces. I therefore felt it was important to offer all participants who wanted to take part the choice of speaking to me by online, either with their camera on or off, or by phone. I did consider conducting online focus groups with people with learning disabilities, but I felt one-to-one online interviews would enable me to gain deeper insights into the personal experiences and perspectives of participants. The research was then redesigned over several months to include online qualitative interviews with people with learning disabilities, family members and paid learning disability support workers.

As well as redesigning the research to shift from face-to-face to online and phone methodology, I also adjusted who would be included in this research. This has been summarised in the table and subsequent text below.

Pre-Covid-19 sample	**Redesigned sample**
• Young person with a learning disability aged 18 to 35	• Person with a learning disability aged 18 or over
• Family member (e.g. a parent) aged 18 or over of someone with a learning disability	• Family member (e.g. a parent) aged 18 or over of someone with a learning disability
• Paid learning disability support worker aged 18 or over	• Sibling aged 18 or over of someone with a learning disability
	• Paid learning disability support worker aged 18 or over

Table 1: Covid-19 sample redesign

I revised the initial plans that had focused on young people with learning disabilities aged 18 to 35 to now include people with learning disabilities aged 18 or over. The justification for this was partly because I thought it might be harder to reach younger people with learning disabilities without having established connections with gatekeeper organisations as I had intended. By changing the age limit to include people aged 18 and above it also meant that older people with learning disabilities who were already parents were able to take part broadening the research focus to also include parenting experiences. Due to the research focus on the ways social contexts shape how individuals understand and experience their learning disability I did not feel it necessary for participants with learning disabilities to have formal medical diagnosis or classifications of their impairment. Therefore, individuals who identified themselves as having a learning disability and were able to communicate verbally in an interview to talk about their views and experiences of parenthood were invited to participate in this research. Only participants with capacity to consent were included, and no individuals expressed interest in the research that did not meet the inclusion criteria. More will be said about capacity and consent in Ethical considerations section later. The inclusion criteria of participants with learning disabilities was purposefully broad in order to capture a range of views and experiences on the topic of learning disability and parenthood.

The pandemic also shaped my decision to specifically target and include siblings of someone with a learning disability. As detailed in Chapter 1, siblings can often be closely involved in the lives of their brother or sister with learning disabilities and they can share unique perspectives of family relational networks. As well as providing new insights about how family members could influence parenting possibilities for people with learning disabilities, I also felt that siblings could help me gain access to people with learning disabilities during the pandemic as lockdown restrictions were still in place. My intention was to ask sibling participants at the end of their interview whether they thought this research would be something their brother or sister with learning disabilities might be interested in, although as I describe later in the chapter, it did not end up working this way.

Siblings and parents of someone with a learning disability who took part in this research did not need to be biologically related, rather they needed to have what they considered a close familial relationship with an individual with learning disabilities. As with all participants in this research, family member participants of someone with a learning disability needed to be aged 18 or over and have capacity to consent (see Ethical considerations section).

The decision to include paid learning disability support worker participants did not change with the disruptions caused by the pandemic. Yet, because of the pressures social care workers were experiencing in the pandemic, I did reflect on and consider the appropriateness of recruiting support staff for the research. I talked about my research with former support worker colleagues to gauge their responses and their positive reaction encouraged me to go ahead with recruitment (see further in this chapter).

3.3.3 Recruitment

Existing literature on disability research has already highlighted some of the difficulties of accessing and recruiting people with learning disabilities for research (see Lennox et al. 2005), and this was something I anticipated experiencing. Recruiting participants was a staggered process that was influenced by the contexts of the Covid-19 pandemic. Before starting recruitment, I created a guide for the order of methods I would use to recruit participants from in each group (see Appendix C). As indicated above, I started by looking to speak with siblings of someone with a learning disability with the idea that this might get me access to people with learning disabilities. Next, I recruited people with learning disabilities, then support workers and parents of individuals with learning disabilities. I used a combination of my existing networks, private disability groups on Facebook, and learning disability advocacy organisations as ways of gaining access to family members, support workers and people with learning disabilities. I had discussed with my supervisors the possibility of using Twitter for recruitment, but I was reluctant in case it led to inappropriate and problematic responses. I was prepared to extend recruitment to Twitter if I was struggling to gain interest and access to participants, but fortunately existing networks, learning disability advocacy groups, and closed Facebook group posts elicited ample interest in the study. The shift to online and phone interviews in response to the pandemic did have some benefits for supporting the recruitment and participation of people in the research. For example, the research was not restricted by geographical location or regional services so by using online and phone interviews I was able to cast the recruitment net wider to access participants from across the UK, rather than be restricted to the local Nort East region. More detail of the recruitment process is detailed in the table below and the three subsequent subheadings: existing networks, Facebook, and learning disability advocacy organisations.

	Existing networks	**Facebook (Personal profile)**	**Facebook (Private group)**	**Learning disability advocacy organisations**
People with learning disabilities	1	0	3	17
Sibling of someone with learning disabilities	3	3	4	0
Parent of someone with learning disabilities	1	0	2	0
Support worker	2	0	1	0

Table 2: Participant recruitment methods

- Existing networks:

In total, seven participants were recruited from existing networks. One participant with learning disabilities who took part in this study was known to me as I used to work as a support worker at the day service she attended. A former colleague of mine who also worked at the day centre knew about my research as we had stayed in touch and offered to talk to her about the study to see if it was something she was interested in taking part in. To support this conversation, I emailed my former colleague a link to the study website I had made as well as copies of the participant information sheet and consent form for people with learning disabilities (see https://research.ncl.ac.uk/parenthoodstudy/ and Appendix D). I then liaised with staff to set up a phone call with her where I spoke in more detail about the research and the interview was scheduled for a few days later. This staggered process of having an initial conversation with potential participants with learning disabilities is described in more detail later in his chapter. Three siblings of someone with a learning disability were recruited through my existing network connections. Two siblings were former colleagues who kept in touch and often asked how I was getting on with my research and wanted to be involved in the study. Contact with another sibling was made through a connection with a PGR friend. Two support worker participants who were known to me when I was working in the role knew about my research from conversations I had with them when I started my PhD and said they wanted to take part. In addition, one parent of someone with a learning disability heard about my research from family connections and said she wanted to be interviewed. All participants contacted through existing networks were sent a link to the study website as well as participant information and consent forms before interviews took place (see Appendix D, also see Ethical considerations).

I was aware that not all people with learning disabilities may be able to utilise or access the internet to read the information sheets, so I collated several participant information packs that were printed out in A4 booklet format. These printed information packs contained: a pack summary sheet, easy read participant information sheet, easy read consent form, an interview 'stop' card and a 'I am feeling…' card (see Appendix E). When participants said they were interested in taking part I asked whether they would like an information pack sent to them in the post or whether they preferred to look at the materials online. All participants with learning disabilities said they preferred to access the information online or asked me to read it out to them so it turned out that no information packs were posted.

- Facebook (personal profile and private groups):

At each stage of the recruitment process I posted a Facebook post on my personal account calling first for siblings of someone with a learning disability, then people with a learning disability, then parents of someone with a learning disability (see Appendix F). I did not post the call for support workers on my personal Facebook group because I already had participants interested from my existing network connections and the closed Facebook group call (see below). Three siblings of someone with a learning disability were the only participants recruited from my personal Facebook post.

In total, 10 participants were recruited from private disability Facebook groups. At the same time as posting participant call outs to my personal Facebook page I requested to join 12 closed disability Facebook groups. I spent time searching on Facebook for groups that had disability or learning disability in their titles to help narrow the traffic to people who I felt may fit the inclusion criteria, or perhaps knew someone who did. To join these closed Facebook groups, I had to gain permission from the group administrator. For each group I requested to join I sent a short summary of who I was, why I was asking to join the group and asked whether it would be possible for me to share a call for recruitment. I did this because I wanted to be transparent about my motives for joining the groups and to minimise any backlash from members about using the space inappropriately. All groups that accepted my request to join then gave permission for me to submit a post about the research which consisted of an image of the recruitment poster and some supporting text (see Appendix F). I sent every person that said they were interested in taking part a direct message on Facebook asking for their email address so I could send them more information about the study.

- Learning disability advocacy organisations:

17 participants with learning disabilities were recruited from learning disability advocacy organisations. No other participant groups were recruited this way. I reached out by email to 12 regional learning disability advocacy organisations based in England to inform them

about the research and ask whether any of their members might be interested in taking part (see Appendix F). A few of these organisations did not reply, and a couple said this was not something they were able to support at the time due to the pandemic. The other responses I received from some advocacy organisations ranged from offering to share the information with their members and four invited me to do an online presentation and Q&A session via Zoom with their members. The number of people with learning disabilities in these sessions ranged from five to 20 and the presentation sessions lasted between 15 minutes to one hour. The recruitment response from the four presentations was positive with only one group saying that none of their members were interested. Members who were interested in taking part either contacted me directly or staff passed on their details on to me. For people with learning disabilities who were interested in taking part but who were not involved in the online presentation and Q&A sessions I arranged phone calls with them to talk more about the research.

During these conversations I introduced myself as a researcher at Newcastle University looking to hear their views about the topics, I stressed that I was not linked to any social services organisations. I spoke about my background as a learning disability support worker, explained what the research was about and what would be involved if they decided to take part. I talked through the easy read participant information sheet (see Ethical considerations and Appendix D) and highlighted some of the topics I would be asking them about (e.g., family, relationships and children). The importance of making participants aware of potential topics that will be discussed in advance is also noted by Gant (2018). I also used this time to find out about their style of verbal communication, capacity to consent (see Ethical considerations later) and the kinds of support networks they had for talking to people close to them about the research. These initial conversations also gave people with learning disabilities the opportunity to ask me any questions they had about me or the research and we then arranged a date (usually a few days later) to conduct the interview. This staggered process of an online presentation and Q&A session or phone call with potential participants and then conducting the interview sometime after was a deliberate response to the shift to online methodology. These multiple interactions enabled me to build trust and rapport with people with learning disabilities, it gave them more time to think about the research and ask me questions.

I wanted to ensure participants felt they had access to support both before and after speaking with me if they needed; this was important for informing my decision whether to go ahead with the interviews (they all did). I explained they could choose to have someone with them when they did the interview, if that is what people with learning disabilities wanted, and said they could choose to speak to me by phone or online – it was their choice. Giving people with learning disabilities some choice and autonomy about how they took part in the interview reinforces the epistemological positioning of empowerment and inclusivity that guides this research. 13 participants with learning disabilities from the same advocacy organisation chose to have a paid staff member with them on the interview. Before starting the interviews, I gently reminded participants that staff should not answer the questions for them because it was important I heard what they thought about the topic; I took the opportunity to say this whilst staff were present on the video call as a polite reminder to them as well. As requested, staff that were present rarely spoke during the interviews and the times staff did talk was to remind and reassure participants that the interview was not a test. Staff from the advocacy organisation who sat in on interviews with some people with learning disabilities seemed to align with the social model of disability as they were supportive in their roles, enabled participants with learning disabilities to answer questions freely, and did not act as secondary participants (see Llewellyn 2009). After participants left the Zoom meeting staff would often add further comments to some of the points participants had made, these comments were not included in the transcriptions, but they did help me understand and contextualise what participants had talked about during their interview. I was initially a little nervous about having staff sitting in on some interviews for fear of being judged on my research or my skills as a researcher, but the staff were very kind and supportive towards me, as well as the participants with learning disabilities.

All participants could choose whether they wanted to talk to me via video call either with their camera on or off, or by phone. For those that chose to speak by Zoom video call I sent out a meeting invite by email that required them to use a passcode, the passcode was sent in a separate email for security purposes. At the start of the interviews that took place via video all participants had their microphones and cameras on – I did tell people with learning disabilities that they could turn their cameras off if they felt more comfortable (but none of them did). Most participants with learning disabilities told me they felt confident using Zoom because most of their advocacy group meetings had been moved to the online platform during the pandemic and some said they had been using Zoom to stay connected with family and friends. I did expect I might have to prompt some people to unmute themselves, but I did not need to do this. All participants were informed before taking part in the research that they would also receive a £10 gift voucher as a token of thanks for giving their time to participate (see Interviews and Ethical considerations sections).

There are both limitations and advantages of recruiting people with learning disabilities through gatekeepers. I found a benefit of recruiting via learning disability advocacy organisations was that staff knew interested participants well and would often share information about their background and experiences to help me support them in the interviews. For instance, during one email conversation with staff at an advocacy organisation they told me about a member they supported who said she would like to be involved in the research, but she had a few worries. Staff explained to me that the member had experienced child removal and she found it hard to talk about it sometimes, they also said she was worried I might ask too many questions at once that might confuse her. I was grateful for this information before arranging to speak with her. Another benefit of using learning disability advocacy organisations to recruit from was members with learning disabilities had already established trusting relationships with staff and many chose to have staff sit in on the interviews with them for support. As I suggest throughout this thesis, staff were not to act as proxy for what people with learning disabilities had to say, rather they were there in a supportive capacity and to help them feel more at ease speaking to me. During the interviews with people with learning disabilities, many talked about the positive impact their advocacy organisation had had on their lives.

While some advocacy group staff enabled me to reach out to people with learning disabilities for them to make their own decisions about participating in the research, this was not the same for every organisation I contacted. For example, during a phone call I had with a manager of a Down’s syndrome support organisation, she explained that she did not feel entirely comfortable supporting the participation of the group members in the research. She said she felt it would be upsetting for people with Down’s syndrome to talk about the topics because of the high rates of infertility, particularly of men, with the condition (see Parizot et al. 2019). Whilst she wanted to protect the people she supported from potential distress, in doing so she denied them the opportunity for them to make their own decisions about whether to participate.

Similar instances of other people gatekeeping opportunities of people with learning disabilities to learn about and potentially take part in the research was restricted by parents of people with learning disabilities. At the end of some sibling interviews I asked whether they thought this research would be something their brother or sister with learning disabilities might be interested in. I did not ask all siblings this as I used my own judgements based on what siblings had told me in the interviews about their brother or sister and whether I felt it would be appropriate. After an interview with a sibling participant, she told me she thought her sister with learning disabilities may also like to hear about the research. However, on the day I was expecting to speak with her sister with learning disabilities to explain the research and ask if she wanted to take part, I received a message from their mother cancelling the meeting. Their mother said she felt it would be ‘cruel’ to ask someone to think about something that will never happen. I replied by politely thanking her for letting me know and wished them well.

I felt frustrated that the person with learning disabilities appeared to have no say in whether she spoke to me or not. I did reflect for a short time on whether it was indeed cruel of me for wanting to speak with people with learning disabilities about this topic, and this was something I talked through with my supervisors. Yet I do believe individuals with capacity to consent should be supported to make their own decisions about research participation which connects to my epistemology: that notions of protection should not exclude or deny people with learning disabilities their right to choose (see Santinele Martino 2022). These examples highlight the powerful role staff and family members can have as gatekeepers by restricting opportunities of people with learning disabilities to make their own decisions about participating in social research. While this section has illustrated some of the tensions of recruiting participants with learning disabilities through staff and family members close to them, I have also described how I found the support and insight from staff incredibly useful as it enabled me to learn about the people I was going to speak to.

Three people, one with learning disabilities and two siblings of someone who had a learning disability, that had previously said they were interested in taking part pulled out of the study before their interviews has been scheduled. Reasons for this were two family emergencies and one said they were too busy. I asked them all if they wanted to reschedule; one said no, and I did not hear back from the other two. Conscious of the unique circumstances we were living through at that time, I chose not to pursue this further.

3.3.4 Sample

Participant group	**Number**
People with learning disabilities	21
Sibling of someone with learning disabilities	10
Parent of someone with learning disabilities	3
Paid learning disability support worker	3

Table 3: Participant groups

In total, 37 participants took part in this research. This consisted of 21 people with learning disabilities, 10 siblings of someone with a learning disability, three parents of someone with a learning disability and three paid support workers. No participants in this study were related to one another. The decision to interview only three parents of people with learning disabilities and three support workers was largely guided by my epistemological positioning and my aim to centre the views and voices of people with learning disabilities. I was also sensitive to the way that parents of people with learning disabilities tend to have a bigger presence within social research than people with learning disabilities themselves.

At the start of the interviews all participants were asked demographic questions (see Appendix H). 21 participants with learning disabilities took part in this research and an overview of the demographic information is provided in the table below. The names of participants have been anonymised (also see Ethical considerations):

Name	**Gender**	**Age**	**UK region**	**Type of home they live in**	**Type of school they went to**	**Do they have children? (Number of children)**
Aimee	F	30s	North West	In-between homes, staying with family member	Mainstream	No
Azeem	M	30s	London	Family home	SEND	Yes (3)
Billy	M	20s	Yorkshire	Family home	Mainstream and SEND	No
Bob	M	40s	North West	Family home	SEND	No
Caitlin	F	20s	North West	Residential home	Mainstream	No
Fiona	F	30s	Northern Ireland	Independent	Mainstream	Yes (1)
Hazel	F	30s	North West	Independent	SEND	Yes (1)
Jenny	F	30s	Midlands	Independent	SEND	Yes (2)
Jodie	F	30s	East Midlands	Residential home	SEND	No
Linda	F	40s	North East	Residential home	SEND	Yes (1)
Maisy	F	40s	North West	Residential home	SEND	No
Michael	M	70s	North West	Independent with support	Institutions	No

Peter	M	50s	North West	Independent	SEND	No
Pippa	F	50s	North West	Independent	SEND	No
Ric	M	50s	North West	Supported living	Mainstream and SEND	No
Rory	M	40s	North West	Family home	SEND	No
Ruby	F	20s	East Midlands	Family home	Mainstream	No
Ryan	M	40s	North West	Family home	SEND	No
Tracy	F	50s	North West	Independent	Mainstream and SEND	No
Vanessa	F	40s	South East	Independent with support	Mainstream and SEND	No
Wendy	F	50s	North West	Independent	No schooling	Yes (2)

Table 4: Demographics of participants with learning disabilities

Eight males with learning disabilities and 13 females with learning disabilities took part in this research and their ages ranged from 22 to 70. Most of the participants identified themselves as white British except one male who identified as British Pakistani. As part of the demographic questions at the start of the interviews, participants with learning disabilities were asked about the type of home they lived in. The rationale for this was to explore the heterogeneous spaces that people with learning disabilities live in and consider how where and who they live with may influence their views and opinions of reproduction and parenthood. Participants with learning disabilities lived in a range of accommodation: seven lived in the family home, five said they lived in residential or supported living accommodation, and nine described living independently[10].

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[10] Some participants who said they lived independently described receiving occasional visits from support staff.

10 sibling participants of someone with learning disabilities took part in this research. An overview of their demographic information as well as their brother or sister with learning disabilities is outlined below.

Name	**Gender**	**Age**	**UK region**	**Name of brother or sister**	**Gender**	**Age**	**Type of home they live in**	**Type of school they went to**	**Do they have children?**
Abigail	F	Late teens	West Midlands	Luke	M	Mid-teens	Family home	Mainstream and SEND	No
Amanda	F	50s	North East	Iris	F	60s	Independent living	Unsure	No
Amber	F	20s	East Midlands	Dylan	M	Under 12	Foster care	Mainstream and SEND	No
Conor	M	30s	East Midlands	Chloe	F	20s	Family home	Mainstream	No
Elaine	F	50s	South West	Sheila	F	60s	Family home	SEND	No
Evie	F	20s	London	Finn	M	Mid-teens	Family home	Mainstream and SEND	No
Francesca	F	30s	South West	Daisy	F	20s	Supported living	Mainstream and SEND	No
Lara	F	30s	East Midlands	Jason	M	30s	Family home	Speech and language school	No
Olive	F	70s	North East	Alison	F	60s	Independent living	Mainstream and SEND	No
Stella	F	40s	East Midlands	Essie	F	30s	Family home	Mainstream	No

Table 5: Demographics of sibling participants

Three parents of someone with a learning disability took part in this study and their demographic information is displayed in the table below alongside information about their son or daughter with learning disabilities.

Parent name	**Gender**	**Age**	**UK region**	**Name of son or daughter**	**Gender**	**Age**	**Type of home they live in**	**Type of school they went to**	**Do they have children?**
Imogen	F	30s	Scotland	Alec and Harvey	M and M	<16 and <16	Family home	Mainstream and SEND	No
Judith	F	60s	East of England	Ralph	M	30s	Residential home	Mainstream and SEND	No
Lorraine	F	50s	South West	Gabby	F	20s	Residential home (term time) Family home (weekends and holidays)	SEND	No

*Table 6: Demographics of non-*learning-disabled *parent participants*

Three support worker participants were interviewed for this research and an overview of their demographic information is outlined below.

Name	**Gender**	**Age**	**UK region**
Freya	F	20s	Scotland
Gus	M	60s	East Midlands
Huw	M	40s	East Midlands

Table 7: Demographics of support *worker participants*

3.4 Interviews

This section will say more about: how the interviews with all participant groups were planned and developed; how the interviews were conducted; how all participants were debriefed afterwards; and reflections from the interviews. I drew upon my own experiences as a learning disability support worker and the academic literature to inform the interview questions and how I conducted the interviews. I decided to use open-ended semi-structured interview questions because they provide some flexibility for participants to talk about issues that are important. This methodology also connects to my epistemology that centres the perspectives of participants and how they understand the world around them through experiences and interactions with others. Interview questions for each participant group were designed and re-drafted over several months with the support of my supervisors (see Appendix G). Reflecting the order of planned participant recruitment (detailed earlier), I first designed the interview questions for siblings of someone with a learning disability, then for people with learning disabilities, followed by support workers and parents of someone with a learning disability.

I shared the questions and rehearsed the interviews for each group of participants with two friends without learning disabilities who have experience of supporting people with learning disabilities for their feedback. I asked for their comments on the themes and topics I wanted to discuss with participants, as well as the accessibility of the questions for people with learning disabilities. This feedback led me to change some of the questions to be more open-ended and to avoid asking questions that seemed similar or repetitive. Setting the interviews without input from people with learning disabilities was challenging because it was difficult to know how participants with learning disabilities would find the topics and wording of the questions. As mentioned earlier, my initial plans to get input from a learning disability advisory steering group and opportunities to spend time with potential participants with learning disabilities to get to know them and their communication styles before doing the interviews were disrupted by the pandemic.

Before starting the fieldwork, I was torn whether I should share the interview questions with participants with learning disabilities before conducting the interviews. While it was possible that this would have enabled participants to discuss the topics with other people and suggest other topics to explore, I was worried that it might affect the spontaneity of responses and that other people might interfere by telling them what to say. One participant with learning disabilities asked if I could send him a list of the questions before the interview and I said of course I would do this. I enlarged the font and spent some time reducing the amount and length of the questions to make it easier for him to read (see Appendix G). Looking back, I think sending the questions before the interview may have limited the depth of conversation because I was reluctant to ask other probing questions if he had not read them in advance. On the other hand, having the opportunity to look at the questions in advance supported his participation in the study. I am still unsure about whether my decision not to share the questions with most participants with learning disabilities before the interviews was the right thing to do. On reflection, I should have asked participants with learning disabilities whether they would have liked to see the questions before the interview; this is a point to learn from and take forwards in future research.

3.4.1 Conducting the interviews

The interviews were conducted between September 2020 and April 2021 and Table 8 below shows what technologies participants from all groups chose to use in their interview. In total, 23 participants across different groups chose to talk to me via Zoom video call and 13 chose to be interviewed by phone.

	Zoom video call	**Phone call**
People with learning disabilities	16[11]	4
Sibling of someone with learning disabilities	4	6
Parent of someone with learning disabilities	2	1
Support worker	1	2[12]

Table 8: *Participant interview choice of methodology*

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[11] Two participants asked to be interviewed by video call together. I have counted this as one interview.

[12] One of these had started as a video call (camera on) but internet connection issues meant it changed part way through to a phone call. Not ideal, but it was a flexible response to the online methodology I was working with.

I was acutely aware of the infantilisation some people with learning disabilities can experience and it was therefore important for me to treat participants like adults (Santinele Martino 2022). Kellet (2010) urges others to speak more slowly and avoid using complex vocabulary when communicating with people with learning disabilities which I tried to do (also see Nind & Vinha 2014). Before recording the interviews, I introduced myself to all participants as a postgraduate researcher and as someone who had previously worked as a support worker for people with learning disabilities. All participants gave their consent for me to record the interviews which was done either by the Zoom record function or by the recording software on my laptop (see more in Ethical considerations). In telephone interviews I found it worked well putting participants on speaker phone then placing my phone as close to my laptop as possible to record the conversation.

After all participants had confirmed their consent, I asked them the relevant demographic questions. As indicated earlier, while the main purpose of asking demographic questions to all participant groups was to help me analyse the data later, but by asking these questions at the start of the interviews it enabled me to get to know participants and build rapport with them (e.g., talking about the areas they lived for instance). As well as the demographic questions I tried to help all participants ease into the interviews by asking them why they wanted to take part in the research. The responses to this varied from some saying it sounded interesting or they wanted to help, to some participants with learning disabilities saying they wanted to make a difference by warning other people about their experiences of parenthood and child removal (see Chapter 6).

I thanked participants for answering the demographic questions and then moved on to start asking the interview questions (see Appendix G and Appendix H). I had anticipated phone interviews being shorter than video calls, but this was not always the case; both phone and interviews varied from 20 to 90 minutes. Interviews with people with learning disabilities ranged in duration from 20 minutes to just over one hour. I was aware that if interviews lasted too long then some participants with learning disabilities might find it difficult to concentrate, which is something Hollomotz (2018) has highlighted in her research. Most interviews with participants without learning disabilities lasted around one hour. Interviews with participants known to me typically lasted longer; for instance, two support worker interviews with former colleagues for lasted around 90 minutes. I suggest as they knew me, they felt comfortable talking in detail with me about their views and experiences on the topic. Although there were times in these interviews when discussions did stray from the focus into broader disability issues, I gently tried to steer it back towards parenting.

Two participants with learning disabilities wanted to be interviewed by video call together. They were in a long-term relationship together and took it in turns responding to the questions and would often say things like *'it's your turn now'* when they felt it was time for the other person to speak to me. I felt neither of them dominated the interview and by talking together they seemed to bounce of what each other had said. Perhaps interviewing them both separately might have enabled me to probe or follow up their responses in more detail but taking part in the research together was something they both wanted to do. Indeed, dyadic interviews with couples with learning disabilities or siblings could be an interesting extension of this work particularly around the topic of reproduction and parenthood (for more on dyadic interviews see Morgan et al. 2013).

I tried to be both flexible and adaptive in my interviews with participants with learning disabilities and I would adjust the depth of questioning depending on how much I felt participants understood and what they said back to me (see Hollomotz 2018). For example, some participants with learning disabilities often gave longer, more detailed, and more comprehensive answers to the questions than others. Also, from what some people with learning disabilities said about the topics of sexuality and relationships, it was clear that this was something many of them had talked about before. Some participants with learning disabilities told me about other research projects they had taken part in previously and one person told me she had been asked *'way harder'* questions about her parenting experiences before. This reinforces the comments made earlier about research with people with learning disabilities that tends to include certain kinds of people that can verbalise and talk about their perspectives, and I will say more on this in the concluding chapter. As well as telling me about other research they had previously taken part in, some participants with learning disabilities told me about the various sexual and reproductive health and parenting courses and workshops they had accessed through their advocacy organisations. This was useful to know because I was able to ask them to tell me more about the kinds of things they had been learning about and probe more into the topics.

At various points throughout all the interviews I asked participants how they were feeling about the questions. I would also sometimes indicate the theme of the next questions to check if it was something they felt comfortable talking about. When asked how they had found the questions, overall, most participants from the different groups said they felt *'good'* or *'fine'* answering the questions. However, a couple of participants with learning disabilities said they found it difficult talking about their experiences of abuse and institutionalisation, but they told me they thought it was important for other people to hear their stories and said this was a key motivation for taking part in the research.

I sensed some discomfort in a small number of participants with learning disabilities that replied with shorter answers so I tried to reassure them there were no right or wrong answers and that I was interested in what they thought about learning disability and parenthood. On two occasions, advocacy staff sitting in on the interviews also reminded participants that *'it's not a test'* and said, even if they did not know an answer that would be helpful to my research. This reassurance seemed to put these participants with learning disabilities at ease as they went on to reply to questions in more detail. For some participants with learning disabilities who found it difficult to articulate their ideas I rephrased questions and used more closed questions (Fitzgerald & Withers 2013). At times I would try to summarise my interpretation of what I felt they were saying by repeating it back to them and ask whether what I had understand them say was correct or not. For the few participants with learning disabilities who still replied with *'yes'*, *'no'* or *'don't know'* answers I sensed they might be struggling so I decided to ask them more general questions about themselves and the sorts of activities they liked (e.g., did they have any pets or what kind of music they listened to). I did this to distract and help those who seemed to be struggling to feel more comfortable before then drawing the interview to a close.

I made a point of asking all participants from the different groups at the end of the interviews how they felt about the questions and if there was anything else they thought I should ask or that I might have missed. For example, a sibling of someone with learning disabilities said I should ask whether having a brother or sister with learning disabilities impacts how other siblings think about their own reproductive options, so I added this question in for future interviews with siblings. Most participants with learning disabilities did not suggest other topics or questions for me to ask others about, but a couple did reemphasise how unfairly people with learning disabilities were discouraged and prevented from having children and the importance of genetics, I then adjusted my questioning to focus more on these issues.

Once the recordings had stopped, participants were asked if they had any questions for me about the research or anything we had discussed. Most said they did not, however a couple took this opportunity to ask me questions about myself. For example, some participants with learning disabilities asked me if I had children to which I replied honestly and said I did not but perhaps it was something I might think about in the future. I did not share any other information about myself unless participants asked. I was not deliberately trying to be secretive, but I was keen to provide ample space for participants to share *their* views and experiences on the topic. With the support of my supervisors, I made the decision prior to conducting the fieldwork that if participants did ask me questions about myself then I would answer them honestly; I felt that if I was expecting them to be open and honest responding to my questions, then it was appropriate for me to do the same. Interestingly, some siblings also asked me if other sibling participants had talked about similar experiences, particularly in relation towards the ‘duty’ and ‘burden’ of care responsibilities. I suggest perhaps wanting to know what others had said points towards the isolation that some siblings can feel, as some said there were few opportunities to connect with other siblings who might share similar experiences.

Before ending the video or phone call, I verbally debriefed participants by reminding them what would then happen with their responses, the recordings, and the writing up of the research. I signposted them towards learning disability organisations that could help if they wanted support with any of the issues we had discussed. Finally, I reminded them of mine and my supervisors contact details if they had any other questions or concerns about the research. After their interview, each participant received a copy of the research debrief sheet (see Appendix I) and their £10 Amazon thank you voucher (see Ethical considerations section) by email, or in the post as one participant with learning disabilities requested.

Some participants with learning disabilities asked me to contact a staff member at their organisation after the interview to tell them how ‘well’ they had done. I told them I would of course do this, but I also reminded them that my role was to hear their views on the topic and that there were no right or wrong answers. I also suggested that participants might find it useful talking to a staff member, or someone close to them, about the interview if they wanted to talk about any of the topics in more detail. In instances where staff from advocacy organisations were not present during the interviews, most staff said they would arrange their own debriefing call with people with learning disabilities to check in on how they were feeling afterwards. I found it reassuring that staff were supporting their members in this way, particularly as I did not know participants very well.

Throughout the interview and transcription process I kept a short reflective diary which I used to help adjust and improve my interviewing style and technique. This enabled me to gain more in-depth responses from participants which then gave me more detailed insights into their views and experiences on the topic of learning disability and parenthood. As a relatively inexperienced researcher I relied quite heavily on the interview guide and in the early stages of data collection I think I utilised it more as a script rather than a guide. However, this was problematic because I tried to ask participants *all* the questions I had mapped out which meant interviews often felt rushed. Once participants had answered a question, I would often move straight on to the next without following up or probing what they had said more closely. This was something my supervisors flagged when I shared the first interview transcript with them. During the early interviews I did not anticipate that genetics would become a key focus of my research and looking back there were missed opportunities to explore this theme further with participants who mentioned it. Perhaps due to a combination of nerves and inexperience, I also noticed whilst transcribing the first couple of interviews that I tended to ask participants more than one question at a time, and not give them enough time to think about and respond to the question. Despite these mistakes, my skills and confidence as a researcher developed throughout the interview process. For instance, I grew more confident in being able to ask *why* participants felt something to be the case or asking them to say a little more about a point they had made, whereas in the earlier stages I was perhaps shy about asking those probing questions. Transcribing after each interview, where possible, also alerted me to instances where I could talk too fast and to questions that could be asked more clearly in the next interviews.

3.4.2 Reflecting on interview methodology

Using phone and online methodologies with people with learning disabilities raises questions about the reliability of phone and internet access. As this thesis has described, people with learning disabilities can experience barriers to accessing phone and internet platforms that may have excluded some people from participating in this research. Furthermore, those who may be reliant on support from others to set up online communication platforms may have been restricted in participation opportunities. Limitations of using phone and online methodologies can be extended to issues with finding private spaces, interruptions and unreliable phone and internet connections.

Lockdown restrictions were in place during much of the data collection process so most participants, like me, seemed to be taking part from home. This meant some aspects of managing confidentiality and disruptions were out my control. For example, some participants, especially those with learning disabilities, suggested finding a private space at home to talk about sensitive topics could be difficult. One participant with learning disabilities lived in supported accommodation and she spoke to me from the laundry room, she said it was the only space she felt she could talk with me in private (although a staff member did walk in during the interview). Participants who spoke with me from their bedrooms were conscious that others in the house might overhear the conversation, one participant with learning disabilities got up part way through his interview to close the bedroom door as he told me he did not want his parents to overhear what he was saying.

Another drawback I experienced when conducting online interviews were interruptions. For example, some participants were interrupted by family or staff members walking into their room. Other interviews were disrupted by their phones ringing and two participants asked to pause the interview to take the call; perhaps on reflection before starting the interviews I could have asked participants to put their phones on silent to minimise disruptions. Hearing a knock at the door, children and pets also interrupted some interviews. I politely asked one participant with learning disabilities to turn his radio off before starting the interview to reduce the disruption. This lack of control over participants' physical environment I experienced during online and telephone interviews is also a limitation of online methodology described by Lo Iacono et al. (2016).

Another challenge I experienced during online data collection was the unreliable internet connection and this seemed to be an issue myself and participants often encountered. Throughout the data collection stage, I did try to mitigate against poor internet connections by disconnecting other Wi-fi devices and switching to my mobile hotspot on when the Wi-fi connection seemed unstable. During one video call with a support worker the connection was so poor we switched to speaking over the phone. In some of other interviews where the internet connection was unreliable, I asked participants to repeat what they had just said to ensure I had heard their views. Other researchers have noted how these technical issues can create a loss of intimacy between the researcher and participants (see Lo Iacono et al. 2016; Seitz 2016). There were times when telephone interviews were particularly challenging because of the lack of non-verbal cues and there would be times when I would interrupt participants thinking they had finished what they were saying.

While there are challenges communicating by phone and online as non-verbal cues and body language can be harder to read at times (Carr & Worth 2001), it is also important to acknowledge that for some participants, especially those with learning disabilities, phone and online participation enabled them to take part in spaces they felt comfortable in. For example, having the flexibility to talk on the phone was something some participants said they liked because it meant they could speak to me without worrying about making eye contact. While the shift to online methods was made in response to the pandemic, it has been instrumental in supporting the participation of people who may have otherwise been excluded from sharing their views and opinions on the topic. I will revisit this point in the final chapter as this flexible and inclusive approach is something researchers can benefit from using beyond the pandemic.

3.5 Analysis

I used thematic analysis to analyse the interview transcript data from all participant groups. Thematic analysis is a flexible approach that provides a useful way for researchers to identify, analyse and interpret themes within the data (Braun & Clarke 2006). It has also been highlighted as a useful tool for relatively inexperienced researchers, like me, to work with (see Nowell et al. 2017; Braun & Clarke 2006). Braun and Clarke (2006) have identified six steps for conducting thematic analysis that consists of: familiarisation with the data; coding; generating themes; reviewing themes; naming and defining themes; and writing up the analysis. The coding process involves identifying small points of interest within the data which then can be developed to inform broader themes that are then used to organise the data and respond to the research questions (Clarke & Braun 2017). Thematic analysis can be deductive (top-down) where the analysis is shaped by pre-exiting theory and concepts, or inductive (bottom-up) where the themes are driven by the data. I used an inductive approach in my analysis of the data in this research which I will now go on to describe in more detail.

I transcribed all the interviews myself into Word documents and these were stored on the Newcastle University secure network (see more in Ethical considerations). For interviews that took place via Zoom I considered using the platform's transcription software but decided against this because of the inaccuracies I found when testing it. Instead, I found that by doing the transcriptions myself I was able to reflect on what participants had said and familiarise myself with the data. While I was doing this transcription work, I kept a note of some issues participants talked about that would inform the coding process later. Much like the data collection process, the transcription and early analysis was a staggered process that started with transcribing, printing out, and re-reading the interviews before coding. Despite having received some analysis software training (e.g., NVivo) as part of my postgraduate research certificate training, I preferred printing out and manually annotating and analysing the transcripts with coloured pens, mind maps and sticky notes (see Appendix J). Dollah et al. (2017) have said that using analysis software has its drawbacks because of the length of time it can take researchers to understand and use the technology confidently and further suggest that it does not help with the way researchers interpret the data.

To help me manage and organise the early analysis work, I began transcribing and analysing the interviews from different participant groups separately starting with siblings of someone with a learning disability. This process of analysis also reflected the order that I interviewed different participants in as mentioned previously. After I had transcribed and refamiliarized myself with some of the interview transcripts, I set out coding the data. Working through one transcript at a time I made handwritten notes in the page margins about codes that I was identifying. Next, I wrote the different codes I had identified onto sticky notes that I put in front of me to help visualise the sibling data. By doing it this way, I was able to move the sticky notes around and group the codes I had identified into emerging themes that I was seeing within the data. I then started creating a series of sticky notes and mind maps illustrating the themes I was starting to generate which also helped me start to see how the data could be tied together (see Appendix J). This process of creating and refining sticky notes and mind maps was time consuming and daunting in the sense that I felt so much of the data was interesting and it was difficult at this point zoning in on what I wanted the research to say. As mentioned earlier, the staggering of the different interviews also enabled me to respond to themes that I was finding in the data and adjust the questions for the other groups. For example, genetics was not something I initially envisaged participants talking in much detail about but from some of the early conversations I had with sibling participants and people with learning disabilities, I included this topic in interviews with other people with learning disabilities, parents of someone with learning disabilities and support workers. I repeated this process across all participant groups by coding interviews with people with learning disabilities, then parents of someone with a learning disability and finally support workers.

Once I had refined and defined the research themes from the sticky notes and mind mapping exercises, I created a Word document where I could pull together participant quotations alongside the themes that I had identified. This copying and pasting exercise worked as I was able to merge quotations from different participant groups together; for ease, I colour coded people with learning disabilities, siblings, parents and support worker participants. From here, I then began writing up some of my analysis. As I had started with sibling participants, my first written analysis focused a lot on what they had told me; for example, I felt drawn to their experiences of kinship, family expectations and the future uncertainties about fulfilling caring responsibilities for their brother or sister with learning disabilities. I also used what people with learning disabilities had told me to further shape the coding structure and identify key themes for starting to write up preliminary analysis. For example, some people with learning disabilities identified experiences of living in supported living accommodations and how this shaped dating and relationship opportunities as well as parenting possibilities. The experiences of some parents with learning disabilities having their children removed was also an area that guided my early writing. There were times during the analysis stages that I found the data overwhelming and I was looking beyond the topics of reproduction and parenthood. Refocusing on the narrative and argument that I wanted my thesis to tell took time, but I found that going back to my earlier notes from transcribing the interviews pulled me back to parenting possibilities, the influence of powerful others, surveillance and social ideas of unfit and incapable parents.

To make it clear which perspectives are being described in the subsequent data chapters, I have indicated the voices of different participant groups by using pseudonyms and referring to them as either: participants with learning disabilities, parents with learning disabilities, sibling participants, non-learning-disabled parent participants or support worker participants. Sibling participants are people with a brother or sister with a learning disability and non-learning-disabled parent participants are parents of someone with a learning disability. The ages of participants are also detailed when using quotations to provide further context to what is being said.

3.6 Ethical considerations

As indicted earlier, initial ethical documentation was submitted to the university ethics committee based on the original research plans. Approval was given in early April 2020 with the caveat that any changes to the research project would need to be considered through the amendment process. After redesigning the research an amendment request was submitted and approved in July 2020.

3.6.1 Informed consent and the Mental Capacity Act (2005)

Central to my research was the inclusion of people with learning disabilities; a group often marginalised and excluded from sharing their voice in social research (as mentioned previously). To safely include people with learning disabilities as informed and consenting participants I drew heavily from the Mental Capacity Act (2005). The Mental Capacity Act applies to people aged 16 and over and is designed to empower and protect decision making of vulnerable individuals. The Act is underpinned by five key principles (Mental Capacity Act 2005, Section 1):

1. Capacity must be presumed
2. People must be given appropriate information for them to make their own decisions
3. People have the right to make their own decisions even if these are considered ‘risky’ or ‘unwise’ by others
4. Any decisions made for or on behalf of people without capacity must be made in their best interests
5. Any decisions made for or on behalf of people without capacity should be the least restrictive intervention on their rights.

The Mental Capacity Act further details four core ways to help someone make a decision: providing relevant information, communicating in a way the person can understand, helping them feel at ease by being aware of how time, location and other people could affect decision-making, and considering if anyone else could support them to make a decision. Mental capacity can be assessed by whether a person is able to understand, retain and use information and to communicate their decision. If all steps have been taken to support someone but they do not have capacity to make that decision, then a ‘best interest decision’ must be made on their behalf by a ‘decision maker’; this is often someone close to the person such as a family member or support worker (Mencap 2023c). Mental capacity can change, and a person might be able to make some decisions but not others. In this research, the Mental Capacity Act was instrumental in shaping how I communicated information about the research to people and how I assessed the capacity of individuals to take part in interviews.

Critical to this research, Northway (2014) suggests the term ‘learning disability’ encompasses people with a broad range of abilities which makes the capacity to exercise autonomy and give consent extremely variable. As well as personal characteristics and abilities, the Mental Capacity Act states that capacity to consent is dependent on how and what information is presented to people with learning disabilities and how understanding is promoted. To support the understanding of people with learning disabilities about this research I created a range of easy read information sheets that had large text font, short sentences in simple English, images, and bullet points (see NHS 2018 and Appendix D). I created a website where people could access written information about the research, I also took the decision to make an audio-recording of the easy read information sheet to support people who may not be able to read[13]. The website and audio recording can be accessed here: https://research.ncl.ac.uk/parenthoodstudy/.

As I have described earlier in this chapter, these written and audio materials were further supported by group Q&A sessions and individual conversations with people with learning disabilities which were a deliberate opportunity for me to talk through the research in detail and explain what taking part would involve. These conversations enabled people with learning disabilities to ask me questions they had about the research that further supported their informed decision making. At the start of the interviews with participants with learning disabilities I talked through the participant information with them again and explained that I would need to verbally record their consent by asking them to answer the consent questions (see Appendix D). I asked one question at a time and participants all confirmed they had understood the information and were happy to take part. Consent for participants without learning disabilities was gained and recorded at the start of the interviews. Throughout the interviews I would often pause and check to ask how all participants were feeling and if they were happy to carry on (they all said they were).

As part of gaining informed consent, all participants took part in this research voluntarily (McLeod 1994). I explained to all participants that taking part was voluntary and it was something they could withdraw at any time, and they did not need to give a reason. No participants chose to withdraw. As mentioned earlier some participants were known to me and some may argue this could put individuals under pressure to take part by making 'it harder for them to say no' (Farrimond 2013: 67) or feeling they ought to answer in a certain way (i.e., what they thought I might have wanted them to say). However, I argue that my positive relationships with them facilitated in-depth conversations and enabled participants to talk openly about their views on the topic. For example, in the post-interview debrief with the participant with learning disabilities known to me I asked how she had found talking to

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[13] The audio recording I made with resources available to me at the time did not have an option to produce closed-captions; this is an obvious limitation but something that can be developed on in future research projects.

me about the topics and she said she felt okay because it was me doing the interviews, but it might have been harder if it was someone she did not know.

All participants agreed to take part in this research on the understanding that their accounts would be kept anonymous, and all participants have been given pseudonyms to protect their privacy and identity. The names of other people, organisations and other potentially identifiable information has also been changed or omitted from this research. Aware that some participants, especially those with learning disabilities, may not be familiar with some of the terminology, I spent time explaining the terms ‘anonymity’ and ‘confidentiality’ and how these applied specifically to their involvement and participation in the study. Most participants with learning disabilities gave verbal nods or made comments when I explained research participation; this helped demonstrate their understanding of what was happening and their ability to consent to take part. For instance, one participant told me that changing her name to protect her identity was important to her. Others asked what I would change their names to which I took as further evidence that they had understood what I had said to them. One participant with learning disabilities told me the pseudonym he wanted me to use for him in the research that I have included. On reflection, perhaps asking participants what pseudonyms they might have like me to use could have given them more control over the research outputs and maybe this is something to consider for future research.

As part of supporting all participants to make informed choices about taking part in the research I was clear and transparent before conducting the interviews that if participants told me they or someone else was in danger that I would have to tell someone. I said I would tell them if I had to do this, however nothing participants said alerted me to potential dangers. Support staff and gatekeepers were also able to advise me on safeguarding issues and concerns. For example, when participants talked about historical abuse, advocacy staff had either told me before, during or at the end of interviews that this was something they already knew, therefore it was not necessary for me to raise new safeguarding concerns.

All participants in this research received a £10 Amazon gift voucher. Early in the research design stages I spent time thinking over whether it was appropriate to give participants a monetary token of thanks for taking part in the study. I was worried that giving people money might alter the dynamics of voluntary participation but after discussing it with my supervisors I decided that a £10 gift voucher was not likely to drastically influence participants' decision to participate. This gift voucher cost was set by the Northern Ireland and North East Doctoral Training Partnership (NINE DTP) funding this research. Furthermore, providing a thank you voucher of this amount is common practice in research of this type as participants are being asked to give up about an hour or more of their time. Once this decision had been made it was included in my application to the Faculty of Humanities and Social Sciences (HaSS) Ethics committee. As most non-essential shops were closed during the pandemic, an online Amazon voucher seemed appropriate. After each interview I either emailed or printed then posted the vouchers along with the debriefing document (see Appendix I) thanking all participants for taking part and reminding them of organisations that could offer support with some of the topics discussed. I spent some time explaining how to use the voucher code and most were happy with this, the few who said they might struggle said they had family or staff they could ask for support.

3.6.2 Researching sensitive issues

Reproduction and parenthood can be sensitive topics for many people, with and without learning disabilities, to talk about. However, instances of sterilisation, reproductive control and surveillance, and child removal are often present in the histories and experiences of people with learning disabilities more than the general population. As detailed earlier in this thesis, researchers have previously excluded people with learning disabilities from taking part in social research that is deemed 'too sensitive' for concerns about the group's perceived vulnerability. From the start of this research, I wanted to create a space for people with learning disabilities to be included in these discussions and for them to be able to share their views and experiences about reproduction and parenthood. Some participants with learning disabilities said this was one of the few times they felt able to talk about the topics because they had previously been discouraged or ignored when trying to talk about it with family members, support workers or other professionals. On the other hand, as I have already noted, some participants with learning disabilities said this was a research topic they had been asked about before.

Participants getting upset in the interviews was one of my main concerns when designing and planning this research and although I could not stop this from happening, I wanted to ensure I had plans in place to support people if they became upset. When conducting the interviews, the distress of sibling participants was most visible; for example, some sibling participants cried as they recalled their brother or sisters' experiences of abuse or how they described the challenges they felt their parents, especially mothers, went through raising and caring for a child with learning disabilities. When I saw sibling participants start to get upset, I asked if they wanted to pause or stop the interview; none of them said they wanted to and they told me they wanted to carry on. While participants with learning disabilities did not show signs of visible upset in the interviews some were angry and frustrated about the ways they and other people with learning disabilities had been treated, particularly regarding past institutionalisation. On the topic of reproduction and parenthood, people with learning disabilities spoke out about the injustice they felt at not having the same opportunities as people without learning disabilities. I checked in regularly throughout the interviews to ask how all participants were feeling and if they were happy to carry on. As part of the debriefing processes detailed earlier, I signposted participants to organisations that may be able to help with some of these issues.

Disability scholars have discussed some of the ethical dilemmas of responding to misinformation that people with learning disabilities have been given, either intentionally or unintentionally (see Löfgren-Mårtenson 2009 cited in Santinele Martino 2022). In my research, some participants clearly lacked reproductive knowledge, particularly about fertility and ageing. For example, one participant with learning disabilities in her mid-fifties talked about her desires to have children one day but she seemed confused about why her GP had said she can't have children (see Chapter 5). At the end of the interview this participant reached out to me asking whether I could help her have children. I kindly explained to her that this was not something I was able to do and restated that as a researcher I was there to listen to her views on the topic of parenting; she seemed happy with this response. I also signposted her to some organisations that might be able to help and suggested she talk with staff from the advocacy organisation who were on the call as well. I found this part of the interview difficult because on one hand I wanted to support her to learn about reproduction and help answer some of the questions she had, but on the other hand, I did not feel it was appropriate for me in my role as researcher to do so in case I caused her more distress. A couple of weeks after her interview I contacted the staff to see whether this was something she had mentioned again, to which they replied she had not.

Hearing accounts of child removal processes and abuse were upsetting to hear. There were times after a handful of interviews when I reached out to my supervisors to talk through difficult content. Perhaps naïvely, I had not expected to hear so many participants talk about experiences of abuse, either about themselves or someone close to them with a learning disability. The topic of abuse was never something I asked participants about but if they brought it up, I always asked if it was something they felt comfortable sharing with me and they all said they did. Rather than try to change the topic of discussion I felt it was important to allow participants the space to tell me as much or as little about what had happened to them as they wanted. Echoing what has already been said, I signposted participants to other organisations that might be able to help and encouraged them to talk with people they felt they could trust if they wanted to talk more about these topics (see Appendix I). Acknowledging the difficulties of hearing some of these accounts I think my previous experience working for a Rape Crisis helpline helped me manage how I reacted and responded to what participants told me. In terms of how I managed these distressing issues myself, I reached out for support from my supervisors, family and friends. Taking regular breaks between conducting and transcribing the interviews also allowed me to compartmentalise some of the distress participants had described. Again, I feel my experiences of working for the helpline had equipped me with how to manage my own response to the distress of others.

Throughout the writing up of this thesis I have been conflicted about how much detail to disclose about participants' accounts and experiences of abuse. I have tried to balance highlighting the abuse people with learning disabilities experience as a serious issue and at the same time I have tried to avoid reinforcing dominant social ideas that people with learning disabilities are vulnerable, at risk and in need of protection. As well I have tried to keep the narrative of this research centred on reproduction and parenthood; abuse can be a part of these discussions, but it is not the focus. It is also important to note that while I do not want to upset people who may read this thesis, at the same time I do want to acknowledge that it happens and to share the experiences of participants by using their own words as much as possible. However, there are certain details of one participant's brutal experiences of rape that I have omitted because I fear it may trigger distress in other readers.

I am aware of the authorial power I have as a researcher, as what participants have said is shaped by my own understandings, interpretation, and analysis of the data (see Welsby & Horsfall 2011). I want this research to reflect as closely as possible *what* participants told me, and *how* they said it. I have avoided correcting grammar and tenses for example. Where local or regional dialect was used, I have provided footnotes to support the readers' understanding of this. In the analysis discussion I have tried to share the views and experiences of everyone who spoke to me. Balancing the voices of participants who were more articulate with those who perhaps gave less detailed responses has been challenging but something I have tried to be mindful of.

Finally, I want to highlight some personal reflections that I have felt whilst conducting this research. I do not currently have children and there have been times while conducting this research where I have frequently paused to think about and reflect on my own reproductive options. I am aware that my fertility is not oppressed in the same ways people with learning disabilities can often experience and I have found the unfairness and injustice, particularly of child removal from parents with learning disabilities, upsetting. I am in my early thirties as I write this, and the threat of child removal is noticeably absent in conversations with my friends without learning disabilities about our own parenthood imaginaries. This sense of injustice and unfairness about who is afforded opportunities to make their own choices and fulfil parenting desires is a significant motive for undertaking this research.

3.7 Conclusion

The methodological approach to this research has largely been informed by the dearth of existing studies that include the voices of people with learning disabilities about the topics of reproduction and parenthood. Concerns about the 'vulnerability' of involving people with learning disabilities in social research has meant many have been prevented from sharing their views and perspectives, particularly about 'sensitive' issues regarding sexuality, reproduction and parenthood. My decision to create a space for people with learning disabilities to be heard and centralised in this work has been influenced by these wider research contexts. In response to the Covid-19 pandemic disruptions, this chapter has highlighted the shift from in-person methodological approaches to phone and online interviews. As well as widening geographical participation, this adaptation to phone and online methods gave people who said they would have found speaking in person uncomfortable the opportunity to be involved and to share their perspectives about the topic of parenthood. This chapter has also detailed the rationale for adjusting the inclusion criteria to include older people with learning disabilities and siblings of someone with learning disabilities, as well as parents and support workers. I have explained how the interviews with participants were conducted and how the data was analysed while also illustrating some of the ethical considerations that shaped this research. I hope that my experiences of conducting this research in a pandemic with people with learning disabilities can be used to inform future research that will continue to include marginalised groups in social research to enact positive change.

Chapter 4. Family relational networks

4.1 Introduction

The significance and influence of support networks for people with learning disabilities can vary depending on the households that individuals live in (Llewellyn & McConnell 2002: 18). As outlined in the literature review, people with learning disabilities tend to have smaller social networks than the general population (Shah 2017), and family members can often be their main source of support (Callus et al. 2019). As well as parents, siblings and other family members can also be closely involved in the lives people with learning disabilities by offering care, companionship, communication support and social understanding throughout the life course (Gant 2018; Dew et al. 2014). This chapter will consider how family relational networks can impact the reproductive imaginaries and experiences of people with learning disabilities. It especially considers the unique perspectives of siblings of someone with a learning disability as they provide insights into familial dynamics and relationships. I argue that family members, especially mothers, can be both sources of support and constraint in the reproductive and parenting opportunities for people with learning disabilities (Llewellyn & McConnell 2002). Ideas of infantilisation that may be held by some family members assumes people with learning disabilities are not interested in, or not capable of having intimate relationships and fulfilling parenting roles. Such views can limit and restrict reproductive decision making (Hollomotz 2011; Dotson et al. 2003). I highlight tensions between family members balancing protection with supporting autonomous decision-making for people with learning disabilities, especially around issues of sexuality, reproduction and parenthood. As well as acknowledging the powerful role family members can play gatekeeping parenting possibilities, this chapter also illustrates how family members can positively support and influence parenting experiences.

4.2 Family members shaping parenthood imaginaries

4.2.1 Protection, overprotection and infantilisation

Ideas around the notion of protectionism was mentioned by many family participants as they described some of the challenges of balancing the rights of people with learning disabilities to make their own life choices about intimate relationships and having children, whilst also feeling a sense of duty to protect them from harm (Jahoda & Pownall 2014). However, families' well-meaning intentions of protection can be experienced by people with learning disabilities as overprotection that restricts their opportunities to have relationships and make their own reproductive choices, as this section will now explore.

Many family member participants talked about the feelings of protection that they, and other family members, have towards people with learning disabilities. Some family member participants suggested this protection was influenced by the ways people with learning disabilities are perceived as vulnerable and at risk. For instance, sibling participant Conor (30s) said he worried people with learning disabilities *'are vulnerable and can be massively taken advantage of'*, particularly when it comes to them experiencing intimate relationships. He went on to say that he and his two brothers *'are quite protective over'* their sister Chloe (20s) who has learning disabilities. Sibling participant Evie (20s) similarly said her family worried about her brother Finn (late teens) going on to have relationships in the future *'because of his learning disability he's much more susceptible to being you know being catfished[14] or being scammed and as a family we're worried about that sort of thing'.* Non-learning-disabled parent participant Imogen (30s) has five children, including two stepsons with learning disabilities called Alec and Harvey who are both nearly 16 years old. Imogen said the idea of Alec and Harvey having intimate relationships in the future *'terrifies'* her :

> *"I just worry about them being taken advantage of… I think a girl could easily take advantage of them, very easily. I think they're very vulnerable boys and I do worry about that side of it."*

Imogen's concern that her stepsons with learning disabilities will be *'taken advantage of'* echoes what sibling participants Conor and Evie say. What some family member participants say here is that it is not the individuals' learning disability *per se* that marks them as vulnerable, rather concerns about the actions of others around them reinforces ideas of risk and protection.

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[14] Catfishing refers to when an individual uses a fictional persona or information and images from someone else to create a new identity for themselves that is used to deceive and target people online, particularly on online dating sites. Victims of catfishing can often experience emotional distress and financial abuse as a result (see Age UK 2023).

While some sibling participants emphasised the importance of protection, others described how they felt people with learning disabilities were overprotected and held back by their parents restricting opportunities for normative adulthood. For example, sibling participant Elaine (50s) said people with learning disabilities can be *'totally mollycoddled'* by parents and *'aren't encouraged to lead a normal life'*. Reflecting on her own experiences growing up, sibling participant Elaine (50s) said her mother had different life expectations for her compared with her sister Sheila (60s); she said: *'I was expected to have a job, a career, get married, have children but that was never expected for Sheila, she was always expected to stay in the house'*. What Elaine says here also resonates with existing disability studies literature that highlights this 'double standard' as in many contemporary societies non-disabled women are often expected to move out of their parents' home, settle down and start a family, but these expectations are not set for disabled women (Kallianes & Rubenfeld 1997: 204). Despite only being a couple of years apart in age, Elaine went on to say her sister had missed out on opportunities for living independently, developing relationships, and thinking about parenthood because it was *'my mother's attitudes'* that *'held my sister back'*. For instance, Elaine said her mother would often say her sister Sheila's *'got Down's syndrome she can't do that, that's impossible she can't do that'*. Elaine further described how her sister was *'never encouraged to have any sort of relationship… it was totally discouraged'* by her parents. She said, *'Sheila even thinks kissing's dirty'* because *'that's how my parents brought her up'*. What Elaine says reinforces how ideas of vulnerability and protectionism can be oppressive and limit the opportunities for people with learning disabilities to be independent and make their own choices.

While some adults with learning disabilities living in the family home can be supported by their parents to experience choice, autonomy, and independence, for many people with learning disabilities, living in the family home can be linked with experiences of overprotection (Callus et al. 2019: 347). Staying in the family home can reinforce stereotypical perceptions of people with learning disabilities as vulnerable, child-like and dependent which further restricts their opportunities to enjoy autonomy and decision making. Many sibling participants shared the view that staying in the family home was a form of overprotection by parents that limited opportunities for people with learning disabilities to make their own choices. For example, sibling participant Olive (70s) said her mother *'protected'* her sister because of her learning disabilities and sibling participant Amanda (50s) also thinks her sister Iris, now in her mid-sixties, *'was shielded quite a lot by my parents… they didn't want her to come to any harm'*. Amanda said Iris lived in the family home until *'our mum passed away… so my sister was in her fifties when she finally got that independence'*, and this was something Olive said she *'could never get my head around'*, why Iris lived at home *'until my mother died'*.

Sibling participant Elaine (50s), introduced earlier, said she felt her parents' attitudes and decisions to keep Sheila at the family home restricted her from imagining herself as ever being able to fulfil parenting roles in the future. On the topic of staying in the family home, Elaine described how her Sheila *'says at times, 'I'd like to live on my own'*, but this is something Elaine feels would be difficult now Sheila is older:

> Elaine: *"Her skills are so limited so we've always done everything, and I say 'well what would you do about washing your clothes and using a washing machine? What about cooking your tea?' you know she takes it all in and then she goes 'yeah I'm better off at home'. A few times I've said, 'well come on, you're the one at home you've got to look after mum and dad you know, we're not there so you've got to do it, you're the eldest' and she nods and says, 'yep that's my job now', bless her."*

Elaine went on to say:

> *"I always felt that she should have gone into a residential home with her peers. She'd have had a much better life, well I feel that, but as time's gone on and my parents are elderly like I've said my dad's 87 and in poor health and mums 86, so she'll come to me now when anything happens to my parents."*

Despite Sheila saying she wanted to leave the family home and live independently; this did not happen for her which highlights some of the challenges people with learning disabilities can experience about being able to act upon their own ambitions. Elaine suggested that the ways her family have *'always done everything'* for Sheila has restricted her from developing the skills to cope with day-to-day tasks. Elaine's quotations also highlight shifting dynamics of care as Sheila feels it is her responsibility and her *'job now'* to look after her elderly parents. Elaine told me she feels *'it's a shame'* opportunities to live independently *'didn't happen for*

Sheila', and she reflected that *'with the right support, there's a lot of things Sheila could have done'*. Elaine's example highlights how the reproductive rights of Sheila were restricted by her parents' concern about her vulnerability and the idea of her having children in the future was not seen by them as a possibility for Sheila.

Echoing what Elaine has said, sibling participant Stella (40s) also talked about people with learning disabilities struggling to fulfil their ambitions for independence because of the power parents can have over them, even as adults. Stella, whose sister Essie is in her thirties and lives in the family home, suggested that not having the opportunity to leave the family home forms part of the disempowerment that makes it difficult for Essie to make her own life choices. Stella told me that she thinks Essie *'could do with living on her own in supported living'* with her fiancé because *'that's what she wants to do… she's always saying how she wants to move out'*. Stella said Essie still living at home contributes to the way she feels treated differently because *''normal' people'* [air finger quotes] Essie's age *'don't live at home'*, especially because *'she is able to look after herself'*. Essie would *'absolutely blossom'* if she moved out of the family home Stella told me.

I asked Stella why she thought that Essie was still living at home, and she said that *'I think my mum's scared, I think she's scared that people might not look after her right'*. This concern that people with learning disabilities may not be looked after outside the family home was also mentioned by sibling participant Francesca (30s), because *'you do hear awful stories of where services are abusive'*. It is important here to make the distinction between ideas and assumptions that people with learning disabilities *can't* live outside of the family home, and families with reasonable concerns about the quality of formal support services. The recent exposure of abuse and inhumane treatment of people with learning disabilities in UK residential homes[15] such as Winterbourne View (2011) and Whorlton Hall (2019) have been widely documented in the media, and as Francesca suggests, these devastating cases will almost inevitably influence the concerns families have for people with learning disabilities living away from the family home (see more in Chapter 5). If parents are determining whether

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[15] I have deliberately avoided using the term 'care home' here because the abuse inflicted on people with learning disabilities by staff in these homes was the very antithesis of care.

people with learning disabilities live at home, it implies an economic and social dependency that is produced by their marginalisation in society, and it can be reasonable for parents to feel this is therefore the only possibility. Indeed, this speaks to wider marginalisation and disability discourse about families trying to navigate what they believe is the 'right thing' for the individual with learning disabilities, thus highlighting some of the challenges families experience balancing support for autonomy and decision making with providing protection (Callus et al. 2019) (see Chapter 7).

Sibling participant Francesca (30s) said, in many instances *'parents keep their children who have learning disabilities at home until the parents die'* because *'that's what the parents think they should do'*. What Francesca says illustrates the ways family members are often acutely aware of the vulnerable and marginalised positionality of people with learning disabilities in society and try to protect individuals by not exploring the possibilities of them leaving the family home. Despite the desires of some people with learning disabilities to leave the family home and live independently, this possibility is often not available to them as parents have the capacity to override their decision making and can remain powerful decision makers until they pass away. Protective desires of parents to keep their adult children with learning disabilities living in the family home can contribute to the ways people with learning disabilities are kept as child-like without realistic opportunities for thinking or making meaningful decisions about intimate relationships, reproduction and parenthood. Not affording people with learning disabilities to make their own choices about independence shows how protection can be understood as a form of oppression and injustice that denies their reproductive rights.

On this issue of protection, sibling participant Amber (20s) also commented that:

> *"I think parents feel that it's their duty to look after them… Especially looking at the older generation, that's just what happened with adults with learning disabilities, they stayed at home because that's what parents' thought was best. Whereas by allowing them the opportunity to progress into some kind of assisted living then actually you're giving them that freedom and the ability to be a functioning member of society and an adult in their own right."*

The generational dynamic that Amber describes here is important to acknowledge. Speaking to family member participants it seems that today parents are more open to the idea of people with learning disabilities living in residential or supported living than older generations of parents.

Whilst it remains the case that many people with learning disabilities do not leave the family home (Mencap 2017), support worker participant Huw (40s) said he has noticed a *'big change'* in family attitudes from when he started working in learning disability services over 30 years ago. Huw said whilst *'there's a lot of people who never stop seeing them as children'* he thinks *'more families look towards them growing up and being more independent and not staying in the family home forever, but on the sexual side of things'*, families do still worry. Rojas et al. (2016) similarly tell us that people with learning disabilities now have greater control over their lives, but they also suggest that people with learning disabilities continue to experience barriers to fulfilling parenting desires because of negative and stereotypical views held by parents and other family members. A couple of other participants also noted a temporal shift in some family attitudes towards independence and said they hoped opportunities to lead a *'normal life'* would be *'better now'* for younger generations (Elaine – sibling, 50s). This view that older parents of people with learning disabilities were typically more protective and held more conservative views towards the topics of sexuality than younger parents is a finding consistent with existing disability literature (Karellou 2003; Aunos & Feldman 2002).

Having so far focused on the views of sibling participants, I will now bring the voices of participants with learning disabilities into the discussion. From the 21 participants of people with learning disabilities, six lived in the family home and all seemed *'happy at home'* (pwLD Ryan, 40s) and did not express an interest in moving out. However, for some participants with learning disabilities, leaving home was considered a marker of a normal life and the first adulthood milestone. For instance, Jodie (pwLD, 30s) was excited to tell me that she had recently moved out of the family home and into a residential care home. For context it is useful to state that Jodie seemed to equate living in residential care as living independently. When I asked Jodie what it was that made her want to move out and live more independently, she told me: *'I can make my big decisions by myself and also I've seen my sister move out, so that gave me a bit of courage like well yeah, I can do that and I was like, if she can do it I will,* *and look at me now'.* Following in the footsteps of her sister, who does not have a learning disability, enabled her to fulfil what she seemed to consider normative life markers of adulthood. For Jodie, being away from the family home gave her more choice and autonomy over the *'big decisions'* she wants to make in and about her life and it seemed to give her a sense of independence and maturity that she felt she had not had previously.

An important aspect of over protectionism emerges from ways family members can infantilise people with learning disabilities that can restrict their opportunities for thinking about and making autonomous choices about the topics of reproduction and parenthood. As I discussed in the literature review, existing disability literature highlights how people with learning disabilities have been perceived as asexual and child-like (Chan et al. 2009; Shakespeare et al. 1996:10) and deemed incapable of having sexual wants and desires (Liddiard 2017: 1). Participants with and without learning disabilities suggested these assumptions influenced the views held by family members that people with learning disabilities are not interested in, or are not capable of having, intimate relationships and fulfilling parenting roles. For instance, Billy (pwLD, 20s) talked about this in relation to his partner Grayce, who also has a learning disability, as he said Grayce was *'trapped in a particular way of life'* because *'her mother is very domineering'* and continues to regard her as a child. Sibling participant Francesca (30s) said she thinks the '*infantilising that happens in families'* continues to deny people with learning disabilities parenting possibilities. Francesca also said trying to balance protection while supporting choice and autonomy could be challenging for any family, but she said this can be *'even harder when it's your child who, you know, perhaps took longer to transition to adult life… who was more like a child for longer'*.

Support worker Gus (60s) also reflected on his work experiences and said the ways parents of people with learning disabilities often infantilise their adult children can be instrumental in both disempowering and restricting their reproductive possibilities. For instance, he said parents that often give their adult children *'plastic toys to play with'* or '*give them cartoons to watch'* and *'Disney songs to listen to'* sustains them in a *'childish world'*. He added that clothing, when chosen by parents or support workers, can also contribute to stereotypical ideas of infantilisation:

> *"You can see it in the way that people are dressed, you know we have a young woman* [early twenties] *at work and she just comes in looking like a character from an Enid Blyton cartoon… but it's a way of keeping her away from development, from adulthood, from the questions of you know, by now you would have been at work, you would have had a boyfriend or a girlfriend, by now you would have had babies, and you avoid those questions by having a perpetual child."*

Recent work by Björnsdóttir and Stefánsdóttir (2020) similarly highlights how clothing can be instrumental in how people with learning disabilities both see and identify themselves, and how others think of them. If people with learning disabilities dress in *'children's style'* (support worker Gus, 60s) clothing, this can prevent them from being considered capable of wanting and successfully raising children of their own, because others assume *'basically they're kids themselves'* (pwLD Jenny, 30s). However, Gus was keen to stress that he often thought parents *'do it out of love, they don't want to see their child harmed'*. This links in with earlier discussions about the *'protection factor'* (sibling Olive, 70s) that siblings talked about regarding their parents' attitudes.

Many participants with and without learning disabilities seemed to share the view that some family members do not recognise people with learning disabilities as sexual citizens which restricts and disempowers them from imagining parenting possibilities in their futures. For instance, sibling participant Elaine (50s) talked about her goddaughter Milly who has a learning disability and is in her late teens. Elaine said Milly's mother *'thinks that she's not having sex, she's never going to have sex, and I'm sure that's how a lot of parents feel'*. Billy (pwLD, 20s) also told me he thinks there is *'a lot of denial'* from parents that people with learning disabilities might want to have intimate relationship and parenthood opportunities like anyone else. I asked Billy why he thought that might be and he replied:

> *"I think some of it's maternal and paternal… oh it's my little child. With every parent there's that thing of, oh they won't be doing that until they go to university… when it's kind of half expected really that they'll have flings and things like that. But in terms of learning-disabled people, the eternal child theory is still there… I think also it's an inability to accept that their child is growing up."*

This quotation from Billy is important because he acknowledges that for *'every parent'*, regardless of whether their child has a learning disability or not, sexuality can be a difficult topic. However, for people with learning disabilities who may not follow popular life-course markers, such as going to university, parents often have different expectations that continue to be fuelled by *'the eternal child'* stereotype and exclude them from full sexual and adulthood status. Billy further suggested that this infantilisation from family members can be dehumanising, leaving people with learning disabilities feeling othered and less than as he said, *'I honestly think there's just this inability to grasp that they're still human'*. What Billy describes here can be considered alongside broader disability literature that suggests individuals who fall outside of the 'able-bodied' ideal become cast as inferior and become marked as 'not quite human' (Barnes & Mercer 2010: 48). The ways people with learning disabilities are infantilised and devalued in this way shapes how their reproductivity is stratified as it is not taken seriously by others around them, a theme detailed throughout this thesis.

As well as infantilisation, the perception that people with learning disabilities are incapable of having and raising children was a judgement some participants with learning disabilities said family members held towards them. For example, Pippa (pwLD, 50s) told me *'I want to have children, but I've got a learning disability'* and described how her mother has repeatedly said to her, *'you can't have children, you can't cope, and all this, you can't know what to do or anything, you can't read, your learning disability, and all this'*. Pippa being told *'you can't'* have children because of her learning disability by her mother is an example of how some family members can directly restrict and disempower the reproductive opportunities of people with learning disabilities. Pippa said to me multiple times throughout the interview she thinks her mother is wrong and *'I can'* be a good mother. Despite disagreeing with her mother, Pippa has less scope to challenge these views or act on her desire to become a mother regardless, which is further indicative of the wider marginalisation people with learning disabilities can experience.

Other participants described the control they felt family members, particularly parents, can have over the reproductive opportunities for people with learning disabilities. For instance, Michael (pwLD 70s) felt family members, especially parents, were in powerful positions to stop people with learning disabilities from having children as he said, '*because don't forget mums and dads, families and carers always put a block on it'*. As discussed previously, this view that parents can be in powerful positions to block and restrict parenting possibilities for people with learning disabilities was also shared by sibling participant Stella (40s). Stella said she felt her mother is overprotective and very much in control of Essie's (30s) life choices, particularly around reproduction and independence. Stella said, *'my mums not open minded'* about the idea of her sister Essie having children of her own, Essie is *'always saying she wants to have babies'*, but *'it would be my mum's worst nightmare… and it would never, never, never, never happen'*. This is significant because Stella suggests her sisters' opportunities for parenthood are dependent on her mother allowing it.

When asked why she thought her mother was against Essie having a child of her own, Stella said it's because she thinks Essie would not cope with the demands of parenting: *'cuz they're cared for, you would then have to care for the baby then wouldn't you'*. What Stella suggests here is also reflected in existing disability literature as some scholars have argued because disability is so intertwined in dominant social ideas of dependency and infantilisation, it is hard for people to imagine them fulfilling primary care giving roles as parents (O'Toole 2002). Again, these stereotypes held by family members a priori assume people with learning disabilities are incapable of successfully raising children and these views manifest as significant barriers to people with learning disabilities making their own choices. Like Pippa detailed above, Essie has been restricted from realising her desires for parenthood by her mother who continues to control her reproductive choices and the wider context of marginalisation makes it difficult for people like Essie to challenge the views of parents and other family members.

Non-learning disability parent participant Lorraine (50s) also said the opportunities for people with learning disabilities to have and successfully raise children of their own *'would depend on their parents and whether they think they would be able to manage'*. When asked what impact other participants thought being told you can't have children might have on the ambitions of people with learning disabilities, support worker Gus (60s) replied, *'well I guess you just get used to it not being an option for you'*. Similarly, sibling Amber (20s) said, *'well negative obviously because if they're constantly told you can't have, you won't have, it's* *simply not possible for you to have that or whatever, then that's just gunna make them feel like they can't, it's not doable, it's not something that they can aspire to'*. What participants say here highlights how people with learning disabilities can internalise the views of others around them and be influenced by negative discourses that suggest fulfilling parenting roles is not something they would be capable of (see also Johnson et al. 2001). These social contexts and messages are examples of how newgenic ideologies are controlling the kinds of people society deems appropriate and valued for reproduction.

Other sibling participants also seemed to describe parents of people with learning disabilities as gatekeepers with the power to grant or deny reproductive and parenting possibilities. For example, Sibling Francesca (30s) talked about how growing up, her sister Daisy (20s) *'used to talk about wanting a baby'* but said that their mother *'would tell her she probably couldn't have a baby, in a very kind way'* because of her learning disability. Francesca described how she feels her mother also controls Daisy's reproductive opportunities through the usage of hormonal contraception. She said she feels '*uncomfortable'* that the decision for Daisy to have the contraceptive implant fitted was made by her mother:

> *"Daisy has always had the implant in her arm, which she knows is to stop her periods, but mums never told her that it stops her having babies. Erm which I've always felt quite uncomfortable with… but if she was having sex, I might have to override mum to make sure that Daisy knew that that's what it did."*

Francesca continued to add:

> *"it's a bit like she's being tricked really…. it's always tricky being the sibling, not wanting to tread on mums' toes… so yeah that's just one battle I haven't picked because I don't think Daisy's trying to have babies. If she was trying to have babies which then the implant stopped her then that'd be different, but she's never had sex I don't think so I don't see it impacting on her."*

This comment highlights how people with learning disabilities, like Daisy, are denied access to contraceptive information and decision making as their contraceptive usage is controlled by others, in this instance Daisy's mother. This reinforces the notion that people with learning disabilities are viewed incapable of understanding and making their own choices about fertility, contraception, and parenthood. It can further be argued that the disempowerment people with learning disabilities experience with their contraceptive decision making resonates with some of the coercive sterilisation practices during the eugenics movement that sought to prevent parenting possibilities for people with learning disabilities. The lack of informed consent around contraception suggests reproductive control is therefore not an historical problem, but as mentioned earlier, the issue continues to oppress people with learning disabilities today (Wiseman and Ferrie 2020; Hollomotz 2011; McCarthy 2009a and 2009b).

While Francesca disagreed with the way her mother was managing her sister's access to contraceptive information, Francesca did share her mother's concern about Daisy's parenting capabilities. When asked why she felt her mother wanted to prevent Daisy from pregnancy, Francesca said her mother thinks she would not be capable of parenting successfully*; 'she thinks that Daisy couldn't do it'*. Francesca added:

> *"I would kind of agree with her, like Daisy would need such an immense level of support to be able to parent she almost wouldn't really be parenting anymore… I think part of the reason mums got an implant in Daisy's arm is she knows if Daisy had a baby, I would never let that baby go into care. If Daisy had a baby and she wasn't allowed to keep it, I would be adopting the baby. Erm and I think mum knows that, so I think some of her protection is not necessarily about Daisy and the baby, but also the impact on me."*

Francesca's comment reinforces this a priori concern about parental incompetence and highlights the powerful position that parents can have in the lives of people with learning disabilities that restrict reproductive opportunities. What Francesca says here also shows how she feels her mother's decision to manage contraception is not only about trying to protect Daisy, but it also seems a way of protecting Francesca from the additional care responsibilities that may come if Daisy had a baby. This example further shows that the issue of child removal from people with learning disabilities is something family members worry about, as well as people with learning disabilities, which will be explored further in Chapter 6.

What Francesca says illustrates the tension between balancing protection with autonomy; while their mother is trying to do what she feels is best to protect both her children, the ways she controls Daisy's contraception is oppressive because it denies her the opportunity to make her own decisions about her body and reproduction. It is significant that Francesca shares some of this concern about how her mother is managing Daisy's contraception, yet Francesca does not feel comfortable discussing it with her mother. This perhaps points towards some of the complexities between how people understand family members roles and responsibilities. It further helps us to see the wider contexts and family care dynamics that can shape parents' decisions to control reproduction. People with learning disabilities, like Daisy, not making fully informed decisions about their contraceptive usage can be understood as a form of newgenics that disrupts the ability of individuals to make meaningful choices about reproduction (Malacrida 2020). This issue of contraceptive control and access to contraceptive information is explored further in the next chapter.

Not all participants with learning disabilities had experienced being told by parents or other family members that they cannot, or should not, have children. Jodie (30s) said she had *'not come across anybody to say that'* to her, and Tracy (50s) similarly said: *'it's up to me if I want children then I can have children, even my mum and dad said it's up to you Tracy, yeah that's what they said to me... nobody ever stopped me'*. However, most participants with and without learning disabilities said parenting possibilities would depend on the permission of parents. As this section has illustrated, this reproductive oppression can be experienced by people with learning disabilities in a myriad of ways, such as: having desires for independence and parenthood ignored; being told they cannot have children and being unable to challenge parents' decisions; and having their contraceptive usage controlled by parents. The influence of protective family members can therefore be considered a powerful tool of regulation that restricts and disempowers people with learning disabilities from imagining parenting possibilities in their futures. By focusing in on familial relations in the lives of people with learning disabilities, it enables us to see that not everyone has equal access to reproductive and parenting possibilities. This issue of unequal access is central to ideas of reproductive justice that people with learning disabilities and other groups of marginalised women continue to experience because their reproductivity has been deemed less than.

4.2.2 'It's not really spoken about'

As well as families telling people with learning disabilities they cannot have children, family members not engaging in discussions with people with learning disabilities about menstruation, sexuality, reproduction, and parenting can also be barriers to reproductive decision making. Sibling participant Francesca (30s) for example suggested that '*when things are hard it's just easier to avoid then isn't it'*. Others, like sibling participant Evie (20s) also said she felt the topics of sexual and reproductive health were something families of people with learning disabilities '*shy away from… they don't want to talk about it, and they don't want to think about it'*. Evie described how her own family avoid talking about the topics of relationships and parenthood with her brother Finn (late teens) because they don't want to *'put ideas in his head'* which further highlights some of the complexities of families wanting to do what is 'best' for the individual with learning disabilities. Sibling Lara (30s) said parenting is not something she feels her family have actively stopped her brother Jason (30s) from having, but equally the topic is not something they have discussed with him because *'we as a family know that Jason wouldn't be capable of raising a family… it isn't something in Jason's future'*.

Stella (sib, 40s) also said her mother ignores the topic of parenthood when her sister Essie brings it up:

> Katrina: *"So you say that Essie talks about wanting children a lot, how do you as a family talk about that?*
>
> Stella: *Mum never speaks about it*
>
> Katrina: *Doesn't she?*
>
> Stella: *No. Essie will say it in the car, and we'll go 'okay'*
>
> Katrina: *Then what?*
>
> Stella: *And that's it."*

I continued to ask Stella whether she thought other people with learning disabilities had much choice about parenthood to which she replied*, ‘it depends on the parents’*. Again, what Stella says here reinforces the powerful position of parents as gatekeepers over the reproductive choices and possibilities of people with learning disabilities.

Wright (2011) suggests some parents may lack the knowledge and confidence to discuss the topics of sexuality with their children with learning disabilities and this was mentioned by some sibling participants I spoke with. Sibling Conor (30s) for example said conversations about sexuality and reproduction are not something his family have had with his sister Chloe. He felt it was a conversation his mother was reluctant about having with Chloe and he said it would be something *‘I would probably discuss’* with her instead.

Sibling participant Francesca (30s) similarly recalled when ‘*mum asked me to talk to’* her sister Daisy about sexuality and reproduction:

> *“It’s just very uncomfortable for families. I know mum’s just asked me to have lots of conversations with Daisy that she doesn’t want to have, and that’s probably because I work in that area and if I didn’t work in the area I wonder if anybody would have those conversations.”*

Francesca worries if she not had *‘a chat about that’s how babies are made’* with her sister, then it’s probably not something her mother would have talked to Daisy about. As siblings, both Francesca and Conor said they notice their parents, especially mothers, not wanting to have discussions with their adult child with learning disabilities. What sibling participants Conor and Francesca both say is consistent with existing disability literature that finds while many parents recognise they have a responsibility to talk about this topic, many feel embarrassed and uncomfortable having these discussions (Hall 2009). This reluctance of family members, especially parents, to engage in discussions about sexuality and reproduction can impact how people with learning disabilities think about the parenthood opportunities that are realistically available to them. For example, some participants said people with learning disabilities *‘don’t really think about’* parenthood and having children because *‘it’s not really spoken about’* by other people around them (pwLD Caitlin, 20s).

This point was also made by support worker Gus (60s) as he similarly said the silence around the topics of reproduction and parenting reinforce social assumptions that *'parenthood is not for people like them'* and so people with learning disabilities *'get used to it not being for you'*. What Caitlin and Gus say here mirrors the point made earlier about how a lack of discussion of the topics from family members reinforces social ideas that parenthood roles are not for people like them. It reinforces the notion that the reproductive imaginaries of people with learning disabilities can be influenced by families choosing to be quiet and not engage in discussions about the topic.

Some sibling participants also said that information about menstruation was not always something family members readily discussed with people with learning disabilities, let alone the topics of fertility and reproduction. Sibling participant Olive (70s) talked about the limited information her sister Alison (60s) had about periods as she said, when Alison *'first got her periods, she thought that she was bleeding to death'*. Olive went on to recall how she felt she had to prompt her mother to discuss the topic with Alison:

> *Olive: "I remember having to say to my mother you'll have to explain it to her because she thinks that she's actually bleeding to death, she couldn't understand why she was having this bleeding, you know*
>
> Katrina: *And was it something that your mum then spoke to her about?*
>
> Olive: *I think yes, my mother did speak to her… funnily enough I remember the one thing my mother did say to her was that this will happen every month she said, now I've got this packet of sanitary towels so you have to use these for about five days every month, and the bleeding will stop after about five days. And that was about as much as my sister ever knew."*

The absence of information about the link between periods, fertility, reproduction, and parenthood is perhaps indicative of the way Olive's mother may have felt Alison would not have been able to understand it, or she may have assumed and expected that having children was not something Alison would have in her future. Again, this example suggests the reproductive rights of people with learning disabilities are not always supported by family members.

Not being told about menstruation was also something participants with learning disabilities talked about. For example, Aimee (30s) said:

> Aimee: *… I didn't really know nothing about anything when I was growing up like certain issues like girl problems I didn't really know, no one taught me… I was in school and then when I was walking home, I was in pain and I didn't know what that was, that was like a girl problem, but no one told me what happens to you, so it kind of shocked me when it happened."*

The sense of shock and distress that Olive and Aimee describe in these quotations about periods illustrates the lack of information people with learning disabilities can get from family members about the issue (also see Wiseman & Ferrie 2020: 322; McGaw & Candy 2010). Aimee told me she feels there *'should be more'* opportunities for people with learning disabilities to learn about sexual and reproductive health, especially because some people might struggle accessing this information from their family and social networks. Not having access to information about the link between menstruation, fertility and reproduction is revisited in the next chapter.

For Aimee, these were topics she said she felt she could not learn about from her mother as she went on to describe the poor relationship she had with her: *'she wasn't really a good mum to be fair, I had like loads of problems growing up'*. Aimee said that her learning disability diagnosis was not something her mother shared with her, and she was incredibly upset when she found this out:

> Aimee: *"…but my mum never told me when I was growing up, so when I went to the doctors for a flu jab I was 20 and I found out through that, because the nurse turned around and said, you've got cerebral palsy and it was a big shock, and then I had to get my medical records to go on the pill and when I saw that I found out I had Autism as well.*
>
> Katrina: *And how did you feel when you found that out?*
>
> Aimee: *I was crying my eyes out, I was in complete shock, I didn't realise if I'll be able to have kids or not in the future."*

Aimee's experiences of feeling upset, shocked and confused highlights some of the challenges people with learning disabilities can face when family members are not sharing this kind of information with them. Aimee suggested it was difficult growing up without access to this information, but today she feels supported to access and learn about these topics from her advocacy group. Her situation reinforces how important it is for people with learning disabilities to have other ways and opportunities to access information about sexual and reproductive health that will enable them to make informed decisions about their own bodies, both now and in the future. This issue of access to information will be revisited in the next chapter and in the conclusion of this thesis.

What is said in this section highlights how some family members can act as gatekeepers capable of restricting opportunities for people with learning disabilities to access information about sexual and reproductive health. This notion of silence about reproduction interfering with choice is also detailed in wider disability literature (see Asch 1988 cited in Kallianes & Rubenfeld 1997). It highlights the powerful influence parents and other family members can have over the reproductive imaginaries of people with learning disabilities, as not talking about reproduction can be understood as a form of newgenics that stops people with learning disabilities from accessing information to make their own choices and decisions (Malacrida 2020). Again, it is important to recognise that many families may think they are doing what they think is 'best', but this protectionism can be experienced as oppression and a marker of reproductive injustice as people with learning disabilities are denied autonomous decision making opportunities. This reproductive control exists within broader social contexts of infantilisation, protectionism and dependency that all continue to deprive people with learning disabilities from making their own reproductive decisions. This reproductive control from family members is indicative of the unequal parenting opportunities people with learning disabilities can often experience. This disempowerment further reinforces social ideas about stratification and the appropriateness of reproduction as people with learning disabilities continue to be discouraged and prevented by others from having children (Saunders 2021). Their reproductive possibilities are not taken seriously and are often regarded as something to be avoided.

4.2.3 Recognising different parenting opportunities and embracing substitute family roles

Many participants seemed to be aware of the unequal opportunities people with learning disabilities have for fulfilling desires for parenthood. Sibling participant Stella (40s) for example told me she noticed the difference in her reproductive opportunities compared with her sister Essie who has learning disabilities. Stella said she was *'just left to get on with'* making her own decisions about parenthood; '*nobody told me when to have children or not'* but *'that's not the same for people with learning disabilities'.* Stella's comments contrast the different reproductive freedoms and possibilities for people without learning disabilities compared to people with learning disabilities. Sibling participant Evie (20s) similarly said she finds it *'a bit upsetting'* noticing the different opportunities she has for relationships and children, whereas her brother Finn (late teens) *'doesn't have'* those same possibilities; despite being *'only two- and a-bit years apart… I'm living a very different life'.* Here, Evie seemed to describe a sense of leaving Finn behind because of the stark differences in their life opportunities. Finn acquired his learning disability through illness at a young age, and Evie said that before Finn's illness her parents' *'expectations for him were the same as every child's'*, that he would *'grow up and go on to do something'*, be independent, have relationships and children. Whereas now her family have different expectations for Finn and wondering whether he is going to be able to lead a normal life *'worries everyone'* in the family, Evie said.

Sibling participant Francesca (30s) thinks it is unlikely that her sister Daisy (20s) will have children because it is not something her mother would want to happen, and Francesca said: *'now I've got a baby I do notice some sadness in her'* sister '*that she's not the one being a mum'*. Francesca went on to tell me that since she become a mother, *'I'm trying to really support her to embrace being an aunty and making the most of that role'*. The ways Francesca, and other sibling participants talked about supporting their siblings to make the most of being an aunt or uncle further demonstrates how sibling participants were aware of the different reproductive opportunities they have compared with their brother or sister with learning disabilities. Some sibling participants described how they try to mitigate against some of these inequalities by purposefully trying to involve their brother or sister with learning disabilities in the lives of their children. This section will later describe how some participants with learning disabilities similarly talked about the joy and fulfilment they felt from being aunt or uncle, however for some others it also reinforced feelings of difference and inequality.

Recognising the often-unequal opportunities people with learning disabilities can have to fulfil parenting ambitions, some siblings spoke about the importance they feel to support their brother or sister with learning disabilities in their role of aunt or uncle. Sibling participant Amanda (50s) said she felt motherhood was a role her sister Iris, now in her sixties, was not given the opportunity to fulfil because of the way she felt her parents overprotected her and *'with hindsight, maybe they should have given her a little bit more freedom'*. I asked Amanda how she felt her sister found being an aunt to her children:

> Katrina: *"and like you've said, she was quite good with your children?*
>
> Amanda: *Yeah, yeah she loved them to the end of the earth, she'd let them get away with murder* [laughs]*, you know she would never hurt them or get them into any unsafe situations, you know she was always very sort of hyper aware that she kept them safe.*
>
> Katrina: *And do you think she enjoys being an aunty?*
>
> Amanda: *Yeah she does yeah, she loves it.*
>
> Katrina: *And what do you think she likes about it?*
>
> Amanda: *I think she really related to them when they were children, because she was very childlike herself in some ways you know, she enjoyed getting on the floor and playing with their dollies you know and have tea parties. She used to take them out, only for an hour or so she used to take them to the park, I would never let her take them shopping you know or anywhere else because you kind of don't know if something might happen but yeah I would let her take them to the park… I think she would have been a great mum actually. I think maybe her role of aunty gave her that something, you know she was never a mother, but she had that instead and now like my grandson she's absolutely besotted with him. Yeah so she got like a substitute family through watching my family… if she'd have had a relationship and had a child, with the right support she would have done really well."*

In juxtaposition to the negative discourses surrounding infantilisation and dominant social ideas that people with learning disabilities cannot cope with the demands of parenting, Amanda says Iris being 'childlike' is a positive attribute that she feels would have been suited to fulfilling parenting roles. Having said this, Amanda still set boundaries on what and where she allowed Iris to take the children. Amanda went on to say she feels Iris *'would have been a great mum'* if she had the opportunity, but this was not possible because of her parents' protection over her. For Amanda, ensuring Iris was involved in the children's upbringing is important as it gives her sister a '*substitute family'*, and this view seemed to be shared by other sibling participants.

The differences in the reproductive opportunities was something many participants with learning disabilities also acknowledged. For many participants with learning disabilities, parenthood was considered a normative marker of adult status and having a baby was seen as something *'most people'* go on to have in their lives (Maisy, 40s). Vanessa (40s) also seemed to view parenthood as a normative and socially valued role but seeing other people in her family fulfilling parenting roles reinforced how she felt different because she did not have children of her own. For example, Vanessa said, *'I always think that you've been born in life for a reason, be born, pay taxes, have kids and then die'* and she feels *'hurt'* because *'all my other cousins have got kids'* and she does not. Pippa (50s) similarly said seeing her cousin with *'a little baby'* was an upsetting reminder of what she did not have and being told she *'can't have children'* by her mother made her feel different to everyone else in her family.

Some other participants with learning disabilities also said they felt sad not having children of their own and told me being an aunt or uncle was incredibly important to them. Tracy (50s) for example said, *'I've got some nieces and they're like my children'*, and she told me how she helped her brother by caring for them with her mother when they were younger:

> "*Yeah, because I reared them up when they were younger, me and my mum and that, and I used to babysit for my brother now and again and that. I just enjoy the two of them, they're my world, I just love them to bits… but I would have loved kids."*

While Tracy spoke about valuing her role as an aunty by being able to support her family and help with caregiving for her nieces, it does not take away the sense of loss and sadness she feels about not being a mother. As detailed earlier, Tracy told me no one stopped her from having children but instead it was something that just *'hasn't happened'* for her. Some male participants with a learning disability talked about valuing the role of uncle, as Michael (70s) for instance said that being an uncle *'is important to me'* and felt that *'it's a God send'* because he doesn't have children of his own.

Some participants with learning disabilities further said their experiences of being an aunt or uncle shaped their views and imaginaries of not wanting to have children, as Bob (pwLD, 40s) told me:

> "*When my mum was alive, I used to you know look after like nieces and nephews and all like that and God, headache, headaches. Nah, they were lovely, they were lovely to look after but nah, don't think I'll be having children."*

In a similar way to how Tracy described helping her mother with the care giving for her nieces, Bob shared similar experiences of taking on care roles however, unlike Tracy, Bob said this had partly put him off wanting to have children. Sibling participant Stella has two children and despite her sister Essie saying that she wants to have children, Stella said that Essie *'didn't like it when they cried'* and that *'might have put her off'* having children. It is interesting here how different experiences of being an aunt or uncle may shape and influence what people with learning disabilities think about having children themselves.

The stark contrast between the reproductive possibilities of people without learning disabilities and people with learning disabilities reinforces how parenthood is stratified and considered more suitable for some groups of people than others. Recognising these differences in parenting opportunities was something some sibling participants found upsetting and unfair. For some siblings, this reproductive inequality made them want to actively support their brother or sister with learning disabilities in their role of aunt or uncle. Despite being involved in family roles as an aunt or uncle, this does not take away the sense of loss and sadness some people with learning disabilities will still feel about not having their own children. In many cases, being involved with their brother or sisters parenting roles may exacerbate feelings of difference and reproductive inequality that some people with learning disabilities experience. Again, these differences in reproductive opportunities reinforce the wider sense of marginalisation and oppression that people with learning disabilities experience as their reproduction is not judged or valued the same as people without learning disabilities.

Despite often well-meaning intentions of protection, this section has shown how family members can overprotect and restrict the autonomy of people with learning disabilities, especially when thinking about opportunities for independence, relationships and reproductive decision-making. As well as overprotection, family members can limit the reproductive imaginaries of people with learning disabilities through assumptions and stereotypes of infantilisation. Dominant social ideas also held by family members that perceive people with learning disabilities as either not interested in or incapable of having desires for intimate relationships and parenthood restricts how they can meaningfully make their own choices on the topics. Family members suggesting people with learning disabilities are unable to cope with parenting roles is another way their reproductive possibilities are limited. This section has shown that in addition to family members saying that people with learning disabilities cannot or should not have children, family members not talking about the topics also shapes the reproductive imaginaries of people with learning disabilities and they internalise this silence. The ways this section has shown that people with learning disabilities are often not expected to and are at times discouraged from having children points to the stratification of their reproduction as it is seen as less than and something to be avoided. The idea that parenthood is widely perceived as incompatible and inappropriate for people with learning disabilities echoes earlier eugenic ideologies and practices. Having so far concentrated on the ways family members can shape what people with learning disabilities think about parenthood, the next section will explore how family members can influence experiences of parenthood for people with learning disabilities.

4.3 Family members shaping parenthood experiences

As detailed in Chapter 2, family support networks can be instrumental in shaping the parenting experiences of people with learning disabilities. In this study six participants with learning disabilities had children and in the they reflected on how their family members had influenced their parenting experiences. This section will show how some parents with learning disabilities can feel oppressed and undermined by family members, especially parents, interfering in childrearing tasks. I will then detail how alternatively, for some parents with learning disabilities, family members can play important roles supporting them to look after their children and help them retain custody.

The notion of excessive control was something some parents with learning disabilities said they had experienced while raising their children. For example, Wendy is a parent with learning disabilities now in her late fifties and when she had her two children, she said she *'got support from my family'*. However, Wendy told me at times she found their support restrictive and controlling: *'sometimes you get your independence taken away because your family want to do more… they think you can't cope'*. Wendy's family assumptions that she could not cope further resonates with existing disability literature which suggests that when people with learning disabilities become parents it is often viewed with concern from others and an individual's ability to manage the complexities of parenting is questioned (Shewan et al. 2014). For Wendy, support became oppressive and controlling when her family members started making decisions for her when she felt this was something she could do herself. She described how she *'don't feel like I was in control, like making my own decisions'* about raising her children *'because I think all the family's making it for you'*. Wendy did not say whether she asked her family to be less 'interfering' in her parenting, or indeed if they would have listened to her, but she did say her family *'started backing off'* as her children got older which she said, *'made me happier'*. What Wendy says here is interesting because despite perhaps seemingly helpful and loving intentions, she highlights how family members can restrict and disempower, rather than support, people with learning disabilities performing parenting roles.

Participant Ruby has a learning disability and is in her early twenties, and whilst she does not yet have children, she thinks that parents with learning disabilities would *'have a lot of like mollycoddling and like your mum would constantly be with you or helping you'*. She added: *'I imagine you'd have a lot more help but not in a good way… like people intruding and just assuming you can't do it'*. As well as echoing what Wendy told me, Ruby's comments here also connect to earlier discussions about parents trying to do what they think is 'best' for people with learning disabilities, but there are times when acts of what families consider 'support' can be oppressive and disempowering. Ruby also talked about the hierarchy of power that family members can have over the parenting opportunities and experiences of people with learning disabilities. She reflected on the experiences of a woman with learning disabilities she knew of who became pregnant and she *'really wanted to keep the baby, but everyone else was like no you can't handle it, her family were like no you're not doing it'* and the baby was removed for adoption. Despite the woman Ruby knew wanting to keep her baby, Ruby suggested that family members had the power to overrule her wishes and removed the baby from her. Child removal will be discussed further in Chapter 6.

In contrast to the familial overprotection and excessive parental control Wendy and Ruby described as limiting and restricting parenthood opportunities, other participants with learning disabilities described how the absence of family members could also impact parenting possibilities. Jenny (pwLD, 30s) has experienced child removal, and described her experiences of being taken into care as a child and the lack of family support she has today. When asked if she had any support from family or friends to help her with parenting, Jenny said aside from her husband who also has learning disabilities, *'no, so basically I had nobody'*.

Linda (40s) is also a parent with learning disabilities who has had her son, Trent, removed from her care by social services. Like Jenny, Linda also talked about her experiences of growing up in care settings:

> *"…when I was a kid, I was abused, put in wet clothes and all that kinds of thing, everything you can think of. Then I was in and out of foster care from the age of nine I think onwards. Got to an age where the social worker said that they'd found an adopted parent who would be good for me, who would be able to meet my needs and all of this stuff but then a few months down the line she started being aggressive…"*

Linda did not say much else about the relationship with her adopted mother until she talked about her experiences of losing custody of her son, Trent. I asked Linda is she received any support from other family members with her parenting to which she replied: *'I didn't get any support whatsoever'*. Linda went on to tell me that while she did not get support from her family to help her raise her son, instead she felt that the actions of her adopted mother she was living with at the time contributed to her losing custody of Trent. Linda said that after she had given birth to Trent, *'I stayed in my adopted mam's where she was supposed to have* *helped us but all she did was go out and play Bingo and sleep all the time'*. Linda further talked about the time where she was admitted to hospital for several days and Trent was left in the 'care' of Linda's adopted mother:

> *Linda: "I had to stay in hospital for six to seven days and she had been looking after him but then the social worker came to see us in hospital and apparently, he had a pair of scissors in his hand and there was all cat hair all over his clothes, he wasn't being looked after. And then I found out she had been smacking him*
>
> Katrina: *Your adopted mum?*
>
> Linda: *Yeah, but instead of questioning her about it, about what she was doing, they were questioning me about half the stuff that was happening that I didn't know."*

As mentioned, Linda had no support from her adopted mother and instead it is reasonable to assume that the way she treated Trent heightened the concern and surveillance that social services had around the family at the time. What Linda says in this example shows us how family members can negatively shape the parenting experiences of people with learning disabilities that may contribute to them losing custody of their children. This issue of risk, child removal and the impact of not having access to parenting support will be revisited in more detail in Chapter 6.

It is important to state that not everyone said family relational networks, or the absence of them, were oppressive to parenting opportunities and experiences. Some said the contrary and suggested that familial support, especially from parents, was instrumental in people with learning disabilities fulfilling their parenthood roles. Some parents with learning disabilities said they were supported by their family, especially their mothers, to fulfil parenting roles; Fiona (pwLD, 30s) for example said her own mother is *'great'* at supporting her with looking after her son. Azeem (pwLD, 30s) lives with his parents, his wife who does not have learning disabilities, and his three children. He also talked about the support his wife received from extended family members as '*when I had baby, my wife's sister-in-law she used to come and support my wife, and my sisters and my mum'*; he told me he feels his *'big family'* support him and his wife to be good parents to their children. Azeem said he thought parenting would be difficult for people with learning disabilities without family support. Azeem is British

Pakistani, and it is worth considering how his cultural identity shapes the way he lives at home with his wider family and the support he receives from them. For instance, many South Asian families can live in multigenerational households with men and women taking on different family roles and responsibilities (Burgess & Muir 2020). I will suggest in Chapter 6 that further research could explore the significance of race and ethnicity on parenting experiences for people with learning disabilities. There is not much scope for this to be considered in this thesis as Azeem was the only participant who did not identify as white British.

The importance of familial support was also detailed by Hazel (30s) who is a single parent with learning disabilities to her daughter Claudia who is under the age of five. I asked Hazel about what kinds of support, if any, she received to help her fulfil her parenting role; she said she didn't get any formal support but that she *'had the support off my mum and my family that backed me up'*. Hazel talked about the good relationship she has with her mother and when she found out she was pregnant Hazel told me, *'my mum said it's up to you if you want to keep the baby… and we'll support you'*. Hazel also said she worried about some of the challenges of being a new mother, for instance when asked if there was anything she thought might be challenging about having a baby she replied:

> *"Looking after her, changing her, feeding her erm all kinds, yeah. But I come over them and I've done it, I done a good job. I was scared at first to change her nappy because she had the umbilical cord still and I thought I'm going to hurt her if I knock it off or anything… I got over that fear and done changed her nappy and that… And giving her a bath and that, I was scared in case I dropped her, or I drowned her or something, that was a bit scary at that time as well..."*

Despite these worries, Hazel reflected on the practical and emotional support she had from her mother and other family around her. She said she feels like *'I'm one of the lucky people, I've had that support, not everyone out there might not have that lucky support what I've got'*. Hazel said she would not have been the parent she is today without the support from her mother which echoes findings from Traustadóttir and Sigurjónsdóttir (2008) as mothers in their study said without family help it would have been impossible for them to keep custody of their children. The experiences outlined here highlight the complex dynamics of familial 'support' as a continuum; not enough or too much, intervention from family members can significantly impact the parenting possibilities and opportunities for people with learning disabilities. It also echoes the challenges highlighted earlier of balancing familial support in order facilitate autonomy and decision making for people with learning disabilities. Many participants across the different interview groups I spoke with shared the view that it would be difficult for people with learning disabilities to bear and raise their own children without the support of family because of the lack of formal support available and accessible to them.

Family participants also talked about the importance of familial support for parents with learning disabilities. For example, non-learning-disabled parent participant Lorraine (50s) said she felt that *'good parental support'* would be vital for people with learning disabilities to raise the children they have or may go on to have. Lorraine also told me that she would support her daughter Gabby (20s) *'if she ever has a baby, be it intentionally or unintentionally'* and *'so long as she wants to keep the baby'*, Lorraine said she would *'help her with it 100 per cent'*.

Of the sibling participants in this study, none of their brothers or sisters with a learning disability currently had children despite some of them wanting to be parents, but some siblings said that if their brother or sister did go on to be parents and have children, that they would also want to help support them as much as they could. Sibling participant Evie, in her early twenties, for example said, *'in the way that I feel I'd have a responsibility to support'* her brother with learning disabilities, *'I'd have a responsibility to support his kids too'*. Evie went on to say that supporting her brother would be 'more *out of want rather than obligation, like I'd want to feel like I was there for him and his family, rather than sort of I'd have to'.* Other siblings in their twenties and thirties seemed to also share this view. This willingness to provide support for their brother or sister with learning disabilities connects with broader disability literature that suggests siblings often anticipate taking on future care roles (Davys et al. 2016).

However, supporting their brother or sister with parenting responsibilities was not something older sibling participants, aged in their fifties and sixties, said they would have been happy doing. I suggest this links in with the broader 'burden' of care responsibilities some siblings said they had already taken on as their parents have got older or passed away (see

Parchomiuk 2014). Amanda (50s) for instance talked in detail about the challenges of caring for her sister since her mother passed away and how she struggles with the assumption that she is *'just expected to get on with it because she's my sibling… if it was your child you wouldn't think twice about it and you wouldn't think of it being a burden, but when it's a sibling it's slightly different because, you know, I didn't give birth to her I didn't choose to have her, and I know that sounds really harsh but you know that's the reality'.* The hesitation she describes caring for her sibling is significant and she feels that this would be different if it was her child. What Amanda says here also ties to wider discourses of siblings feeling a familial duty and responsibility to care for their brother or sister with learning disabilities.

In contrast to what non-learning-disabled parent participant Lorraine said earlier, non-learning-disabled parent participant Imogen (30s) told me she would not want to be heavily involved in supporting any of her five children, including her two stepsons with learning disabilities, with parenting roles. Imogen said:

> *"I've finished having kids so that's me done. I'm not doing it anymore, I never got support from my parents with my children and I certainly- I'm not going to be the sort of grandparent that's going to take the kids all the time, I know that sounds really harsh but if they need me for help or advice or anything like that then I'll totally be there, but I'll not be taking them all the time, not a chance. I've got too many kids and I've had them for far too many years, so no… and I know that sounds really harsh, but I just feel like we've been through an awful lot together, my husband and myself, the four years we've been together has been hell so we're looking forward to the future."*

The hesitancy Imogen describes is like what sibling participant Amanda talked about previously. Both Amanda's and Imogen's accounts illustrate how ideas of family roles and care boundaries differ between individuals. Amanda is hesitant to take on care roles because she is not her parent, and yet Imogen is a parent, but she is also reluctant to take on future care responsibilities if her stepsons have children of their own.

This section has shown the parenting experiences of people with learning disabilities can be shaped by the influence of family members around them. Parents with learning disabilities that had supportive family members had more positive parenting experiences than those who felt their families were interfering and overbearing. Parents with learning disabilities who said they had no family members in their lives also endured hardships in their parenting that they felt contributed to them having their children removed from their care (see Chapter 6). These accounts reinforce how the influence of family members can vary and how this can impact parenting possibilities of people with learning disabilities.

4.4 Conclusion

This chapter has highlighted a myriad of ways in which family members can impact the reproductive imaginaries and experiences of people with learning disabilities. The research findings show that family members can find it difficult negotiating the rights of people with learning disabilities to make their own life choices whilst also recognising their vulnerable position in society and wanting to protect them from harm. Concerns about the vulnerability of people with learning disabilities reinforces ideas of protectionism as family members tend to be more involved in their lives and decision making than many people without learning disabilities. Hollomotz (2011: 11) has previously argued that an exclusive focus on an individual's 'vulnerability' can become oppressive and deny people with learning disabilities opportunities to make their own decisions, this was a view many participants seem to share. As demonstrated in this chapter, whilst this protectionism often comes from parents' feelings of love and a sense of duty to shield individuals from harm, it can also be experienced as reproductive oppression and disempowerment as people with learning disabilities are not supported with making free and informed decisions about their bodies and reproductive possibilities. Parents' reluctancy to engage with their children with learning disabilities in discussions about reproduction reinforces social ideas that parenthood is not for people like them. In addition to this silence on the topic, the reproductive choices of people with learning disabilities can also be restricted by family members, especially parents, telling them that they cannot be parents or regulating their contraception. This gatekeeping and disempowerment are exempla of reproductive control that people with learning disabilities can experience because of the judgements made about their parenting capacity.

Findings from this study show that people with learning disabilities are aware of the different parenting opportunities available to them and many find this reproductive inequality incredibly upsetting. Judgements of capability alongside the power dynamics at play here are indicative of wider social ideas of stratified reproduction that prevent people with learning disabilities from reproducing and having children (Ginsburg & Rapp 1995 cited in Saunders 2021). This reproductive stratification is resonant with wider social discourses and marginalisation that surround disability. As this chapter has shown, there is an element of family members deliberately trying to prevent people with learning disabilities from having children as well as family members thinking parenthood possibilities are not relevant for people with learning disabilities. The outcome of these perspectives is the same, but the way it occurs is important to recognise for thinking about how things could be different going forwards for people with learning disabilities (see Chapter 7). By exploring some of the ways parenthood options can be regulated and controlled by family members, this chapter has highlighted the reproductive justice argument that not everyone has equal access to reproductive decision making. Drawing from the concept of reproductive justice it also shows how parenting possibilities can be influenced by power dynamics as family members often have control over the life choices of people with learning disabilities.

Chapter 5. Organisational contexts and actors

> *"Well the one that I always saw as a horror was the erm communal pot of tea, you know the gallon tea pot with like 20 tea bags and half a bag of sugar and a pint of milk and everybody got that, that's how little choice you had, you couldn't even choose how you took your own tea so what chance did you have on whether you became a parent or not."*
>
> Support worker Huw (40s)

5.1 Introduction

This chapter will explore how organisational contexts of social care, educational and health can shape the parenting possibilities of people with learning disabilities. From the mid-late nineteenth century in Britain, large groups of people with various disabilities, including people with learning disabilities, were kept in large-scale institutions that ostracised and isolated them from the rest of society (Geller & Morrissey 2004: 1128; Thomas 2017). In this chapter I consider how this history of incarceration and the power imbalances between staff and people with learning disabilities at the time restricted opportunities for them to form intimate relationships and make reproductive choices (Hollomotz 2011). This is followed by an exploration into whether and how the reproductive possibilities of people with learning disabilities have changed through UK policy reform. Significantly, these reforms were set out in the National Health Service and Community Care Act (1990) that advocated for care in people's own homes instead of institutions. While the act recognises the importance of living within the community as a way of promoting independence and avoiding social isolation, the extent to which this can be considered a success is still debated. In this chapter I argue that staff surveillance, coupled with the lack of access to private spaces, continues to restrict relationship opportunities for people with learning disabilities that can make it difficult for them to realistically imagine fulfilling parenting roles. This chapter further intends to shed light onto some of the ways the thoughts and actions of paid support staff can be shaped by organisational contexts and how this affects whether and how they engage with people with learning disabilities around the topics of sexuality, reproduction and parenthood. Next, I illustrate how other institutional settings are shaping what information children, young people and adults with learning disabilities can access and how this is informing what they think and experience regarding reproduction and parenthood. I then look at whether and how opportunities to access this information in formal spaces is changing for people with learning disabilities.

5.2 Life in institutions

Historically in the UK, large numbers of people with learning disabilities lived in long-stay large-scale institutions that were often characterised by locked doors, high walls and barbed wire (Goffman 1961 cited in Hollomotz 2011). Living conditions within institutions was poor and people with learning disabilities were ostracised and isolated from the rest of society (Johnson & Traustadóttir 2005 also see Chapter 2). In such institutions, people with learning disabilities were discouraged from having relationships, and opportunities for any kind of sexual experiences were severely limited (Collins & Cozens 1999; Shakespeare et al. 1996). In this study Michael and Ric, aged in their 70s and 60s respectively, were the only participants with learning disabilities who said they had lived in institutions. Ric did not talk in a lot of detail about his experiences of institutionalisation, so much of the focus of this section is predominantly on what Michael told me. Michael's story is important as it highlights the oppression that many people with learning disabilities endured in all aspects of their lives and specifically regarding their sexuality and reproductivity. Even though this is the voice of one person, a lot of what Michael says is indicative of the experiences of many other people with learning disabilities living in institutions (see Johnson & Traustadóttir 2005).

Today, Michael lives in his own home with daily support from staff and although he said he has had relationships in the past, he is currently single and does not have children. During his interview, Michael talked in detail about his experiences of being incarcerated from the age of *'11 or 12'* in several different institutions for most of his life. Michael did not say when he moved out of these institutions, but he suggested that it was some time ago. Reflecting on the over 30 years he spent living in institutions, Michael described the unequal power and control he felt staff had over his life. He talked about the physical abuse he had experienced, and the way staff would *'batter you and beat you up'* in these institutions *'because you had a learning disability':*

> *"The staff then, they come straight from the army into society like that, and there was a lot of beating up going on, a lot, you name it. Talk about jail, it was nothing like it, you know, jail is comfortable, places where we were weren't comfortable at all… it was no good for a person with a learning disability."*

In addition to the abuse Michael said he experienced, these institutions were also often synonymous with over-crowding and unsanitary living conditions (Kilgannon 2021; Johnson & Traustadóttir 2005). Michael added:

> *"It weren't nice tidy... it was cold shower or nothing, or a cold bath and the bath was never changed, it was always filthy. If you've got something wrong with your body or anything like that, you'd be getting bathed in the same water as all the others, it would never get changed, never."*

Michael went on to tell me he feels *'one of the lucky ones what come out of'* the institutions, but these experiences have '*damaged me completely'.* The abuse Michael endured highlights the general disregard for people with learning disabilities as they were often seen as a burden on society and treated as second-class citizens within these institutions (Johnson & Traustadóttir 2005).

Segregation within institutions was something Michael said he had also experienced as he remembered *'being in a dormitory with all men and boys'* and recalled how men and women with learning disabilities in the institution were separated from each other and *'stopped from having girlfriends'* by staff. He went on to say that occasionally they did have social dance events within the institutions that *'used to be great'*, but he suggested staff were in powerful positions to restrict and control interactions between men and women. For example, Michael said, *'you could never touch the ladies, you could talk to them, but you couldn't put your hand out to touch them or anything like that, it was against the law'*. This notion that it was *'against the law'* reinforces the unequal power dynamics and control staff had over the lives and relationship opportunities for people with learning disabilities living in institutions. The ways Michael here describes being kept apart from women in institutions shows both the structural and attitudinal barriers that restricted the opportunities for people like him to form intimate relationships.

On the topic of parenthood, I asked Michael if he had ever thought about having children and he replied saying he did and that he '*wanted children mostly in my life than anything else',* but said he felt unable to make his own choices about having relationships and children because staff in the institutions *'always put a block on it'*. He said that relationships and parenthood possibilities were not taken seriously by staff because they thought *'you're thick, you're stupid, you're mental and all them things and that's what they class you down as'*. Michael continued to detail why he felt staff blocked his opportunities for reproductive decision making:

> *"I got told I can't have them, we've always been said, no you can't look after the child, you can't look after yourself so, you know, and that's always been the case… They all say, no you can't have it, you can't have kids, you haven't got any experience and all this crap."*

Here, Michael seems to suggest staff assumptions that people with learning disabilities were a priori unfit to fulfil parenting roles because *'you can't look after yourself'* was a barrier that prevented him from realising his desire to have children of his own. He told me he thought these assumptions made by staff were wrong and he felt people with learning disabilities should have been able to make their own decisions on having children as *'it should've been their choice',* he said. Like others said about family members in the previous chapter, Michael was unable to challenge the views of powerful staff to act on his own desires for parenthood which further points to the marginalisation people with learning disabilities experienced in institutions.

Michael went on to suggest staff continued to restrict his reproductive possibilities when he eventually left the institutions and moved into community-based supported living as they threatened to withdraw his support and benefit income. He said staff would say to him, '*if you have a child or anything like that, we can't come in and support you or anything like that, you won't get your money or anything to do with that'.* Michael described how he felt he did not have a choice because he had no access to employment opportunities and was reliant on staff for day-to-day support. The threat of withdrawing support and benefits made by staff reinforces the power imbalances that people with learning disabilities were subjected to.

Again, this example highlights the coercion and control staff and organisations have had over the reproductive possibilities of people with learning disabilities.

Like Michael, Ric (pwLD, 60s) has lived in different institutions throughout his life. Ric now lives in supported living and has been in a long-term relationship with his fiancé, who also has learning disabilities, and he does not have children. Ric detailed similar experiences to Michael as he told me that the time he spent in institutions were *'the worst years of my life'*. Ric described the power and control he felt *'the horrible staff'* had over the lives of people with learning disabilities living in institutions as he said opportunities for parenthood *'would never happen'* because *'in the old times, our lives were being run for us, not by our sorts'*.

Ric reflected on his time living in institutions and talked about the experiences of a woman with learning disabilities, called Lizzie, who '*got herself pregnant… but the baby was taken off her'*. Ric commented on the lack of choice he felt Lizzie had on being able to keep and raise her baby as *'she had no say in the matter'*. When speaking to Ric about this, I noticed he seemed upset and frustrated about what Lizzie had experienced; he suggested that it was *'unfair'* that people with learning disabilities had no say nor control about what happened to them or their babies. Ric said he felt the reason the baby was removed was because she lived in an institution and suggested that staff assumed she would not have coped with the demands of parenting. He told me that witnessing Lizzie have her baby taken off her influenced how he thought about his own lack of opportunities to have children. For example, I asked him if having children was something he had ever thought about and he replied, *'it would never happen, it was impossible because of the situation'*. This notion that parenthood was *'impossible'* is powerful as it recognises the levels of restriction and lack of access that people with learning disabilities faced and their lack of choice about raising children.

Further echoing the restrictions imposed by staff that Michael and Ric both described, sibling participant Amber (20s) also commented on how during this period of institutionalisation she felt that *'everybody with a learning disability was just shafted off and locked away, they didn't have the right to do anything, they were deemed as totally incapable of anything'*. Participant Huw (40s), a support worker for over 30 years, also said that he remembers within these institutions people with learning disabilities had little choice about anything that happened to them, let alone to make decisions about parenthood. Repeating the quotation that opened this chapter, Huw talked about the *'horror'* of the communal pot of tea:

> *"…you know the gallon tea pot with like 20 tea bags and half a bag of sugar and a pint of milk and everybody got that, that's how little choice you had, you couldn't even choose how you took your own tea so what chance did you have on whether you became a parent or not."*

This powerful quotation from Huw here demonstrates how people with learning disabilities often had their lives run by others and the extent to which they were restricted from making everyday choices, let alone autonomous decisions about reproduction. As this section has highlighted, Huw's comment further points towards the reproductive inequality that people with learning disabilities experienced living in institutions as decisions about their lives were influenced by institutional contexts and staff working within them. The segregation of men and women within institutions restricted people with learning disabilities from forming intimate relationships with the opposite sex and from thinking realistically about the topic of parenthood. This lack of choice is indicative of how people with learning disabilities were historically treated as second class citizens and denied full and equal participation in society because of the ableist assumptions made about them. The concept of stratified reproduction is helpful to apply here because it shows how value judgements oppressed and disempowered people with learning disabilities from making their own reproductive decisions (Ginsburg & Rapp 1995 cited in Saunders 2021). This dominant negative perception and devaluing of people with learning disabilities denied them full participation in society and opportunities for thinking about relationships, sex and parenthood were non-existent. Michael's story detailed in this section illustrates the immense power and control staff and organisations had over the reproduction of people with learning disabilities. Threats to withdraw support and financial benefits are exempla of these regimes of control that restricted people with learning disabilities from making their own autonomous choices about reproduction and parenthood. The myriad of ways people with learning disabilities were restricted by institutional contexts and staff power dynamics reinforces wider social ideas that people with learning disabilities are unfit to have children.

5.3 Contemporary social care staff and organisations

The closure of institutions in the UK began in the 1960s and was influenced by a shift in social policy and philosophies of normalisation (Nirje 1972; Wolfensberger 1972). This process of deinstitutionalisation saw people with learning disabilities move out from institutions into community-based care that included living with family, group homes, halfway houses, and independent living services (Kempton & Kahn 1991: 99). Research indicates that in 1976, there were just over 51,000 people with learning disabilities living in state-operated institutions in England, and by 2002 this number had fallen to 3,638; a decrease of 93 per cent (Emerson 2004: 79). Report findings by Mencap (2017) states that today, most people with learning disabilities known to local authorities in England tend to live either with friends and family, in a registered care home or in supported accommodation. However, many learning disability advocates have questioned the rights people with learning disabilities have within these settings. These discussions have intensified over recent years with the revelation of scandals such as Winterbourne View and Whorlton Hall that have shown the abuse and inhumane treatment people with learning disabilities can still endure living in residential homes. Indeed, such cases have raised questions about the quality-of-care people with learning disabilities are receiving which leads us to consider how much has changed following the introduction of the National Health Service and Community Care Act (1990). For example, Altermark (2017: 1318) tells us about the disappointment following the closure of large-scale institutions into community-based care as it remains that 'people with learning disabilities still lag behind in more or less every standard of living or socio-economic measurement scale there is'.

As indicated in Chapter 1, support workers are often poorly paid and report feeling undervalued in the work that they do which has contributed to poor staff retention levels throughout the care sector in England (Skills for Care 2023). This section will unpack some of these issues and focus in on how organisational contexts and staff working within them can shape the lives of people with learning disabilities today. It will consider how opportunities of people with learning disabilities to experience relationships can be shaped by where they live and whom they live with and question what impact this has on how they think about parenthood. I will argue that instead of staff power disappearing with the closure of previous large-scale institutions, that rather the power of staff has changed and transformed

(Altermark 2017). People with learning disabilities are still restricted by staff working in organisational contexts that impinges on their autonomous decision making, particularly around the topics of sexuality, reproduction, and parenthood. I will also show how the reproductivity of people with learning disabilities can be controlled by the disciplinary effects of knowledge and power as they are often under the gaze and surveillance of others.

For context, it is useful to be reminded that from the 21 participants interviewed seven lived in their family home, four lived in a registered care home, five lived in supported living with support from staff, and six participants lived independently, but did mention receiving support from staff (see Chapter 3). This demographic information largely reflects wider figures by Mencap (2017) mentioned earlier. As well as where participants with learning disabilities live, it is also important to say that while 10 participants with learning disabilities said they were currently in a relationship, of those, only three lived with their partner. This reflects findings reported by Mencap (2016) that shows only three per cent of people with a learning disability live as a couple, compared to 70 per cent of the general population.

5.3.1 The influence of support workers' views

It is important to acknowledge that some participants suggested that today, they feel people with learning disabilities have more opportunities to have relationships and have children of their own. For instance, Ric (pwLD, 70s) said his move away from staff control in institutions to now living in his own flat with support means '*I run my life the way I want to run it and not having it run for me'*. Ric seemed to further suggest with the closure of institutions, people with learning disabilities now have more opportunities to take control of their lives and the decisions they make, particularly about parenthood as he said, if people with learning disabilities *'want to start a family, they have every right to'*. In a similar vein, sibling participant Amanda (50s) also said:

> *"Just think years ago, like in my sisters' time, these children would have just been put into institutions and left to rock in their chair really. I'm so glad that society has moved on massively and actually given these children a chance. You know, they're going to mainstream school, they're working, you know they're having families, they're getting married. So I think from when my sister was younger to now, there's a huge jump in the right direction, I think in putting them into the community, it's shown people that*

> *actually they are able to achieve stuff. You know, they don't need to be locked away where nobody can see them like an embarrassment, they're actually worthy of being alive."*

This shift from institutions towards community-based care that Amanda talks about here is also heavily documented in the existing literature as being a pivotal step in trying to recognise the rights of people with learning disabilities to lead normal and fulfilled lives, although the success of this is still debated. While some other participants across all groups interviewed suggested they felt the lives of people with learning disabilities had improved through the process of deinstitutionalisation, many did not share Ric and Amanda's optimism about the opportunities for them to have relationships and children.

Support worker Huw (40s) for example said that he felt opportunities for people with learning disabilities to make choices and think about reproduction have not changed as staff still have the power to say, *'you're not allowed'* to have a baby, which Huw said still *'feels like 1930'*. Caitlin (pwLD) in her early twenties also said, *'in the institutions they didn't really get that decision about having a kid and stuff like that'* and when I asked her whether she felt reproductive opportunities might have changed for people with learning disabilities today, Caitlin said, *'no, because staff have the control'.* What Caitlin says here highlights the disconnect between the rights of people with learning disabilities to make decisions about starting a family and what is realistically possible for them given the powerful influence of staff as organisational actors. This power manifests itself in the ways staff can limit and restrict the autonomy and decision making of people with learning disabilities, as this chapter illustrates.

Many participants seemed to share the opinion that staff can still act as powerful gatekeepers and relationship and parenthood possibilities are largely dependent upon the staff working closely with them, as Amber (sibling, 20s) said, *'it depends what the carers are like and what their attitudes and beliefs are'*. Furthermore, staff holding negative and outdated assumptions of people with learning disabilities as child-like and asexual was also described by some support worker participants as being instrumental in restricting parenthood possibilities. For example, some suggested that dominant social ideas held by staff about people with learning disabilities as asexual and infantilised means it can be difficult for people with learning disabilities to think meaningfully about the possibilities of relationships and parenthood if staff do not take their desires seriously. Reflecting on his own experiences as a support worker, Gus (60s) suggested the sexual identities and reproductive possibilities of people with a learning disability still *'just isn't taken seriously'* by staff:

> *"There's still a reluctance to acknowledge that people with learning disabilities can have any form of sexual or romantic desires... There's still absolutely almost zero understanding or view that the people we work with may be sexual beings or may have emotional attachments, or anything other than manufactured relationships that people laugh about rather than take seriously, you know, and it's sad to believe that, and it's sad that that's still the case."*

Gus continued to comment on how some staff he has worked with have seen relationships between two consenting adults with learning disabilities and yet staff still *'treat it like if it was two five-year-olds, you know'*. Echoing what Gus said about relationships not being taken seriously by staff, support worker Huw (40s) also described some of the negative views staff he has worked with had towards the sexuality of people with learning disabilities as he said they thought *'the idea of them having a sex life was a bit of a joke'*. This idea that romantic and intimate relationships are not taken seriously by support staff is also described in existing disability work by Black and Kammes (2019) who similarly suggest romantic and sexual desires of people with learning disabilities are often degraded and infantilised as 'puppy love'. This assumption held by some staff that people with learning disabilities are not recognised as sexual actors contributes to their social position as child-like which restricts their opportunities to think meaningfully about parenthood. It raises the question of how people with learning disabilities can make meaningful decisions about relationships and parenting if staff close to them *'still have this attitude… basically they're kids themselves'* (Jenny pwLD, 30s). Sibling participant Amber (20s) also said:

> *"It's not something that people often think about and then when the question's posed people kind of go, 'oh somebody with a learning disability having sex, is that even possible?' And you can even have conversations with people who work in the sector, and they still think that it's not acceptable… How could they possibly be having sex when their behaviours present as a three-year-old, but they're in a body of a 21-year-*

> *old? You know that kind of thing, one minute they're playing with a children's toy and the next minute they're talking or thinking about sex or whatever… they perceive them as, a child."*

Amber continued to add that *'if they're perceived as a child'*, the question then often asked is *'how can a child have a child?'*. I asked Amber and some other participants how they thought these assumptions might impact relationship and parenthood opportunities for people with learning disabilities, to which Amber replied:

> *"If they're constantly told you can't have, you won't have, it's simply not possible for you to have that or whatever, then that's just gunna make them feel like they can't, it's not doable, it's not something that they can aspire to."*

This quotation from Amber highlights the challenges for people with learning disabilities to think about and make meaningful reproductive choices when they are surrounded by staff who hold negative views and assume it is something they do not have the desire nor capabilities for. This notion of staff ideas about infantilisation and how this can influence what people with learning disabilities can realistically imagine about parenthood echoes family relational discussions in the previous chapter. What Amber says also raises questions about how care organisations are recruiting and training staff who hold these kinds of negative attitudes. It is reasonable to argue that as well as limited resources, care organisations are not doing enough in the recruitment and training of staff they provide to ensure staff values align with rights-based ideologies. This is significant as it shifts the issue from individual staff attitudes to wider organisational and structural problems that are letting people with learning disabilities down by restricting their opportunities for making informed and autonomous choices.

Sibling participant Francesca (30s) spoke about how she felt opportunities for people with learning disabilities to be intimate could be influenced by what staff felt was *'appropriate'* for men and women. For instance, Francesca said negative staff attitudes about sexuality and intimacy would be held *'more towards women'* because of the ways *'women are more vulnerable sexually'*, she further commented on the *'sexism at play in most areas of society'* and feels this is *'unlikely to be less of a thing for people with learning disabilities'*. Francesca told me:

> Francesca: *"… I work with lots of people who display inappropriate sexual behaviour or risky sexual behaviour, and everyone worries about it, but a man masturbating won't make people feel uncomfortable nearly as much as a woman masturbating. And that's not about vulnerability at all, that's about being a sexual being really isn't it. But yeah, if a woman does it, that makes people feel much more uncomfortable.*
>
> Katrina: *And if it's a woman with a learning disability?*
>
> Francesca: *Oh, I think even more so."*

What Francesca says here highlights broader social discussions about how the intersectionality of gender can impact the sexual and intimate opportunities for people with and without learning disabilities. For women with learning disabilities, a combination of gender, disability and the involvement of staff in their lives can be barriers to them having intimate relationship opportunities.

Other participants suggested that in addition to staff perceptions of people with learning disabilities as asexual and child-like, dominant a priori assumptions of parental incompetency and inadequacy held by staff were significant barriers to people with learning disabilities being able to make their own reproductive decisions and fulfil parenting ambitions, if desired. Support worker Huw (40s) for example, said he felt a significant concern shared by some staff he has worked with is '*if you let them have babies who is going to look after the baby?'* which illustrates the overwhelming assumption that people with learning disabilities cannot cope with the demands of parenting and that providing them with help is somehow a problem or burden. Participant Hazel (30s) is a parent with learning disabilities living independently and receives support from her mother and other family members to help her raise her young daughter Claudia, who is under five. Like Huw, Hazel also said she thought it would be difficult for people with learning disabilities to have children, particularly in care homes or supported living because staff still have the control to say, *'no you can't have kids'* as they might assume *'you won't be able to cope or look after them'*. This assumption by staff that people with learning disabilities will be unable to care for their children described here echoes what

Michael (pwLD, 70s) said staff told him when he lived in institutions, indicating that staff continue to be in positions of power to restrict parenthood possibilities.

Support worker Freya (20s) also described how she felt some staff she has worked with think parenthood is not a role people with learning disabilities can fulfil or make choices about because they are perceived as incapable. For example, she told me about some comments she said she has heard other staff members say, such as: *'you can't put your own earrings in so I doubt you'd be able to dress a child',* and *'you struggle to dress yourself… you might also struggle to dress a baby'*. She then told me that *'a couple of care plans that I've seen it says, if such and such gets pregnant, these are the steps we follow'* that had been set out by social workers. It can be argued that the way pregnancy scenarios are mapped out in people's support plans indicates organisational validity and acceptability; again, barriers to parenting opportunities for people with learning disabilities are restricted by more than individual support worker attitudes as they are reinforced by wider structural and institutional contexts.

I then asked Freya what the steps to follow were and whether this had happened to any individuals she has supported to which she replied, *'yeah it's happened to at least six of them'* where they have either had an abortion or their baby was *'whipped away and put up for adoption'*. Freya said she feels the assumption here is *'you're not capable of looking after a child'* and *'you're incapable of making these decisions'* and so any opportunity for reproductive decision making is taken away from them by staff and other powerful professionals. While Freya said it seems these decisions are taken in their best interests, she seemed to find this level of reproductive control and oppression upsetting:

> *"It baffles me to be honest… because I've never thought like that. I've always thought people with learning disabilities should have as much choice as we do, why are they being treated differently?"*

Again, the assumption described here is people with learning disabilities are not capable of thinking about or making their own decisions about reproduction and parenthood. It further indicates the lack of reproductive choices people with learning disabilities have as others without learning disabilities are in positions of power to make decisions for them that are deemed in their best interests. People with learning disabilities are often unable to challenge these decisions made by others because of unequal power dynamics, which points towards their wider marginalisation and oppression (see Löfgren-Mårtenson 2004). Findings detailed in this section show that rather than the power of staff disappearing with the move away from large-scale institutions, instead this power has changed and transformed to more subtle coercive control that limits people with learning disabilities from fulfilling parenting ambitions (Altermark 2017). The concept of stratified reproduction is helpful to use here as it shows us how staff continue to sustain barriers to people with learning disabilities fulfilling parenting ambitions based on myths and assumptions that they lack the skills to successfully carry out parenting duties. Value judgements made by staff that they are child-like and parentally incompetent seem to justify the reproductive oppression and disempowerment many still experience (Ginsburg & Rapp 1995 cited in Saunders 2021).

5.3.2 The surveillance of support workers

Löfgren-Mårtenson (2004: 204) claims that people with learning disabilities often live in a 'protected world' as they are closely watched by others around them, particularly in social care contexts. The monitoring and surveillance by support workers is perhaps unsurprisingly something people with learning disabilities experience living in supported living accommodation but people with learning disabilities living in the family home also talked about how support workers made it harder for them to enjoy intimate relationships. This section will first consider staff surveillance in residential settings before moving later to look at how this issue impacts people with learning disabilities living at home when they go out into the community.

Many participants like Fiona (pwLD, 30s) seemed to share the view that opportunities for people with learning disabilities, not already living with a partner, to build and maintain relationships *'would be quite hard'* because the social spaces they occupy are often regulated and surveiled by staff. Support worker Gus (60s) also described how staff surveillance in these spaces can limit relationship experiences for people with learning disabilities, as he said '*it's very hard to have a relationship when you've got a support worker either side of you'* watching over you. Support worker Huw (40s) similarly shared this view as he remarked, *'how do you have a relationship when there's always someone sat there'* and he added that people with learning disabilities *'never really have any private time'* because of the constant presence and surveillance of staff. Michael (pwLD, 70s) said, *'even when they go to discos, there's always staff there looking at them'*, I asked Michael how this surveillance might make people with learning disabilities feel, to which he replied, *'it's hurtful'*.

The notion that staff surveillance is a barrier to people with learning disabilities experiencing relationships and thinking about parenting possibilities was also described by other participants I spoke to. For instance, Caitlin (pwLD), in her early twenties, also told me *'it's not easy'* being in a relationship in supported living because it can be difficult for her and her partner to have time alone together. Unlike most participants with learning disabilities I spoke to, Jenny (30s) currently lives with her husband, but she also acknowledged the impact staff presence and organisational rules can have on relationship opportunities for people with learning disabilities in supported living. She said it would be *'much harder because in supported accommodations they can't have their boyfriend stay so it's like difficult to actually have a relationship'*. Spaces where people with learning disabilities feel monitored, surveilled, and controlled therefore make it challenging for them to imagine themselves fulfilling parenting roles in the future.

Non-learning-disabled parent participant Lorraine (50s) also described how she thinks staff surveillance, monitoring and regulation in care homes and supported living limits opportunities for privacy. Reflecting on the home where her daughter Gabby, in her early twenties, stays during the week, Lorraine said:

> *"They're not allowed in each other's bedrooms, occasionally the girls get permission to go upstairs together and even then, they have to ask and then it's an open-door policy... If Gabby wanted to pop down to one of the houses, or one of the others did, then they have to get permission to go, they have to get permission from their care staff and then it has to be convenient for the care staff in the other house as well. They also wouldn't be on their own particularly, they might get 10 or 15 minutes next to each other on the sofa together chatting but that's it, but other people come and go in the room, you know, there's not, oh those people are having a private time in that room, that doesn't ever happen… sexual intercourse and things like that would definitely be a complete and utter no, no."*

This sense of needing permission from staff to experience relationships highlights their powerful position as gatekeepers of organisational rules, capable of granting or denying access to relationship opportunities. As well as a ban on over-night stays and open-door policies, other disability studies writers have commented on how single beds in care homes and supported living reinforce the notion that intimacy, sex, and reproduction is not something people with learning disabilities should be engaging in (Rushbrooke et al. 2014; Hollomotz 2009a). Restrictions on overnight stays and open-door policies are exempla of the power and control staff and organisations continue to have over the intimate lives of people with learning disabilities that deny them opportunities to make decisions about sexual relationships and parenting possibilities. These regimented policies and practices therefore echo the previous large scale institutional control that sought to segregate and discourage people with learning disabilities from having intimate relationships and reproducing.

Non-learning-disabled parent Lorraine (50s) continued to detail how she feels the lives of people with learning disabilities are surveilled and monitored by staff more closely than people without learning disabilities. Reflecting on her daughter Gabby's (20s) residential accommodation, Lorraine said:

> *"There are probably a lot more rules and regulations in place than there would be at say a university campus, if a young woman on a university campus chooses to have a relationship with a lad at the university campus, nobody gets involved do they, whereas when you've got a learning disability there's always somebody around."*

This quotation reinforces the challenges of experiencing relationships when staff are always there as well as highlighting the difference in opportunities people with learning disabilities have for thinking about and experiencing intimate relationships and parenthood possibilities compared with people without learning disabilities. This recognition of the differences in relationships and reproductive opportunities also echoes what some sibling participants said in the previous chapter as most people do not experience restrictions on their intimate lives, and this difference illustrates the broader marginalisation and oppression people with learning disabilities endure.

Lorraine further commented on how support staff can go beyond passive surveillance to actively policing and blocking relationships between people with learning disabilities. Thinking about staff views and behaviours at Gabby's former SEND school, Lorraine said, if a girl with learning disabilities *'even sat next to a boy, they'd assume they were hopping into bed with them'* and staff would say, *'you can't sit next to that person, especially if they knew they liked each other, they'd even stop them from sitting on a bench together'*. This assumption of hyper-sexuality sits in juxtaposition to other dominant social ideas about people with learning disabilities as child-like and asexual highlighted earlier. It is significant because from what Lorraine details here, the idea of unruly sexuality justifies staff intervention and control to prevent relationship possibilities for people with learning disabilities.

This notion that staff are in a powerful position to stop people with learning disabilities from relationship opportunities was also described by support worker Huw (40s). Huw talked about an incident during his time as learning disability service manager where he was interviewing someone for the role of support worker and one of the questions asked was on the topic of sexuality to which the person replied: *'oh my God, you can't have that we'd have to stop that immediately, we'd have to separate them'.* Huw said he found it *'bizarre'* that someone would have that view towards a couple with learning disabilities and it was far removed from his own supportive attitudes towards the sexual and reproductive rights of people with learning disabilities. Support worker Gus (60s) similarly commented on how some staff can feel it is their responsibility to stop people with learning disabilities from relationship and parenting opportunities. For example, Gus reflected on how some staff walked out of an awareness and training course about sexual relationships for people with learning disabilities he had recently attended:

> *"Three support workers walked out because they felt it was immoral and they shouldn't be talking about these things… they didn't think it meant actually talking about it and about people actually being allowed to do it, they thought we were going to talk about how wrong it was and how we should stop people."*

This quotation highlights the negative views of some support workers towards the sexuality of people with learning disabilities as *'immoral', 'wrong'* and something they ought to be prevented from engaging with. The use of the word *'allowed'* is also significant as it points towards the power inequalities people with learning disabilities can experience; support workers can play a powerful role in restricting access and being able to *'stop'* opportunities for sex, reproduction, and parenting. These power dynamics are enabled by organisational contexts concerned about risk and protection in which ideas of safety and appropriacy trump autonomous choice and decision-making for people with learning disabilities. This is theme of risk aversion is discussed further in Chapter 6.

Participants described other ways they felt staff were in powerful positions to control and restrict relationship opportunities and experiences for people with learning disabilities. For example, non-learning-disabled parent participant Judith (60s) shared with me how she felt her son Ralph's relationship with his fiancé Joan is being controlled by staff in the care home Joan is living in. Ralph and Joan, both in their thirties, currently live in separate care homes, and they rely on support workers to assist them with maintaining their relationship; for example, supporting them going out for dinner. In the interview Judith recalled an incident where a senior staff member, called Max, tried to stop Joan going out for a meal with Ralph:

> *"Ralph rang me that morning distressed and said, we can't go for this meal, Max said Joan can't go for this meal. And I said, what do you mean Max says Joan can't go for this meal, it's all been agreed. Ralph said, Joan's just rang me in tears because Max has said she can't go now this evening. So, I just got straight on the phone to Max and said, Max what's this all about, and of course he backed off at a rate of knots, you know, but I thought, don't play those games. That really did make me cross because Joan wouldn't make that up, there's no way she'd make that up, so to me there was some sort of controlling behaviour there and I think there's a lot of that that goes on."*

This quotation reinforces the powerful position that support staff can have as gatekeepers; they have the power to grant or deny people with learning disabilities access to relationship opportunities. I asked Judith why she felt Max might have initially said Joan could not go out for dinner with Ralph and she said she expected it was a combination of negative staff attitudes towards their relationship and it perhaps not being convenient for staff to support them that evening. I continued to ask Judith whether she felt staff are generally supportive of people with learning disabilities wanting and having relationships, to which she replied, *'no*

I don't, because of what's happened with Joan'. As noted earlier, Judith's example reinforces how some staff still do not prioritise or take seriously the relationships of people with learning disabilities as they are often perceived as child-like and tokenistic. Judith's comments that staff have the power to stop people with learning disabilities going out on dinner dates echoes what Michael (pwLD, 70s) said about how staff stopped and restricted his opportunities to have relationships while living in institutions. Staff continuing to deny opportunities for people with learning disabilities to build relationships concretises the view that it is something they should not be engaging in and reinforces how staff can still prevent people with learning disabilities from imagining and realising parenthood desires.

Non-learning-disabled parent participant Lorraine (50s) said that while she thought the surveillance and monitoring of support staff would make it incredibly difficult for people with learning disabilities to make decisions about sex and reproduction, she also suggested the control could be justified as a form of protection:

> Katrina: *"Do you think that is hard for people with a learning disability if they might want that private time?*
>
> Lorraine: *Yeah probably, but it is difficult because yes, it's hard, but it's made hard partly because of their safety… They're around what you call care and support staff who have got a duty of care."*

What Lorraine says here indicates some of the tensions highlighted in disability studies literature by the way support workers 'walk a fine line' between their professional legal duty of care to safeguard and prevent harm with their duty to support people with learning disabilities with autonomous decision making (Petner-Arrey & Copeland 2015: 42, also see Hawkins et al. 2011). As Lorraine's comment suggests, within organisations protection is often considered a priority that can restrict the ways staff are able to support people with learning disabilities with topics of intimate relationships and reproductive decision making. However, protectionism can also be experienced as forms of oppression and disempowerment that deny people with learning disabilities agency over their own decision making. A call for care organisations and staff working in them to better balance some of these tensions between protectionism and the right to autonomy of people with learning disabilities is picked up later in the conclusion chapter of this thesis.

Having so far focused on staff surveillance in residential accommodation, I now turn to explore how this shapes the lives of people with learning disabilities living with family when they go out into the community. Some participants with learning disabilities who did not live in care home or supported living described how surveillance from community support staff was restricting their opportunities for intimacy and limiting their future possibilities of parenthood. For example, Billy (pwLD), in his early twenties, described the challenges of surveillance from support workers and the impact he feels it has on his relationship with his partner Grayce, who also has learning disabilities. Like most people with learning disabilities, Billy and Grayce do not live together as they both still live in their family homes with their parents (Mencap 2017). Billy spoke about feeling *'very irritated'* by the lack of access he has to private spaces to be intimate with Grayce because of the constant surveillance of Grayce's community support staff. Billy said he's been in a relationship with Grayce for *'over two years but we have yet to have a date on our own'* because there is always a staff member present, he added:

> *"When it comes to any intimacy whatsoever, even if it's just a little kiss or something like that… you have to do it in split moments when nobody's around, which feels like you're doing something wrong when you're not."*

This notion that *'a little kiss'* between two consenting adults, both aged in their early twenties, feels naughty and *'wrong'* because staff are watching and making judgements reinforces the power and control staff surveillance can have on relationship and intimate opportunities for people with learning disabilities. This air of secrecy Billy alludes to as he feels he only has '*split moments'* of intimacy echoes work by Fitzgerald and Withers (2013) who also find people with learning disabilities often hide their relationships fearing the consequences of getting caught being intimate. Billy added that staff watching over his relationship with Grayce made their relationship seem *'child-like'* and he suggested that their intimacy was not taken seriously by staff which mirrors what support worker Gus said earlier about staff infantilising relationships of people with learning disabilities (also see Black & Kammes 2019).

When I asked Billy whether he felt this level of surveillance was shared by other couples with learning disabilities he seemed unsure:

> *"From what I know of other people with learning disabilities and their relationships, I don't know if I'm honest. All I know is from what I've seen from other people they actually have quite normal relationships where they go out by themselves, just with each other really, and not have this person in-between… I've not met many people in a similar situation to me, put it that way."*

Interested in if, or what, impact this staff surveillance had on his thoughts of parenthood, I asked Billy if having children was something he had ever thought about and he replied by saying, '*I'm not 100 per cent sure with the current relationship'.* Billy continued to suggest because of the presence of Grayce's staff, they have no opportunities to be alone or intimate with each other which makes realistically imagining the possibilities of parenthood difficult. What Billy says here illustrates how staff presence and surveillance can restrict and disempower people with learning disabilities from thinking about future parenthood possibilities.

In addition to relationships and opportunities for intimacy being restricted by staff, other participants with and without learning disabilities described how the reproductive decision making opportunities for people with learning disabilities can further be limited by staff as they surveil and regulate contraceptive access and usage in residential and supported living settings. Support worker Freya (20s) told me she supports adults with learning disabilities in their own home and she detailed examples of staff actively restricting and controlling the relationship and reproductive opportunities for people with learning disabilities by discouraging sexual intercourse and confiscating condoms. Freya described an incident where a woman with learning disabilities she supported, called Kayleigh, had confided in her that she was having sex with a partner and Freya said she *'wanted to make sure she was safe'* so she bought her condoms to use, but Freya said her manager told her she *'can't be having sex… and confiscated these condoms'.* She told me her manager said she should not be *'encouraging'* or *'exhibiting sex'* for the people she supports.

Freya also added she felt the ways people like Kayleigh get treated differently because of their learning disability is *'just not fair, they're human you know, I don't come to your house and stop you from having sex… I wouldn't stop you buying condoms from a shop'*. Like non-learning-disabled parent Lorraine and other participants mentioned earlier, Freya recognised the unequal differences in reproductive opportunities for people with learning disabilities compared to those without. When I asked Freya why she felt her manager had reacted that way and confiscated the condoms from Kayleigh, she suggested it was because people with learning disabilities are assumed to be *'at risk and vulnerable'* and in need of protection. Ironically however, by restricting access to condoms it can be said this may expose Kayleigh to more harm, such as sexually transmitted infections (STI's) and unplanned pregnancy. This notion of risk to STI's and unplanned pregnancy is discussed further in the next chapter.

This scenario Freya describes seems not to be an isolated incident as support worker Huw (40s) also detailed how people with learning disabilities, especially women, he has previously supported were prevented from making their own reproductive decisions by staff and other professionals regulating their contraceptive usage. For example, he said, *'if you're in like a residential setting or even supported living sort of setting, your medication can be administered by other people and regulated that way'* by staff. He went on to describe the experiences of a woman with learning disabilities, called Chelsey, who lived in supported living where Huw worked. Huw recalled how Chelsey had been prescribed the contraceptive pill, however he and other staff supporting her *'realised that she was palming her contraceptive pill… she was pretending to swallow it'*, he said. Huw noted the contraceptive pill was the only medication Chelsey pretended to take, and when I asked him why he thought Chelsey did that, he replied, *'because, well, she knew what it did, and she wanted to get pregnant'*. Huw said staff were watching and documenting that Chelsey was routinely not swallowing the pill and then *'after talks with other medical professionals… she ended up on the Depo'* contraceptive injection. The way Huw describes staff watching and documenting what Chelsey did with her contraception further illustrates how staff can create a normalising gaze that positions people like Chelsey as inferior objects of examination (Foucault 1991 cited in McIntosh 2002).

Reflecting on Chelsey's experiences, Huw said he felt *'it was obviously seen as in her best interests'* as the overarching objective was to *'take any risk of pregnancy out of her hands'*. Interested by Huw's use of the word risk, I asked if this was how he thought it was perceived by other support staff and medical professionals:

> Katrina: *"And you said, a risk of getting pregnant, do you think it was seen as a risk?*
>
> Huw: *That's why I used that term yeah, yeah, because that was definitely how it was viewed, it was like, well we can't have that happen, it was a risk, it was definitely seen as a detrimental thing."*

After hearing Huw talk about Chelsey's story, I asked him whether he felt people with learning disabilities living with staff closely involved around them might have opportunities to think about parenthood, to which he replied, *'no, no I don't'*. He said that while he thought contraception regulation was part of the bureaucracy in place *'as a blanket to protect people'*, he also acknowledged the limitations and restrictions this has on parenthood opportunities. He said that staff, and others such as medical professionals, are in powerful positions to limit and restrict parenthood possibilities as people with learning disabilities almost need to seek staff's permission and ask, *'am I allowed to have a baby?'*. This sense of people with learning disabilities asking permission to have a baby echoes what other participants said earlier about staff gatekeeping relationship possibilities, thus reinforcing how power imbalances between support staff and those being supported can actively restrict people with learning disabilities from making their own contraceptive and reproductive decisions.

From what Huw says here, it seems Chelsey understood that taking the contraceptive pill stopped her from having a baby. However, attempts at autonomous decision making about her own body and reproduction were restricted by staff and medical professionals observing and making judgements about what they thought were in Chelsey's best interests. This sense that it was staff and other professionals who seemed to decide what was in Chelsey's best interests, without discussion with her, further points towards the lack of choice many people with learning disabilities have over their lives as they are unable to challenge decisions made for them. Huw's comments illustrate how risk management and staff's duty of care takes priority over supporting people with learning disabilities to make autonomous reproductive choices. It further highlights how organisations' occupation with risk is used as justification for the level of monitoring and surveillance people with learning disabilities can experience.

While it seemed that most participants shared the view that staff could be powerful gatekeepers who often discourage and block people with learning disabilities from building and maintaining intimate relationships, this does not reflect the views or experiences of everyone I spoke to. For example, Maisy (pwLD) is in her forties and lives in supported living with staff present throughout the day and night. Maisy is in a relationship with her now fiancé Bryan, who also has learning disabilities, and like most people with learning disabilities, they do not live together. I asked Maisy how she found having a relationship with Bryan while she is living in a supported setting, to which she replied, *'I find it easy'*. She went on to tell me how Bryan *'comes down for tea'* and *'support staff come along, and they talk to Bryan'*, and she added that staff also do *'kind of leave us on our own'* at times. Here, Maisy seems to suggest staff help her maintain her relationship with Bryan by supporting them together but also allowing them privacy and time alone together. Maisy's positive experiences offer us ways of understanding how staff can support relationship opportunities for people with learning disabilities while also being able to uphold their professional duty of care (see Chapter 7). However, Maisy's story differed from what most participants said about staff impacting relationship opportunities and experiences. The overwhelming view amongst most participants seemed to be that staff were still very much considered powerful gatekeepers that often-restrict relationship and intimate opportunities for people with learning disabilities.

This section has described some of the challenges restrictive organisational policies and staff surveillance can have on the opportunities for people with learning disabilities to experience intimate relationships and think meaningfully about parenting possibilities. Findings suggest that people with learning disabilities cannot realistically think about the possibilities of parenthood when access to private spaces and intimate opportunities are controlled by powerful staff working within organisational contexts. This lack of access combined with constant surveillance and control reinforces the notion of staff acting as 'institutional walls' that continue to oppress and disempower the reproductive possibilities of people with learning disabilities (Löfgren-Mårtenson 2004). These power imbalances between individuals who are seen as care-givers and those who are cared-for is also detailed in disability literature by Scior (2003) and Löfgren-Mårtenson (2004). In addition to policies and staff surveillance restricting intimate opportunities for people with learning disabilities, this section has also illustrated how staff can regulate and control contraceptive usage for people with learning disabilities that denies them reproductive agency. The routinised use of hormonal contraception for women with learning disabilities is disturbingly reminiscent of earlier eugenic practices, such as sterilisation, that sought to restrict and prevent people with learning disabilities from reproducing (Crossley 2020). Similar examples of this form of contraceptive and reproductive control have been documented by Malacrida (2020) as a form of 'newgenics' that continues to oppress the parenthood imaginaries and decision making of people with learning disabilities. Therefore, restrictive organisational policies and staff surveillance in particular reinforce social ideas that the reproductivity of people with learning disabilities is not taken seriously and is something that should be prevented and guarded against. The surveillance of people with learning disabilities is exempla of the gaze that Foucault describes that enacts social control as these power dynamics reiterate the types of reproduction society wants.

5.3.3 The silence of support staff and social care organisations

People with learning disabilities often have smaller social networks and fewer opportunities to learn about sexual and reproductive health information from friends and peers than the general population (Llewellyn & McConnell 2002). For many people with learning disabilities, what they know and understand about these topics is influenced by support staff and professionals around them (Jahoda & Pownall 2014; Meaney-Tavares & Gavidia-Payne 2012; Pownall et al. 2012). Echoing what has been said earlier in this chapter, the personal views of staff and the organisational contexts they work within can shape what, if any, information about the sexual and reproductive health they share with people with learning disabilities. In England there is currently no mandatory training for social care staff to undertake about the topics of relationships and sexuality (Skills for Care 2021), and despite recent recommendations made by the Care Quality Commission (Care Quality Commission 2019) for staff to receive specialist training on the topics, providing this training remains at an organisation's discretion (Skills for Care 2021 also see Chapter 2).

Support worker participant Gus (60s) was the only support worker interviewed who said they had received any kind of formal training about supporting people with learning disabilities about relationships; this mirrors recent research that finds most support staff do not receive training on this topic (Skills for Care 2021). Support worker Freya (20s) suggested that this lack of formal training and guidance means that some staff can feel reluctant to engage in discussions or feel unsure about what is *'appropriate'* to say to people with learning disabilities about intimate relationships, sexuality and reproduction. Freya said: *'it can be such an awkward topic to talk about'* and so these discussions often get avoided altogether.

As well as not having adequate staff training on the topics, Freya also suggested staff do not get paid enough to support individuals with such important and potentially lifechanging discussions and decisions. For example, Freya said staff are often *'overworked and underpaid'* to deal with the enormity of such conversations about reproduction and parenthood. Freya further commented that *'care workers often don't have the time to be honest, to just kind of sit with someone'* and talk about it. What Freya says here is significant as it points towards broader structural issues that can present challenges to staff supporting people with learning disabilities to think about and make meaningful choices about reproduction and parenthood: time and money. Unlike the silence of family members around the topics of reproduction and parenthood, this notion that staff do not have the training, time or get paid enough to engage with these conversations is an insight into the dynamics of paid care work. It highlights how staff responses towards the topic can be influenced by the wider institutional context and conditions in which they work.

Freya also said some staff she worked with deliberately avoided talking to people with learning disabilities about these topics at times fearing they might get into trouble with management. For example, Freya said following an incident where she was *'told off'* by her manager for discussing the topics, she said herself and other staff often *'wouldn't talk about it'* with people with learning disabilities because *'why would we deliberately put ourselves in that sort of awkward position'* and risk *'getting myself sacked'*. Freya's point that staff are worried about-facing discipline from their employers by engaging in discussions of sexuality echoes findings by Abbott and Howarth (2007). Listening to Freya's account, she felt staff could be better supported by management and the care organisation to have these conversations with the people they support, this is point that is revisited in Chapter 7.

Echoing what non-learning-disabled parent participant Lorraine (50s) said earlier, sibling participant Francesca (30s) and support worker Huw (40s) both talked about some of the challenges staff can face with supporting the rights of people with learning disabilities to form and experience intimate relationships whilst balancing this against their professional duty of care to protect people from harm. Sibling participant Francesca also works with people with learning disabilities, and she commented on how she felt there is a *'fear I think in terms of the legal framework and mental capacity'* among staff and organisations. She continued to suggest that it could be particularly difficult for staff to try to *'keep people safe without restricting all of their freedoms and liberties'*. Support worker Huw gave an example of supporting a young man with learning disabilities to buy condoms from the shop, when asked whether he felt other support workers would have done the same, Huw replied:

> *"I hope so, I mean it's your job isn't it… You do what you need to do don't you, you're there to enable these guys to do as much as they can do, whether it's uncomfortable for you or goes against your own beliefs or whatever, I mean you just get on and do it don't you… It's not about you, you're being paid to enable them."*

There is a difference between the example Huw gives here and the way support worker Freya (20s) previously said her manager confiscated the condoms she had bought for someone with learning disabilities she was supporting. This highlights how opportunities for people with learning disabilities to experience intimate relationships and make choices about reproduction can be shaped by different organisational and institutional relations, and not just views and beliefs of individual support staff. As well as supporting the rights of people with learning disabilities, Huw also said he felt some staff may worry about the responsibility of talking to people with learning disabilities about these topics and the potential risks this might come with; especially when staff have a *'moral obligation and duty of care, and all that sort of thing'*. Huw continued to comment that from his work experiences, he thought some staff felt having these discussions could be *'a lot of hassle'* and it was easier for them not to mention sexuality and reproduction *'and then toss it to one side'*. What Huw suggests here also points to broader discussions of vulnerability, risk and overprotection that are restricting whether and how staff engage with people with learning disabilities about sexuality and reproduction.

When asked what he thought the impact of this silence from staff around the topics might be, support worker Gus (60s) suggested that it reinforces the assumption of asexuality and the idea that relationships, sex, and parenthood is not taken seriously and *'is not for people like you'*. The way the intimate relationship and parenting possibilities of people with learning disabilities seems to not be taken seriously is exempla of stratified reproduction as their reproductive rights are oppressed and devalued by staff as organisational actors.

The lack of conversation and discussion about reproductive possibilities can be understood as a form of oppression that restricts people with learning disabilities from making their own choices. As organisational actors, whether and how staff engage in discussions about relationships, sexuality and parenthood with people with learning disabilities is shaped by the contexts they work in. As this section has illustrated, staff can be reluctant to have conversations with people with learning disabilities about sexuality, reproduction and parenthood because of a lack of staff training. This mirrors existing findings in the literature as Santinele Martino and Perreault-Laird (2019) suggest, organisations can engender a culture of silence and fear around talking about topics of sexuality, reproduction, and parenthood as the threat of getting into trouble and risk of losing their job restricts them from challenging reproductive oppressions. This difficulty of wanting to empower people with learning disabilities with information but at the risk of losing their job was something support worker Freya talked about. Furthermore, staff have a professional duty of care, and some staff can be reluctant to talk about and support people with learning disabilities with intimate relationships and reproductive choices because of the potential risk of harm and emotional upset this might expose them to. Consistent with research findings by Petner-Arrey and Copeland (2015), participants in this study said poor wages were a barrier to some staff supporting the autonomy and decision making of people with learning disabilities around the topics of intimate relationships, sexuality and reproduction. This silence from staff as organisational actors can be understood as a form of reproductive oppression as the lack of access to information restricts the reproductive choices and decisions people with learning disabilities make. All three support worker participants said there should be more training for staff to feel confident talking with people with learning disabilities about sexual and reproductive health. This is also something that Rushbrooke et al. (2014) comment on as they call for staff to be better trained and supported to help people with learning disabilities around the topics of relationships, sexuality, and reproduction (See Chapter 7).

As this section has illustrated, reproductive oppression goes beyond the actions of individual support workers; instead, it is rooted in wider organisational contexts and regimes of power that reinforce the disempowerment of people with learning disabilities. It further illustrates how support workers and institutional organisations can and do operate as agents of discipline that restrict the reproductive opportunities of people with learning disabilities. Support workers can themselves feel disempowered and somewhat threatened by organisations to help people with learning disabilities access the information they need to help them make their own reproductive choices. Significantly, the dominance of care organisational contexts extends beyond the topics of sexual and reproductive health; for example, national scandals about the abuse of people with learning disabilities in care organisations points towards ongoing problems with how many are still being mistreated.

5.4 Other institutional settings as sources of information

As well as in care organisations and support workers, it is important to look at the role other institutional organisations and actors can have in shaping what people with learning disabilities know about sexual and reproductive health and what impact this has on their parenthood possibilities. Access to sexual and reproductive health information is important for anyone making decisions about intimate relationships, sexuality and parenthood (McConnell & Phelan 2022; Daly et al. 2019; Wheatly 2005). Most participants in all groups I spoke with suggested access to information about sexual and reproductive health is important and something people with learning disabilities should be included in. Yet when I asked participants about what information they had received about the topics of sexual and reproductive health, responses varied from a few participants saying they had some, to others recalling having none.

As described in Chapter 2, it is now compulsory for all schools in England to provide Relationships Education and Relationships and Sex Education that must be accessible for all pupils, including those with learning disabilities (Commons Library Research Briefing 2023). Prior to these recent changes in legislation, the provision of sex education across many educational institutions has been critiqued for being patchy, inconsistent and dominated by the risk of pregnancy (Setty & Dobson 2023; Emmerson 2018). Hall (2009: 20) writes that sexual and reproductive health education in the UK has been, and continues to be, a 'strategy for damage limitation' that predominantly focuses on the avoidance of sexually transmitted infections (STI's) and guarding young people against the risk of becoming pregnant at an inappropriately young age. For many people with learning disabilities, the barriers they can experience in accessing formal sexual and reproductive education denies them opportunities to make their own decisions (at any age) about becoming pregnant and having children. This context of poor sex education is what many of the participants with learning disabilities in this research would have experienced growing up, as this section will illustrate.

A small number of participants with learning disabilities said sexual and reproductive health was something they had learnt in school. For example, Tracy (pwLD, 50s) told me she went to a school for children with Special Educational Needs and Disabilities (SEND) and then a mainstream school. Tracy said she received some information about sexual and reproductive health when she was in mainstream school, when asked about the sorts of things she remembers learning she told me it was *'about condoms and contraception'* and she continued to tell me she felt she had a good understanding about sexual and reproductive health. Like Tracy, Maisy (pwLD, 40s) who went to a SEND school also told me *'I think there's enough information'* about sexual and reproductive health in schools for people with learning disabilities.

However, most participants with learning disabilities I spoke with detailed how they felt access to formal information about sexual reproductive health was either not good enough, or non-existent. This deficiency of sex education in schools was something participants with learning disabilities of different ages talked about. Hazel (pwLD, 30s) recalled receiving some information about sexual health and reproduction in the SEND school she went to, but unlike Tracy and Maisy, Hazel suggested the information she received was not very detailed. Hazel said, *'we didn't get talked about that much, like we only got told certain bits of it like periods and that'*. Hazel saying here that she feels she '*only got told certain bits*' about the topics of sexual and reproductive health suggests that judgements and decisions were made by others about what information people like Hazel should have access to. Like Hazel, non-learning-disabled parent participant Lorraine (50s) similarly commented on how she felt the information her daughter Gabby, now in her early twenties, received about sexual and reproductive health at her SEND school *'was softened down a bit'*. Billy (pwLD, 20s) also said he received some sexual and reproductive health information at the SEND and mainstream schools he attended, however he remarked that the quality of this information *'really was pitiful'*. What participants say here about the poor information received is also highlighted in existing disability literature that describes how sexual and reproductive information is often vague or watered down for people with learning disabilities (Shah 2017; McDaniels & Fleming 2016). From what participants with learning disabilities said, it was not clear whether the type of school, SEND or mainstream, affected whether and what information was disseminated; I suggest that this could be considered for further research.

Billy also commented on the gendered difference in access to sexual and reproductive health information. He described how boys at his schools had less access to this than the girls:

> *"From my school experience they always took the girls aside and gave them a lot more information than they gave the guys. With the guys it was just basically condoms really."*

Billy suggests here that the information he received in school centred on guarding against and avoiding the risk of pregnancy. Caitlin (pwLD, 20s) who went to mainstream school also said the sexual and reproductive information she received similarly focused on how *'not to get pregnant'*. She added that there was no information about how to have a baby, if that is what people wanted. As noted previously in this section and in the literature review, this discourse of risk and pregnancy dominates formal sex education teaching (Hall 2009), but it is especially problematic for people with learning disabilities like Caitlin, as they can often have fewer opportunities to access sexual and reproductive health information elsewhere. For example, many have smaller social networks or limited access to the internet than people without learning disabilities (Chadwick et al. 2017; Chadwick et al. 2013).

Caitlin further commented that she felt the ways this information is disseminated in formal education settings needs to be more carefully thought through and tailored to support people with learning disabilities. For example, while she said she received some information about sexual and reproductive health, she told me more needs to be done to help people with learning disabilities to remember what they have been taught because '*a lot of people with a learning disability can forget information over time, if we're not taught it every so often it will just go out our memory'*. As well as issues with remembering, other participants talked about how some people with learning disabilities might benefit from having opportunities to re-access this information as they get older. For example, sibling participant Francesca (30s) told me about her sister Daisy's (20s) experiences:

> *"My experience with my sister is they did try and do some sex education at college, but she absolutely wasn't ready. They said she just wouldn't listen, she wouldn't engage in it, she had no interest in it whatsoever, which I think would have been different if she was 20, 25 or 30, I think she might be more interested now."*

Non-learning-disabled parent participant Lorraine (50s) also described how her daughter Gabby received access to some sexual and reproductive health information at school but said, *'I don't think she understood it'*. These examples suggest that the lack of adjustments to support people with learning disabilities to understand this information continues to exclude them from this topic and further restricts their ability to make informed decisions about intimate relationships, reproduction and parenthood.

As mentioned, while a few participants with learning disabilities said they did receive some information about sexual and reproductive health in school, albeit generally poor in its quality and accessibility, others said they had no opportunities to access this information in school. Some said they felt they were not told about sexual and reproductive health in spaces like school because it was assumed they would not be able to understand the information because of their learning disability. This seemed to be a view that was especially shared by older participants with learning disabilities and those who went to SEND schools; for example, Linda (pwLD, 40s) went to a SEND school told me:

> "Linda: *I didn't have no sex education whatsoever, so how am I supposed to know*

> Katrina: *Why do you think you didn't get a sex education?*
>
> Linda: *Apparently the school I was at, they thought it wasn't a good idea. They didn't think that that's a subject they should talk about."*

Similarly, Jenny (pwLD, 30s) also went to a SEND school said:

> Jenny: *"I weren't even told about it, they wouldn't tell people. They didn't teach learning disabled people about sex education. We weren't taught.*
>
> Katrina: *Why do you think you weren't taught it?*
>
> Jenny: *They didn't think we could handle it.*"

These quotations from Linda and Jenny here highlight the ways they both felt their access to sexual and reproductive health information was controlled and restricted by other actors at their schools. This notion of gatekeepers restricting access to information also echoes what Hazel (pwLD, 30s) said earlier as she felt her school only told her *'certain bits'* of information.

Peter (pwLD, 50s) who went to a SEND school also suggested people with learning disabilities are not given opportunities to learn about sexual and reproductive health in schools because others assume they are topics people like him will not understand. Peter said people with learning disabilities *'seem to be left behind'* when it comes to opportunities for accessing information about sexual and reproductive health because *'sometimes people say you're stupid or you're a bit thick'*. Peter then added, *'but that's not the case, yeah we might be a bit slower, but we still have feelings… and we have just as much right as normal people'* to learn about sexual and reproductive health. These examples illustrate how judgements about appropriacy and assumptions that people with learning disabilities cannot handle learning about sexual and reproductive health can restrict and disempower people with learning disabilities from making autonomous reproductive decisions.

Other participants suggested assumptions of asexuality and infantilisation play a part in restricting access to formal information about sexual and reproductive health as Ruby (pwLD, 20s) for example said: *'it comes down to the thing of people assume that they don't want to* *have sex or they're not having it'*. Similarly, Jenny (pwLD, 30s) said for many people, the idea of people with learning disabilities having sexual relationships and having children *'doesn't exist in their mind because they've got learning disabilities'*. This sense of denial that Jenny points towards here was also described by Billy (pwLD, 20s) who also described how dominant social ideas of people with learning disabilities as child-like was a barrier to them accessing information about sexual and reproductive health:

> *"I think it's all to so with the eternal child view of learning disability, they view us generally as eternal children and oh they don't have any inclination that way, oh they won't think of having relations… I think there's still a lot of denial on that."*

Some participants with learning disabilities reflected on how they felt not having opportunities in school to access information about sexual and reproductive health seemed unfair. Aimee (pwLD, 20s) she said she did not receive any formal education about the topics at the mainstream school she attended and told me thinks *'it's wrong'* that people with learning disabilities are left out of these discussions:

> *"Everyone's equal if they have a disability or not so everyone should be included so everyone should know what's going to happen when they grow up and how a woman changes, how a man changes, so people with disabilities should be included in that as well, and I feel strongly that they're not."*

As well as not being able to access information about sexual and reproductive health from care organisations and schools, some participants with learning disabilities described being let down by healthcare professionals, such as GP's, when it comes to learning about these topics. For example, while Pippa (pwLD, 50s) seemed to know that menstruation was in some way linked to reproduction, she still had questions around her own fertility. Pippa told me, *'I want children'* but said she has been told by her GP that she cannot have children. However, Pippa seemed confused and upset about this as she feels it has not been explained to her: *'I don't know why I can't have children'*. Pippa described how her periods stopped after an operation on her thyroid but still had questions about how this affected her ability to have children:

> *"My periods stopped when I had my thyroid problem, over-active or underactive and my periods stopped like that… I got thyroid problem and that's why my periods stopped and everything like that… but I don't know why I can't have children."*

Pippa was then asked whether it had been explained to her that her periods might stop after she had her thyroid operation, to which she replied: *'no, no, no, no, nobody told me, nobody told me why my periods stopped'*. It could be argued that if Pippa *was* told her periods may stop, then the information was not relayed to her in a way that she could understand. Alternatively, it is possible that Pippa *was not* told her periods may stop after the operation because medical professionals might have assumed she would not have the desire nor capability to be a mother because of her learning disability. In either case, Pippa's experiences here highlight gaps in the dissemination of accessible information about reproduction for people with learning disabilities, thus further restricting their capacity to make meaningful choices about parenthood. This is something Dotson et al. (2003) have suggested in their work as they describe how some medical professionals may not use clear language and terminology to explain reproductive health education, and this can leave people (mainly women) with learning disabilities confused or not fully understanding what has been discussed. It is important to highlight that the issue of periods stopping can have wider health implications for women other than fertility, but this is beyond the focus of my study. The lack of access to sexual and reproductive health information has meant Pippa has been unable to fulfil parenting ambitions because she seemed to not fully understand the connection between periods and fertility, and about reduced fertility with age.

Like Pippa, Vanessa (pwLD, 40s) also said she wanted to be a mother but felt her GP did not explain why this was not possible for her. Vanessa seemed confused about how her periods ceasing because of the contraceptive implant and her age affected her reproductive possibilities:

> Vanessa: "*I want to have kids, but I've been told that I can't have kids, but they haven't given me the reason why I can't have kids*
>
> Katrina: *Who told you?*

> Vanessa: *My GP. I don't have my periods but that's because I suffer from really bad periods that I'm on the implant sort of thing and I am over 40 but I know people in their 60s and 90s that have had kids and just because I'm 40 doesn't mean I can't have kids… if I had the courage, I should have said but why can't I have kids*
>
> Katrina: *And when you went on the implant, did they tell you what it would do?*
>
> Vanessa: *No."*

Vanessa desired to be a mother, but she seemed to have little information about reproduction, contraception or fertility that would have enabled her to make informed choices about fulfilling this ambition. As the above quotation indicates, Vanessa seemed to be unaware that the contraceptive implant would prevent her from getting pregnant. Women with learning disabilities using contraception without being fully informed of its uses echoes what sibling participant Francesca said in the previous chapter (also see McCarthy 2009a and 2009b). Vanessa further said her GP has not *'given me the reason why I can't have kids'* which she said was *'upsetting'* and confusing. Like Pippa, it is however possible that Vanessa may have received information about the implant, but it may not have been relayed to her in a way she felt she could understand. Either way, by not having access to this information, Vanessa has not been able to make a fully informed choice about her own body and reproductivity.

Other participants also seemed to suggest GPs, and other medical professionals, were in powerful positions with capacity to control access to information about contraception. For example, Ruby (pwLD, 20s) suggested medical professionals' gatekeeping access to information could impact the opportunities for women with learning disabilities to make meaningful decisions about their contraception. Ruby said, *'if you discuss your options with a doctor… I don't imagine there's a lot of help and yeah, I think a lot the time the decision is taken away from them'*. Hazel (pwLD, 30s) also said she thought that the information and support women with learning disabilities might get with their ambitions to become parents would vary *'depending on the doctor'*. Hazel told me:

> *"If I went to the doctors and asked them, I want to have kids but I've got a learning disability, they maybe look at me differently, they could say, no you've got a learning*

> *disability. So, you're a person who might not get a choice and you might not get it because of you having your learning disability."*

Hazel is already a mother, but for other women who may want support fulfilling parenting desires she said they may experience resistance from medical professionals because of their views about learning disability. Her comment that they *'might not get a choice'* powerfully articulates how the reproductive opportunities for women with learning disabilities remain heavily restricted by gatekeepers in the form of medical professionals.

This section has highlighted that participants with learning disabilities report a range of experiences of accessing sex education in different institutional settings. The failings of schools, teachers and medical practitioners to make adjustments to support the inclusion of people with learning disabilities to help them understand sexual and reproductive health information impinges on their opportunities to make informed reproductive decisions. Withholding of information, whether intentionally or not, is exempla of the power imbalances between professionals and people with learning disabilities that restricts them from making their own reproductive choices. This reinforces social ideas about newgenics that suggests the reproductivity of people with learning disabilities is something that should be prevented and avoided which is again indicative of subtle forms of stratified reproduction. As mentioned in this chapter, it is reasonable to suggest that even if professionals did want to support people with learning disabilities to access this information, some may feel they do not have the time, support or resources to do this. Again, this illustrates how wider organisational contexts can influence access to information that shapes what people with learning disabilities think about the topics of reproduction and parenthood. It is important to note that the views of teachers, medical practitioners (e.g. GP's) and other professionals were not included in the participation criteria for this research. The accounts given in this thesis are thoughts, experiences and interpretations of the ways participants feel institutional actors have interacted with people with learning disabilities about the topics of reproduction and parenthood. Finding out what teachers, medical practitioners and other professional themselves think about learning disability, reproduction and parenthood would be an interesting extension of this study (see Chapter 7).

5.5 A temporal shift in information accessibility?

As well as challenges to gaining sexual and reproductive health information from formal institutional and organisational contexts, some participants with learning disabilities further commented on how small social networks can also make it challenging for people with learning disabilities to learn about these topics. People with learning disabilities can have fewer opportunities to exchange information, stories and experiences about sexual health and reproduction from their peers compared to non-disabled people (see Pownall et al. 2012; Wheatley 2005). Vanessa (pwLD, 40s) for instance told me she finds it difficult knowing about sex and reproduction because *'I haven't got many friends'* to talk about it with. As well as smaller social networks, people with learning disabilities can find it challenging to be able to access the internet. This was highlighted by some participants as a potential barrier to finding information about sexual and reproductive health. Sibling participant Francesca (30s) for example said, *'most young people will have a phone and will have access to the internet, but even that's more limited for people with a learning disability'*. Both Francesca and Vanessa's comments help to illustrate some of the barriers people with learning disabilities can experience when trying to access information about sexual and reproductive health outside of formal institutional settings. Their comments further highlight how wider social contexts of marginalisation restrict opportunities for people with learning disabilities to access this information compared with non-learning-disabled people.

When participants were asked what they thought the impact of not being able to access information about sexual and reproductive health might be, some described how it was a barrier to people with learning disabilities being able to make informed choices about their own bodies and reproduction. Azeem (pwLD, 30s) for example told me people with learning disabilities *'can't make choice'* about sex, reproduction, and parenting possibilities if they cannot access the information. Caitlin (pwLD, 20s) also suggested that by not being able to access this information, people with learning disabilities are getting *'all sorts of choices taken off them'*. As will be expanded upon in the conclusion chapter, these findings indicate that more needs to be done to ensure formal organisations and actors, such as support staff, teachers, and medical professionals, do more to ensure people with learning disabilities can access information about sexual and reproductive health.

Having said this, some participants with learning disabilities said they think there are more opportunities for people with learning disabilities to learn about sexual and reproductive health information now than previous generations had access to. Caitlin (pwLD, 20s) for instance, said in *'the past it was bad'* because people with learning disabilities *'didn't get taught it'*, however she went on to say that today, *'I think the younger ones have a more understanding of it because now in schools and colleges they go more into detail about it'*. Michael (pwLD, 70s) now in his early seventies said when he was younger *'there was no sex education at all, it weren't even thought of in them days'*. Michael suggested the lack of opportunities to access sexual and reproductive health information was fuelled by wider social assumptions about asexuality and ideas that *'you can't have sex'* because you have a learning disability. Like Caitlin, Michael reflected on how he felt access to sexual and reproductive health information has *'got a lot better now… you've got young kids they understand what it is today and what it means'*.

This temporal shift in accessibility of sexual and reproductive health information is important to recognise, however many said they still felt more could be done to support people with learning disabilities with opportunities to access these topics. Jenny (pwLD, 30s) seemed frustrated about the lack of opportunities people like her still have to learn about sexual and reproductive health as she told me she feels it is *'a really distressing situation'* that people with learning disabilities *'are still not getting these things'*. Echoing some of Jenny's frustrations, Hazel (pwLD, 30s), suggested she had a key activist role to play in improving access to reproductive health information. Hazel said she hoped that younger generations would have better support and access to reproductive health information so they would feel able to *'get over them barriers'* and be able make decisions about choosing whether to start a family:

> *"…us adults with learning disabilities are changing it for the young ones to get more help, so it's not for us, it's for the young generation as well that they're not going to have the barriers and they know where to go and stuff like that."*

Many participants with learning disabilities seemed to voice concerns about the lack of accessible information and offered suggestions on how they felt this could be improved. Ryan (pwLD, 40s) for instance said, *'half the stuff we don't know'*, so *'pictures and easy read'* resources are important for helping him, and other people with learning disabilities, to learn about sexual and reproductive health. Michael (pwLD, 70s) also said, *'nice and clear'* and easy-read information with *'pictures to look at'* can help people with learning disabilities *'find out what it's all about'* and understand that *'you can have children, you can have relationships and all that'*. He then talked about the accessible resources available at the advocacy organisation he attends:

> *"We've got a few pictures in our office over there that tell a story about a man and a woman in bed and having relationships and all that, we've got that in one of our booklets and it works out quite well because the man and woman and the person with a learning disability is finding out what's happening…"*

Other participants also highlighted the important role that their advocacy groups have supporting members with learning disabilities to access information about sexual and reproductive health. For instance, Aimee (pwLD, 30s) said the information available via the advocacy group website is *'brilliant'* because *'they have it in easy-read and I go on it all the time'*. I asked Aimee if she did not have access to her group's resources, how did she think she would learn about sexual and reproductive health, to which she replied, *'I wouldn't have a clue, I wouldn't know where to start'*.

Most participants said it was good for people with learning disabilities to have opportunities to access information about sexual and reproductive health, yet the shared experiences of some participants suggests that many people with learning disabilities still endure barriers to being able to access this information. Myths and assumptions that people with learning disabilities are child-like and asexual, or that they are incapable of understanding, means that people with learning disabilities continue to be restricted by gatekeepers and excluded from opportunities to access adequate information about sexual and reproductive health (Kulick & Rydström 2015). In instances where some formal information is accessible, the content can often be poor and watered down as people with learning disabilities are only told some bits about the topics (Shah 2017). This lack of adequate sexual and reproductive health information reinforces the notion of newgenics and reproductive control that restricts the parenting imaginaries and possibilities of people with learning disabilities (see Malacrida

2020). This further shows us how choices are being taken away from people with learning disabilities thus highlighting reproductive injustice and oppression.

Participants who said they received some information described how getting pregnant and parenthood was strongly discouraged and something to be avoided, this reinforces how the reproductive possibilities of people with learning disabilities are stratified and devalued. The ways that gatekeepers can control access and the dissemination of this information is indicative of reproductive oppression as individuals are unable to make free and informed choices about reproduction and parenthood. It further illustrates how social control is enacted by powerful others determining what access to reproductive information people with learning disabilities receive. This lack of autonomy denies people with learning disabilities access to full-reproductive citizenship and continues to marginalise them. A call for more accessible sexual and reproductive health information was made by participants to help address this issue of reproductive injustice and support people with learning disabilities to make their own decisions about having children. People with learning disabilities cannot make meaningful choices about reproduction when they have no opportunities to access information. The concepts of reproductive justice and stratified reproduction therefore help us to see how the lack of opportunities to access parenting information and support is a form of reproductive control that people with learning disabilities endure because value judgements are made about the appropriacy and suitability of them having children.

5.6 Conclusion

Löfgren-Mårtenson (2004) argues that today, people with learning disabilities are in the middle generation as they are situated between old and new obstacles that restrict their opportunities for intimacy and reproductive decision making. Despite the old institutional obstacles being removed, findings from this research support how Löfgren-Mårtenson says staff can frequently act as the 'new institutional walls' due to the ways they can restrict people with learning disabilities from thinking about and experiencing intimate relationships and parenthood opportunities (see McConnell & Phelan 2022). This example of powerful others making reproductive decisions echoes what has been detailed in the previous chapter on family members and their role in restricting parenthood experiences and imaginaries for people with learning disabilities. Consistent with existing disability literature, this chapter has also detailed how widely held ideas about infantilisation reinforce the ways intimate relationship opportunities for people with learning disabilities are not always taken seriously by staff (Black & Kammes 2019). Negative staff attitudes can also mean people with learning disabilities encounter barriers to accessing private spaces to experience intimate relationships. Hollomotz (2009a) has argued that access to privacy in the home should be the norm, not a privilege, but as this chapter has shown this is not the case for many people with learning disabilities in care homes or supported living who live under organisational restrictions and staff surveillance (also see Rushbrooke et al. 2014; Pownall et al. 2012).

As well staff blocking relationship opportunities, the ways staff can surveil and restrict contraceptive usage was also detailed as a form of oppression and disempowerment that quashed the reproductive choices of people, particularly women, with learning disabilities. The issues discussed in this chapter highlight how barriers to reproductive decision making extends beyond individual support workers as wider organisational contexts shape whether and how staff talk to people with learning disabilities about the topics. Staff concerns about protection from harm and risk management shape whether and how people with learning disabilities access information about sexual and reproductive health and parenting. Participants detailed how low pay and a lack of formal training and guidance from organisations about the topics can mean staff are unaware or uncomfortable about how to engage in these discussions with people with learning disabilities. Staff reported feeling unsupported and disempowered by organisations that fail to recognise the rights to autonomy and decision making that people with learning disabilities have. I am sensitive to the way this chapter details, almost entirely, the ways participants felt staff can, and do, restrict and control the reproductive opportunities of people with learning disabilities. Accounts of staff supporting reproductive decision-making were scarcely mentioned by participants. Recommendations for thinking about how staff can balance both their professional duty of care and their duty to promote autonomy to support people with learning disabilities in their reproductive decision making will be revisited in the final chapter of this thesis.

As well as care settings, findings from this study show the exclusion of people with learning disabilities from discussions about sexual and reproductive health is also apparent in other institutional settings, such as schools and GP practices. In the concluding chapter, I will talk about in more detail about how there is scope to expand this research focus to include the views of social service professionals, teachers and medical professionals. The ways people with learning disabilities can encounter barriers to accessing sexual and reproductive health information reinforces social ideas that while the reproduction of some groups of people is prized and encouraged, yet for people with learning disabilities, their reproductivity is often seen as something to be avoided and guarded against (Saunders 2021). The way their sexual and reproductive citizenship is devalued points towards the wider marginalisation, oppression and reproductive injustice they endure (Barnes & Fledderjohann 2020). This disempowerment is indicative of wider social control and reproductive stratification that regulates the types of people society wants in the world.

Chapter 6. Dynamics of risk

6.1 Introduction

This chapter explores how social contexts of risk and safeguarding policies are shaping how people with learning disabilities think about and experience parenthood. This discussion is presented in three sections: sexual violence and unplanned pregnancy; child removal processes; and genetic technologies. Using a reproductive justice framework, I first argue that as well as the right of people with learning disabilities to choose to have children, they also have the right to choose *not* have children. However, without opportunities to access sexual and reproductive health information people with learning disabilities are at risk of not being able to make choices in response to sexual violence, unplanned and unexpected pregnancy. I also argue that a dominant discourse of risk within contemporary social work practice influences child removal practices as parents with learning disabilities are deemed unfit and incapable to raise their children that seems to justify removal intervention, rather than supporting them to keep custody and raise their family. I detail how parents with learning disabilities can feel they are judged and scrutinised by stricter criteria than non-disabled parents. This section will also argue that the risk of child removal is further influencing the reproductive imaginaries of people with learning disabilities who do not yet have children. The third section in this chapter considers how ideas about genetics and reproductive technologies are influencing what people with learning disabilities, and family members, think about having children. Knight (2017: 77) has previously argued that whilst twentieth century eugenic policies have waned, social rhetoric concerned with avoiding the risk of having 'defective' offspring continues to dissuade people with learning disabilities from having children (also see Malacrida 2009). In this section I describe the range in understandings participants held about if, and how, parents with learning disabilities might 'pass on' their learning disability to their children and the influence this has on parenthood possibilities.

6.2 Sexual violence and unplanned pregnancy

Existing literature shows that people with learning disabilities are at increased risk of sexual abuse and exploitation (Aunos & Feldman 2002), and more recent work has identified that people with learning disabilities are twice as likely to experience sexual abuse compared with the general population (Paulauskaite et al. (2022). Echoing these findings, some participants I interviewed seemed to suggest that a lack of access to information about sexual and reproductive health could mean that experiences of sexual abuse go undetected and unreported. For example, sibling participant Amanda (50s) described *'a really nasty incident where'* her older sister Iris (60s), who has a learning disability and lives independently, was *'being sexually abused'* by her male neighbour. Amanda described what happened:

> *"It was a neighbour that was abusing her, and I'd met the neighbour many times and he seemed a very nice person… we thought he's a guy that's taken my sister under his wing, so we had no concerns whatsoever. Then we had this bombshell one day, she said, oh he told me that I was his girlfriend, but I wasn't allowed to tell anybody else… He said to her, I'll be your boyfriend, and if you're boyfriend and girlfriend they go to bed together she said… and well he was having sex with me. She obviously never had any sex education at school, but her understanding was that well he's told me he's my boyfriend and that's what you do when you have a boyfriend… So yeah, it was a massive bolt from the blue, but she just thought he's my boyfriend you know because that's what he told her, but it wasn't really a relationship it was just abuse. Basically, he was grooming her."*

Echoing what has been said so far throughout this thesis about the marginalised position of people with learning disabilities and lack of access to sexual health information, Amanda said her sister Iris was *'especially vulnerable'* because she *'never had any sex education'* and she was therefore unable to recognise the signs of rape and sexual abuse. Reflecting on what had happened to Iris, Amanda said she felt strongly that other people with learning disabilities should be able to access information about sexual and reproductive health, she said that it should be *'hammered home to them'* that *'if somebody tries to force you to do stuff you don't do it'*.

Concerns that people with learning disabilities could be vulnerable to grooming and abuse because of a lack of awareness and understanding was something sibling participant Conor (30s) also talked about. For example, Conor said he does get concerned about his younger sister Chloe (20s), who has learning disabilities, as he said people like her *'are vulnerable and can be taken massively advantaged of'*. Conor said there *'needs to be more education'* for people like Chloe to learn about sexual and reproductive health for them to be safe and so they can make their own informed decisions about relationships and reproduction.

Linda (pwLD, 40s) described her own experiences of sexual abuse as she said she was raped by a man known to her. Linda said she did not know she was being raped at the time and could not understand what was happening to her:

> *"My towel was off us, and something was happening, but I couldn't find what it was. I tried to push him off, but you know when you just don't have the strength. And then he was- had his fist and he was punching us in the mouth and everything, pulling my hair, stay still you stupid cow."*

This comment Linda makes about feeling *'something was happening'* but not knowing '*what it was'* is incredibly distressing. She did not understand that she was being raped because it was not something she had information about. She also told me she worries that a lack of sexual and reproductive health information is putting other women with learning disabilities at greater risk of sexual abuse and rape, as Linda said, she fears they *'will get advantages taken of them'* because they may not know or recognise it as abuse. Of course, it is important to recognise that the abuse Linda was subjected to would not have been avoided by having access to information, but it may have helped her recognise and understand what had happened.

From her experiences as a support worker, Freya (20s) also said she worries that the lack of information about sexual and reproductive health people with learning disabilities receive, and have access to, is impacting how they understand sexual experiences and puts them at greater risk of abuse. For example, Freya said she remembered a woman she supported, called Bianca, and recalled while supporting Bianca with personal care she noticed *'semen on her bed sheets'*. When Freya talked to her about it, Bianca described what had happened and said she had been *'hugging a boy'* from next door. Freya told me she felt that Bianca *'didn't really like understand the concept of sex'* and *'she didn't really know it had happened'*. What Freya says highlights how Bianca seemed unaware of the potential risks of abuse, sexually transmitted infections (STI's), and unplanned pregnancy she was potentially exposed to in this situation. A lack of access to information about sex and the terminology may mean that some people with learning disabilities struggle to articulate their experiences and inform others; in certain cases, this may mean when incidences of sexual abuse happen, it goes undetected and unreported.

Other participants also described how few formal opportunities for people with learning disabilities to access information about sexual and reproductive health can mean they are not able to learn about issues like consent which can put them at increased risk of sexual abuse. Concerns about the lack of information people with learning disabilities have about consent and being able to say 'no' to sexual relationships was something Caitlin (pwLD, 20s) for instance, talked in detail about. Reflecting on the experiences of other people with learning disabilities she knows, Caitlin said:

> *"A lot of people didn't know that they had the choice to say to the man, oh wear a condom. A lot of people didn't know they had the choice to say, I'm not in the mood right now go away… Or if people change their minds, then that's ok, but that's not talked about. Changing their minds that's not talked about. It's just if you have sex you can say, I don't want to, I want to stop, that's not really talked about, it's about what not to get pregnant really."*

What Caitlin says here reinforces how she feels sexual and reproductive health information focuses on avoiding pregnancy, rather than empowering people with learning disabilities to engage in positive, safe, and consensual sexual relationships. This quotation further highlights how the sexual and reproductive choices of people with learning disabilities can be restricted and limited by a lack of access to information. It is important to say that a small number of participants with learning disabilities seemed to know about consent and were keen to share this with me. Ric (pwLD, 50s) for example described how it was a topic he had recently learnt about through his advocacy organisation and said, *'it doesn't matter how long a relationship takes… there has to be a certain amount of consent of everything'*. However overall, many participants seemed to suggest that this was another area that people with learning disabilities should have more opportunities to access information about.

This risk of unplanned pregnancy was something sibling participant Elaine (50s) commented on as she worried, *'some girls will have sex and not realise what the consequences of having* *unprotected sex are'.* Out of the six participants with learning disabilities that had children, only Azeem (pwLD, 30s) said he planned to have children, the other five said their pregnancies *'just happened'* (Wendy pwLD, 50s) and were unplanned. I asked Jenny (pwLD 30s), a mother of two, whether she had planned on getting pregnant to which she also replied, '*no, I never planned on it at all… it was a bit of a shock'*. Of course, non-learning-disabled people can also experience unplanned pregnancies, but their opportunities to access information about sexual and reproductive health is generally less restricted than people with learning disabilities.

Support worker Freya (20s) similarly described how she felt a lack of information about sexual and reproductive health was restricting the opportunities for women with learning disabilities to make choices about engaging in unprotected sexual activity that is putting them at risk. She described how she had supported *'at least six'* women with learning disabilities who had experienced unplanned pregnancies and suggested they did not understand about sex and pregnancy because it was not something they had information about. Freya further talked about how she tried to help some people with learning disabilities to learn about sexual and reproductive health by having conversations with them. For example, she said while *'I didn't go into great detail'* with one woman, *'she was very grateful that I'd spoken to her about it'*. However, as detailed in the previous chapter, Freya worried about getting in trouble with her manager for discussing these topics with people with learning disabilities and feared losing her job. Freya's experiences highlight some of the challenges and power dynamics impacting the opportunities people with learning disabilities have accessing information about these topics.

Hazel, now a mother with learning disabilities in her thirties, said she *'weren't planning on having kids'*, but she was on the contraceptive implant to help manage the pain she had with her periods and to help control her epilepsy. Hazel said she did not know stopping her contraception could lead to pregnancy:

> *"I went on the implant to stop my periods because every time I was in pain with my periods it was triggering seizures… but I just wanted a little break from it, I didn't know I was going to get caught getting pregnant… It was very much a shock."*

Hazel's experiences here show how a lack of information about contraception meant that she was unable to make fully informed decisions about engaging in unprotected sexual intercourse, which resulted in pregnancy. The issue of a lack of information about contraception was also something Caitlin (pwLD, 20s) mentioned as she recalled the experiences of some women with learning disabilities she knew who *'was getting raped and having kids to people that they didn't even like because they didn't even know about protection or how to protect themselves'*. Both Hazel's experiences and Caitlin's comments here highlight how the lack of information about contraception puts people with learning disabilities at greater risk of experiencing unplanned pregnancy.

As detailed earlier, Linda (pwLD, 40s) was raped which resulted in her becoming pregnant. She then went on to detail how the lack of information about sexual and reproductive health also meant she had *'no idea'* that she could be pregnant from being raped:

> Katrina: "*How did you know you were pregnant?*
>
> Linda: *I had to go the hospital… but I didn't know I was pregnant, I thought it was just a water infection or something… I thought they were just winding us up until they showed us the test and then I'm thinking, how did that happen because I didn't ask to get pregnant*
>
> Katrina: *Because did you know how to get pregnant, did you know what needs to happen?*
>
> Linda: *No, and that's the honest truth, I didn't. How are you supposed to know anything, I didn't have no idea. I didn't have no sex education whatsoever, so how am I supposed to know."*

As well as not understanding how she got pregnant, Linda went on to describe how her lack of information about sexual and reproductive health also meant she did not know the signs of labour:

> *"I didn't even know I was in labour… because I didn't know the signs. I thought I just had a bad stomach; I didn't know I was in labour; I didn't know my waters had*

> *broken. You just don't know do you… how was I supposed to know if I hadn't been told what to do."*

What Linda says here also points towards the lack of formal support she received during her pregnancy, despite service professionals knowing she was pregnant. Understandably, Linda seemed distressed by her experiences and the lack of information about the topics of sex and reproduction also made it challenging for her to understand what was happening to her body. Once she had been told she was pregnant, I asked Linda whether she received any information about pregnancy and childbirth, she replied, *'nah, didn't get any, no nothing, none of that'*. Linda's example highlights how her right to make explicit choices, and not just face the consequences of rape, were compromised by a lack of information.

Linda then told me that even if she had known she was pregnant earlier that she would not have terminated the pregnancy: *'I can't go round killing a child, that would make me being a murder… nah I can't do that'*. This is what Linda said, yet it is reasonable to suggest that other women with learning disabilities in a similar situation to Linda may have chosen to have an abortion if this was information accessible to them. In either case, what is important to acknowledge here is the lack of choice people with learning disabilities have when it comes to continuing or terminating their pregnancies because of a lack of information and wider marginalisation. Linda's experiences therefore point to the wider reproductive injustice that people with learning disabilities can experience.

Support worker Freya (20s) similarly described how one woman with learning disabilities she supported, called Zoey, also did not seem to know that unprotected sex could lead to pregnancy, as Freya said:

> *"She didn't really understand what was happening, you know she was getting like you know, heavy, but she couldn't understand, you know. She told me that she'd just been eating too many cakes…. I don't think she really understood what like having a child meant... they've done a scan and they've went, oh you're pregnant, and she's like, well what does that mean."*

Not knowing that unprotected sex can lead to pregnancy restricts the reproductive choices people with learning disabilities make about engaging in sexual activity, using contraception, accessing emergency contraception, and making decisions about continuing or choosing to terminate the pregnancy. The importance of access to this information in a timeframe that enables women with learning disabilities to make choices about responding to unprotected intercourse, be it consensual or not, is also reflected in existing literature by Conder et al. (2011). For instance, without access to information about the signs of pregnancy, some people with learning disabilities might not realise they are pregnant until late on in the pregnancy, and if beyond 24 weeks, termination will (usually) no longer be an option.

In addition to a lack of information about pregnancy restricting the reproductive decisions of some people with learning disabilities, other participants with learning disabilities said not realising they were pregnant till late on also gave them less time to prepare for the baby's arrival and access parenting information and support. Most of the mothers with learning disabilities interviewed said they would have liked to have received more information about pregnancy and parenthood before they gave birth. It should be considered that not recognising the signs of pregnancy and feeling unprepared and unsupported for baby's arrival can put parents with learning disabilities at greater risk of child removal. An exploration into the impact of not having access to parenting information and how this might influence parenting outcomes is considered further in this chapter.

Previous studies suggest people with learning disabilities have limited information about sexual and reproductive health or the information they do have is not always correct (Wright 2011; Isler et al. 2009). This research has also found that a lack of access to sexual and reproductive health information is putting people, especially women, with learning disabilities at increased risk of harm and sexual violence. People with learning disabilities are enduring traumatic experiences of sexual abuse and rape without the information to understand and report what has happened to them. As mentioned earlier, access to information will not prevent against the risk of abuse, but it can enable individuals to respond and report to others when they have been harmed. In addition, the lack of access to this information is further limiting and restricting the decisions people with learning disabilities can make about consenting to unprotected sexual intercourse which then puts them at greater risk of unplanned pregnancy (Cheng & Udry 2005). Not knowing the early signs of pregnancy means some women with learning disabilities are carrying babies they do not want to have to full term because they do not have access to information about emergency contraception or abortion. Scenarios where women are having babies they do not want echoes the wider reproductive justice movement and lives of other marginalised women, such as black or poor women, who are restricted by lack of access to information, contraception, and safe and legal abortion services (see Frederick et al. 2019). Despite the right to decision making, reproductive autonomy is not something all people have equal access to. By connecting this to wider reproductive issues it reinforces the need for all people, including people with learning disabilities, to have access to information that enables them to make their own decisions about accessing emergency contraception and abortion services (Conder et al. 2011). By not having access to this information, people with learning disabilities are at risk of being unable to make informed decisions about sex, pregnancy and parenthood that further highlights their reproductive injustice and oppression.

6.3 Precarious parenting

Even when people with learning disabilities do have children, their position as parents is precarious because of the threat of child removal. Existing disability literature suggests contemporary social work practice is often characterised by an over-zealous attitude towards risk where child protection is prioritised over the rights of parents (Höjer 2011, also see Wilkins & Forrester 2021). Of course, the safety of children and their welfare is paramount, but it is important for social service professionals to also consider the rights of parents. The Working Together with Parents Network (2016) for instance has called for the closer working of children's and adult services to ensure the wellbeing and rights of both groups are being upheld through child protection investigations. Whilst an exact figure is difficult to know, it is estimated that in the UK and internationally, somewhere between 40 – 60 per cent of parents with learning disabilities experience child removal processes (Emerson et al. 2005 cited in Theodore et al. 2018: 185, also see McGaw & Candy 2010). Disability writers O'Hara and Martin (2003) have stated that all too often, learning disability is the sole reason why parents with learning disabilities lose custody and have their children removed because assumptions of parental incompetence identify their children as being at risk (James 2010; Booth & Booth 1994). This notion that dominant social myths and assumptions that people with learning disabilities are not, and cannot learn to be, ‘good enough’ parents was a theme that was mentioned by most participants across the different interview groups. It is helpful to be reminded that social worker professionals were not interviewed as part of this research. What is described next are the accounts and reflections of people with learning disabilities, family members and support workers about social worker services and professionals, not the views of social workers themselves.

As explained in Chapter 2, when social services are notified about child safeguarding concerns, section 47 of the Children Act 1989 and the strengthened focus on child safeguarding in the Children Act 2004 states that enquires into these reports must then be made to assess the potential risk to a child before decisions about child removal are then made. Despite this, many participants suggested parents with learning disabilities are discriminately targeted by child protection proceedings, when compared with other parents without learning disabilities. From the six participants with learning disabilities who had children, two mothers (Jenny, 30s and Linda, 40s) had their children removed from their care. Linda (pwLD, 40s) told me she feels parents with learning disabilities are unfairly targeted ‘*because social workers has got in their heads, they’ve got learning disabilities they won’t be able to do it’* and they assume they cannot be good parents. In the interview she seemed upset about the scrutiny and victimisation she feels people with learning disabilities can experience, as she said:

> *“It’s not fair that normal people, that’s not a very nice thing to say, but normal people should be able to have a child but people with learning disabilities can’t. It seems like it’s favouritism doesn’t it. So do you know like you see a lot of parents out there who would physically hurt, like beat their child up, but then social workers don’t look at that, they go for the people who have got a learning disability, thinking that they’re stupid… they think we’re stupid, totally, I think they think we are daft… Targeting people with special needs is wrong.”*

As well as social services Linda said negative perceptions of the parenting capabilities of people with learning disabilities was also held by wider society that reinforces ideas of surveillance. Linda said she felt people *‘put us down because of my learning disability, and that’s the problem… they grass on parents with learning disabilities, but what about some* *parents who are out there now who are smacking them or murdering them or whatever'*. Linda's experiences of feeling criticised and scrutinised about her suitability for parenting highlights how parents with learning disabilities are judged against stricter criteria and are at greater risk of losing custody of their children than parents without learning disabilities (Kitson & Wilson 2019: 5).

The comments made by Linda here about negative stereotypes and assumptions she felt social service professionals and wider society held against parents with learning disabilities was also something support worker Huw (40s) mentioned as he described a double standard that exists for parents with learning disabilities. For Huw, parents with learning disabilities are perceived as risky by the wider public and these ideas reinforce the monitoring and surveillance parents with learning disabilities are subjected to:

> Huw: *"It's definitely there isn't it, this double standard… I think others are sat there waiting for them to fail. I think the majority of people- I think on the majority of streets if a learning-disabled couple moved in with a kid everyone would be watching out, they'd either be telling their kid to keep away or they'd be watching them like hawks for the slightest thing they saw out of the ordinary and ringing social services.*
>
> Katrina: *Like expecting them to fail you said?*
>
> Huw: *Yeah I really do, just waiting. It might be like you're a family with like five kids they're all drug addicts this that and the other, but those learning-disabled parents they've just let their kid out and he's got a dirty face for the third day running, I'm ringing social services. Different standards, totally different standards. It's like they've got to be beyond any kind of criticism haven't they, otherwise people will take action a lot quicker. They've got to have a load of prenatal assessments and what have you, yet other people can just pop them out willy nilly."*

For Huw, these assumptions that a priori label people with learning disabilities as unfit parents already restrict their reproductive opportunities before they have been given a chance to try. Huw continued to say that he felt *'if you've got a learning disability, it's almost as if you've got to earn the right'* to have a baby, *'you've got to prove'* you can learn the skills and successfully be a parent. This idea that parents with learning disabilities have to prove themselves as 'good enough' parents is also detailed in existing literature by James (2010).

Like many other participants in my study, Huw described how *'it's just not fair is it'* because *'no one else has got to prove they can have a baby'*. When asked why he felt there was this double standard, Huw said the idea of people with learning disabilities becoming parents is still considered *'a risk'* and there is a fear they will inevitably harm their children in some way. The way that Huw suggests that people would be *'telling their kid to keep away'* is significant for thinking about how individuals and families of people with learning disabilities experience marginalisation and discrimination. This sense that parents with learning disabilities will inevitably fail in their parenting roles reinforces wider ideas about incompetence and risk that means other people take responsibility for watching and reporting them to professional services. Again, this shows how parents with learning disabilities are disempowered, devalued and othered in the ways they become the objects of surveillance.

Furthermore, while some shared these views that people with learning disabilities are likely to experience more intense monitoring, scrutiny, and surveillance over their parenting than most other people, a few described how women with learning disabilities would be subjected to more intensive surveillance compared with men with learning disabilities (see Aull Davies & Jenkins 1997). Billy (pwLD, 20s), who does not yet have children, for example referred to traditional Western ideas of gendered family roles as he said mothers are typically viewed as primary care givers and will therefore experience more scrutiny and surveillance over their parenting abilities. Billy said, *'social services don't bother with us because there's that assumption that it's the woman that's going to look after the child, the father tends to be not part of the conversation'*. The scrutiny and surveillance mothers with learning disabilities experience is intensified by discourses of risk that undermine and call into question their parenting capabilities. I then asked Billy whether, and if so how, he thought that might affect men and fathers with learning disabilities to which he replied:

> *"If they want to be a father it's a slight positive in some regards because that means that there's less chance of you having your child removed from you, but that's only under the assumption that you're with a non-learning-disabled woman. But if you are both learning disabled, you're a bit done for."*

Billy's comment here that *'you're a bit done for'* if both parents have learning disabilities seems to further suggest that child removal processes are almost inevitable because of dominant social ideas of incompetence. This sense of inevitability that social services will step in and remove children from parents with learning disabilities was something sibling participant Lara (30s) felt would happen if her brother Jason had a child:

> *"I think if Jason was to have a baby… especially if Jason was in a relationship with someone who had the same sort of learning disabilities as Jason, I think eventually it would go down the lines of bringing in social care workers and things like that, and probably not very nice things happening because I just don't think there's the support there."*

Lara's comments here echo what Billy said previously about mothers with learning disabilities being targeted more than men and if both parents have a learning disability then, as Billy says, *'you're a bit done for'*. This reinforces the notion that the involvement of social services is more a case of when they get involved, not if. The lack of support parents with learning disabilities receive with parenting is a view most participants with and without learning disabilities shared.

Some parents with learning disabilities suggested they were not afforded the same opportunities as other parents to learn skills and demonstrate their parenting capabilities because social worker professionals have a priori marked them as risky parents incapable and unfit to fulfil parenting roles. Reflecting on her own upsetting experiences of having her first baby removed at eight-weeks old and her second at birth, Jenny (pwLD, 30s) said she wished she had the opportunity to *'learn the right parenting skills'*. Jenny suggested she was not able to access parenting workshops or classes because social services had already decided motherhood was not a role she was capable of fulfilling. She said she had been told by social services several times that *'you can't be a parent'* because of her learning disability, and when she became pregnant, Jenny recalled how she felt judged and she *'got criticised'* by social services:

> Jenny: "*Basically, while I was pregnant, I just got looked down at and basically that's what happened*
>
> Katrina: *Who was looking down at you?*

> Jenny: *Social services. They were the ones who had the negative problem… They turned round and tried to say it was my learning disability instantly."*

Jenny added how she felt criticised by social services during her pregnancy she said, it was *'because they didn't think because of my learning disability, that I was able to cope'*. Jenny suggests here that she felt social services had marked her as incapable of fulfilling parenting roles because of a priori assumptions of incompetence and risk. She added that people with learning disabilities *'can't be a parent because you don't get a chance'* to learn parenting knowledge and skills. However, Jenny told me that she felt she could have been a good mother if she had access to parenting support: *'if I would have had the support, I wouldn't have been so confused, I would have been like, I know what I'm doing, but because they didn't do that'* she had her babies taken away from her. When asked what skills she felt might have been useful she replied, *'like how to bath a baby, how to do all of these things that people have to know, because babies don't come with handbooks*'.

Linda (pwLD, 40s), who had her son Trent removed from her care when he was three years old, similarly told me she had been let down by social services as they failed to support her with parenting lessons. Linda told me, '*social services said that I was going to get parenting lessons, but I didn't get them… I ended up with a child who I didn't know how to look after, I didn't get any support whatsoever'.* Linda said she wanted to access *'parenting lessons'* that would have helped her to learn about *'what it was like to having a child, what to do if you have a child'*. Linda also suggested she wanted to access information and support with pregnancy and parenthood because she *'was frightened'* about becoming a mother:

> "*I didn't know what to do, you've got hold baby a certain way to bath them, just scared me completely, completely scared us… People with learning disabilities maybe don't know how to look after a child, but until someone tells us, how are we gunna know… how are we going to be good parents if we haven't been given the book or whatever."*

Reflecting on her experiences Linda said it was hard raising Trent without support, but had he not been removed from her care she told me: *'it would have come to a point where it would have been hard… it would have been too much, and my mental health was getting really, really bad'*. Linda said she felt it was *'right for him and myself'* but *'not because I didn't want to be* *a mum, it's because I couldn't'*. Linda went on to say that if she had access to parenting information and support, she might have found raising her son *'less hard'* and she may have been able to keep custody.

James (2010) tells us that people with learning disabilities *are* able to learn new parenting skills when they have opportunities and are afforded the time to learn these skills. This was certainly a view both Jenny and Linda shared as they said they could have been good mothers if they had access to parenting information and support. It is possible that in a culture of risk aversion social services may have considered child removal a 'safer' and 'easier' option than working with Jenny and Linda to provide them with the help they wanted to raise their children.

The sense that there is a dearth of opportunities for people with learning disabilities to access parenting information and support was highlighted by other participant groups, as support worker Gus (60s) for example said:

> *"After 40-odd years as a carer, I honestly wouldn't know where to get somebody that help. I wouldn't know who to ring up and say, this guy and this woman are thinking of having a baby they need support, I wouldn't know who would do that, so that kind of says to me that there must be a lack."*

Like Gus, support worker Freya (20s) also said, *'I don't think there's really any support to be honest, I haven't seen any support, you know'*. Echoing what Jenny and Linda said earlier, Gus and Freya also seemed to suggest dominant social assumptions that people with learning disabilities either do not want, or are incapable of raising children, make it difficult for them to access information and support opportunities. When asked why there was so little formal support to help parents with learning disabilities who want it, participants with and without learning disabilities said it was the lack of social care funding:

> Katrina: *"Why do you think there's such a lack of support for parents with learning disabilities?*

> Billy: *Funding and Tories. The facts speak for themselves that the lack of funding, particularly to different services, makes it so that there isn't enough support."*

Non-learning-disabled parent participant Lorraine (50s) similarly told me *'it's a postcode lottery'*. For instance, Lorraine said she knows *'there are mother and baby units out there'* for parents with learning disabilities but accessing these is limited by *'funding basically and it's like everything else these units are shutting down'*. This suggests that even if some social work professionals do want to support parents with learning disabilities to access information and support, they may be unable to help because like support workers, they too are constrained and restricted by the wider organisational and social contexts they work within. Again, supporting parents with learning disabilities is not seen as a priority which points to wider levels of disempowerment and marginalisation that people with learning disabilities endure.

Across all interview groups, many shared the view that there should be more opportunities for people with learning disabilities to access parenting information and support because currently, *'there's not much out there'* (Hazel pwLD, 30s). For example, Bob (pwLD, 40s) said, *'there should be more help for them people with learning disabilities'* who might want to have children. Azeem (pwLD, 30s) also said he felt, *'there should be more support'* for people with learning disabilities who are, or might want to become, parents. When I asked Azeem what support he thinks might be useful he replied: *'have some workshops and training to go to'* and *'if they have baby how to support baby, how to look after them yeah'*. Sibling participant Stella (40s) also proposed that *'lessons to do with care and things like that, support to do night feeds… and just guidance really, would be a good thing'* to support people with learning disabilities as parents.

As mentioned, from the six participants with learning disabilities interviewed that had children, Jenny (30s) and Linda (40s) had lost custody. Both Jenny and Linda described difficult familial backgrounds of growing up living in care and experiencing abuse, they suggested that not having the support of family members contributed to them losing custody of their children. For instance, Jenny said, aside from her husband Grant who also has a learning disability, *'basically I had nobody'* to talk to about parenting. The isolation that Jenny said she experienced can be linked to broader discussions about the impact of smaller social networks many people with learning disabilities have, compared with other groups of non-learning-disabled people. It is possible that social services were aware of Linda and Jenny's background in care and the lack of positive family support they both had. These circumstances may have been perceived as risky by social services and may have influenced the decision to not offer them parenting information or support but to remove their children.

As indicated in Chapter 4, having supportive family relationships was considered fundamental in helping people with learning disabilities keep custody and be able to raise their children. For example, in contrast to Linda and Jenny's experiences, Hazel said she felt supported during her pregnancy and after the birth by *'a really nice health visitor'* and support from her own mother:

> *"I got support from my midwife and my health visitor and support from the children's centre, but I had the support off my mum and my family and that backed me up… I'm one of the lucky people, I have had that support. Not everyone out there might not have that lucky support what I've got."*

Reflecting on the practical and emotional support she has from her mother and other family around her, Hazel said she feels like *'I'm one of the lucky people… not everyone out there might not have that lucky support what I've got'*. Without support from her own mother, Hazel said she worried that she would have *'to give Claudia up for adoption or something like that, that's what I was thinking sometimes'*. What Hazel said about worrying about what would have happened had she not had the support from her mother echoes findings from Traustadóttir and Sigurjónsdóttir (2008); as mothers in their study said without family help it would have been impossible for them to keep custody of their children. Azeem (30s) is a father with learning disabilities who also shared Hazel's view that *'family support'* is important for helping people with learning disabilities with parenting information and skills. It is important to mention here that many participants who did not have children also recognised that access to familial support was something many non-learning-disabled parents also rely upon to help them fulfil parenting roles. Michael (pwLD, 70s) for instance said he thinks people with learning disabilities are capable of parenting and some *'do need that support'*, but he also suggested that *'all people need support to have children'*.

In addition to the importance of family support, some participants highlighted how their learning disability advocacy group has helped them learn the skills to become good parents and retain custody of their children. Azeem (pwLD, 30s) for instance was keen to tell me about the parents group he attends through his learning disability advocacy organisation and that he values the opportunity it gives him *'to get together and talk'* with others about their experiences of parenting with a learning disability. When asked about the sorts of topics they discuss at these groups, Azeem said: *'we talk about different kind of stuff what people have, and we talk about teenagers, kids, everything yeah, and we invite guests to come to speak to us'*. For Azeem, having access to this support group was incredibly important to him and it enabled him to successfully fulfil his parenting role.

Like Azeem, Hazel (pwLD, 30s) also described how the advocacy group she attends has been instrumental supporting her to access parenting skills and gain more confidence reaching out for support for her daughter. For example, she told me:

> *"If I get stuck with her homework and that, I just go into the school and say, listen I can't help her with this, would you be able to put that little extra support in for her. If I didn't go to* [name of learning disability advocacy organisation] *for them to helping me speak up, I wouldn't be able to do it."*

Some participants who were not yet parents also recognised the value and importance of having learning disability advocacy organisations to support people to access parenting information and skills. This was something Billy (pwLD, 20s) talked about as he asserted:

> *"Advocacy groups for learning disabled parents are quintessential. They should be the central point that a learning-disabled person needs to go to when they find themselves being set upon by social services, they need to straight away find an advocacy group."*

The words that Billy uses here to describe the way he feels parents with learning disabilities might be *'set upon by social services'* is powerful and reinforces how some people with learning disabilities may feel targeted by social services. It further adds to the tensions highlighted earlier in this section about how parents with learning disabilities manage assumptions of risk as well as the acrimonious feelings parents with learning disabilities can have towards professional social services *'getting involved'* (Jenny pwLD, 30s). What Billy says highlights the importance of access to learning disability advocacy organisations to give people the chance of learning parenting skills and being able to keep custody of their children.

Reflecting on their experiences, Jenny (pwLD, 30s) and Linda (pwLD, 40s) both said having their children removed by social services has shaped what they think about having more children in the future. For example, Jenny said:

> Jenny: *"I mean I keep on getting implants put in my arm because I'm not risk having any more kids*
>
> Katrina: *Was that your choice, getting the implant?*
>
> Jenny: *That was my choice, I had enough of them trying to take kids off me, so I just said, right I'm having the implant. They're not doing it every time with me. If they think that I'm going to let them do that every time, then no."*

What Jenny says here illustrates how the threat and risk of child removal has shaped her decision not to have any more children in future as she says it was her *'choice'* to be on the contraceptive implant to avoid the *'risk'* of child removal happening again. As detailed earlier in this chapter, Jenny talked a lot about the tensions between herself and social services and it seemed her decision not to have any more children and to have the implant was a way for her to resist the power and authority of social service intervention. However, it could be also argued that Jenny's decision to go on the contraceptive implant is not a free and informed choice when she feels threatened by the risk of losing custody to any more children she might have.

Like Jenny, Linda is now using contraception to avoid pregnancy. As previously noted, Linda became pregnant from being raped and her decision to go on contraception was something she said she had chosen to protect herself in case it happens again: *'obviously, I'm on the pill... so then it's comfort for me so if I get hurt again, this won't happen like it did happen'*. The 'hurt' Linda describes here highlights her ongoing fear of being abused and becoming pregnant again; this was something she talked to me in detail about as now, for instance, she is supported in her residential group home by female only staff. Linda also said her experiences of child removal have influenced her decision not to have any more children:

> Linda: *"But one thing I can tell you, I won't have another child again*
>
> Katrina: *You won't?*
>
> Linda: *No because I would be frightened it would be taken off us."*

Linda said that other mothers with learning disabilities she knows who have also had their children removed share her views as she said: '*and do you know what, all those parents in that mam's group will never have a child again because they're worried it will be took off them, and that's how it feels, and that's not fair'.* Linda also described how the threat of child removal was shaping what other people with learning disabilities think about having children in the future. She told me that seeing other people with learning disabilities have their children removed '*will put off a lot of people'* from going on to start families of their own. Linda's comments highlight how reproductive choices can be limited and restricted by the threat of child removal. This was something Vanessa (pwLD, 40s) who does not yet have children told me she worries about as she said, *'because I've got a learning disability that social services won't let me keep my child'*. Jenny (pwLD, 30s) and Azeem (pwLD, 30s) similarly said that other people with learning disabilities are *'just scared'* (Jenny) to think about and have children because of the threat of child removal from social services:

> Jenny: *"It scares them to have kids, they're too frightened to have them. They think that if they had a kid, it's just going to be taken off them… Some of them are like, I want to have kids, but they're just so scared to because they know they're gunna have the kid taken off them."*
>
> Azeem: *"When they listen to other people's stories that the social workers take their babies or kids in care… that's why they say no they don't want to have kids, they get scared I think."*

These examples further highlight how the risk of child removal shapes how people with learning disabilities might think about reproduction as parenting possibilities are restrained and constricted by previous child removal experiences and seeing it happening to others (see McCarthy 2009a; Llewellyn & McConnell 2002). It further reinforces the notion that people with learning disabilities are unable to make meaningful choices about parenthood because they are restricted and coerced into not having children by the fear of having them removed (Sigurjónsdóttir & Traustadóttir 2010). Most participants seemed to share the view that hearing the stories of parents with learning disabilities losing custody of their children would scare other people with learning disabilities into not starting a family of their own.

On the topic of child removal, sibling participant Elaine (50s) shared the tragic experiences of a woman with learning disabilities she knew, called Alysha, who had lost custody of her three children and how she felt this experience was exacerbated by her social vulnerability:

> Elaine: *"… ended up with three children and she had a total breakdown and had to have her children removed because she couldn't cope with them. She used to be taken advantage of you know she'd had these boyfriends who had taken all her money off her that she'd have for the children. I mean she lost her three children; they were adopted together which is something, but nevertheless I mean the impact on the children, they were little at the time, but the impact on her, I mean she's in her forties now and I see her roaming the streets and you just think, God this is dreadful. And that happens a lot it does, you know it does happen a lot you know women with learning disabilities will have children and they can't cope."*

What Elaine says in this quotation about Alysha's 'boyfriends' financially abusing her also reflects what other participants said earlier in this chapter about the vulnerabilities of people with learning disabilities at risk of abuse. When I asked Elaine more about what she knew about Alysha's experiences, she said she did not have many friends or family that could support her with the parenting role. Alysha's story highlights how lack of access to parenting information, support, and smaller social circles can make parenting possibilities more challenging for people with learning disabilities. Elaine told me access to parenting information and support have *'got to be the most important things'* and she felt Alysha might have been able to keep custody of her three children if she had access to these. Of course, this is an interpretation based on what Elaine and other participants said in this study and talking with social service professionals may shed alternative perspectives on cases such as Alysha's (see Chapter 7). It is important to recognise that some social service professionals do support and empower people with learning disabilities to fulfil their ambitions of parenthood, but as Sigurjónsdóttir and Traustadóttir (2010) have suggested, access to good and empowering support from social service professionals seems to be the exception, rather than the rule.

This section has highlighted how support networks, and the lack of support, can shape parenting outcomes for people with learning disabilities. Parents with learning disabilities without access to familial support networks are being let down by inadequate formal support services that focus on potential risk and do not take the parenting rights of people with learning disabilities seriously. As detailed in this section, Jenny (pwLD, 30s) and Linda (pwLD, 40s) both said they felt they were not given a chance to raise their children because social service professionals had already decided it was too risky and not something they were capable of. They both seemed to suggest that this perception of risk and incompetence explained why neither of them received the parenting lessons they said they were promised. Their experiences reinforce how parenting opportunities can be restricted by social service professionals acting as gatekeepers with immense power to deny and override the reproductive desires of people with learning disabilities. Booth (2003: 205) tells us that social service professionals have an over-zealous concern with the risk to the child that loads the dice against people with learning disabilities from being able to fulfil parenting roles. This is exempla of the system abuse that continues to fail parents with learning disabilities by discriminately removing their children from their care before they are given opportunities to access adequate support and demonstrate improved parenting capabilities (Working with Parents Network 2016). This notion that people with learning disabilities are not given a chance to be parents can be understood as a form of newgenics and reproductive injustice that prevents them from fulfilling parenting roles. Value judgements are made about the reproductivity of people with learning disabilities which is generally seen as unequal and less than which echoes sentiments of the eugenics era. These power relations that determine whether people with learning disabilities have the chance to be parents are indicative of wider social control and reproductive stratification. In addition to discourses of risk, it is also possible that social services feel unable to provide parents with learning disabilities with the range of adequate and ongoing support because of poor funding and resources available to them; thus child removal is the easier option.

Parents with learning disabilities who had experienced child removal said they do not want to have more children in the future in case they get taken away from them. The way that future decision making about having more children is shaped by child removal experiences is also detailed in earlier research by Conder et al. (2011). Reflecting on the discriminatory child removal processes outlined in this chapter, my findings reinforce the notion that disabled women experience 'precious motherhood' as Crossley (2020: 244) also identifies in their recent work. Their status as mothers is more fragile than parents without learning disabilities who do not usually encounter the same levels of judgement, surveillance and scrutiny as parents with learning disabilities. This is also reported for black, poor, and lesbian mothers who also experience oppression and regulation of their reproduction as their parenthood is often seen as undesirable, problematic and something to be avoided (Frederick et al. 2019). The way certain groups of people are scrutinised and monitored and prevented from fulfilling parenting roles is exempla of the social control and power that produces the types of parents society wants. An awareness of this precarity and the widespread practices of child removal from people with learning disabilities is also influencing the future parenthood imaginaries and reproductive choices of people with learning disabilities who do not yet have children. People with learning disabilities know that social service professionals perceive people like them as risky parents that makes them a target for child removal. This threat of child removal can scare people with learning disabilities, and it means many are not making free choices about parenthood, as instead, they are coerced into not having children by fear that any children they may have will be taken away from them.

6.4 Genetic and reproductive technologies

As presented in Chapter 2, developments in genetic testing and screening technologies have sparked significant social and ethical discussions around 'normative' embodiment (McLaughlin 2017), what it means to make 'responsible' reproductive decisions (Boardman & Hale 2018), and the impact these technologies are having on disabled communities (Shakespeare 1995). On one hand, advances in genetic screening and testing technologies are supported by the argument that it enables society to 'move away from our dependency on nature and take control of our fates' (Leefmann et al. 2017: np). Yet critics have questioned how different this technology is from the eugenic schema of the past, as

Shakespeare (1995: 30) for example writes, ‘we may not be seeing eugenics at the level of population and nation, but we are seeing eugenics at the levels of individuals and families’. More recently, Thomas (2017: 179) has commented that the use of prenatal and genetic screening technologies provides a commentary on the types of lives that are valued that reflects how particular ways of being in the world are threatened, stigmatised and denied.

This section will explore what understandings participants had about genetics and reproduction, with a specific focus on how ideas of genetic risk are influencing the reproductive decision making of people with learning disabilities and siblings of someone with a learning disability. From speaking with participants with learning disabilities in this study, it was clear individuals had a range of different ideas about genetics, but very little was said about genetic screening and testing technologies. Many participants with learning disabilities did not know much about the science or technologies that could be available to them, but they had absorbed social ideas that genetics was somehow important, and this influenced their reproductive decision making. For instance, some participants seemed certain that because they had a learning disability, that any children they may go on to have would also inherit their impairment.

For example, Vanessa (pwLD, 40s) said she believed, *‘because I’ve got the learning disability gene in my body then that would get passed onto my children because it’s already in my body’*. Vanessa also seemed to think her learning disability being passed on would be an opportunity for her to support her child as she said, *‘obviously it will be a struggle but at least I know what they’re going through because of me having a learning disability’.* When asked more about what she meant by this, Vanessa described how her experiences of living with a learning disability have been negative due to the way society responds to her, rather than the impairment itself:

> Vanessa: *“I was always bullied at school… it was horrible*
>
> Katrina: *Because of your learning disability?*
>
> Vanessa: *Mhmm, yeah.”*

From speaking with Vanessa, it was unclear where her knowledge and ideas about genetics came from, and like most participants with learning disabilities who spoke about this topic, Vanessa did not talk about the possibilities of accessing genetic screening in the future. The certainty Vanessa implies in her narrative about *'the learning disability gene'* point to a range of assumptions being made and not being challenged by others. Regardless of whether it would be something Vanessa would choose to use, I suggest that it is unlikely she was informed by medical professionals or genetic counsellors about the kinds of screening and testing technologies available because, as detailed earlier, information about contraception and reproduction was something she struggled to access from her own GP.

While Vanessa said having '*the learning disability gene'* does not dissuade her from wanting to be a mother, not everyone shared this view. Concerns about genetic risk and learning disability being passed on through the genes was something a lot of participants talked about, and it was apparent these worries were impacting the reproductive decisions and imaginaries of some people with learning disabilities and sibling participants as well. Caitlin (pwLD, 20s) for example talked about biological destiny as she said people with a learning disability *'have to think more about genes'*, but unlike Vanessa, Caitlin spoke about she feels it can be harder to make choices about parenthood and *'having a child because of the genes'*. Caitlin added she feels people with learning disabilities have to *'think about every disorder you have, and can your child have that disorder'*. Caitlin further reflected on her own learning disability and mental health issues as she seemed to strongly believe she inherited these from her mother. She said it made her feel angry, upset and at one time suicidal that her mother did not consider her genes would be *'passed on'*:

> *"At one point I didn't want to live, and I regretted having my disabilities, so I would say to mum, why did you bring me to this earth having a disability and all that without like thinking of the genes and everything being passed on… I think people are ashamed of what they might give the child, like me, I'm ashamed of having my disorders so if I had a kid would they hold that grudge on me, there's a lot of stuff that you have to think about."*

This quotation here points towards broader discussions around genetic responsibility (Frederick et al. 2019) as Caitlin seems to suggest she feels her mother is to blame for passing on her learning disability. I asked Caitlin whether she felt this notion of genetic risk and responsibility was something other people with learning disabilities might think or be worried about, she replied saying, yes '*because people are scared and that they'll hurt another life*'. Despite her having lots to say about the topic of genetics, Caitlin still thinks *'it isn't really explained or talked about'* with people with learning disabilities because the wider social assumption remains that they will not, and should not, have children. Furthermore, while Caitlin was upset at the idea her learning disability could be *'passed on'* to children she may have in future. Like most participants with learning disabilities, Caitlin did not mention the possibility of accessing genetic screening or testing technologies and information that might help inform her reproductive decision making and assess the level of risk.

Non-learning-disabled parent participant Imogen (30s) talked about how ideas of genetics were influencing what her two stepsons with learning disabilities, Alec (mid-teens) and Harvey (late-teens), thought about having children in the future. Imogen said while Alec *'says he does want kids when he's older'*, but the idea of having children terrifies Harvey:

> *"When I spoke to Harvey about like having kids and stuff when you're older he's terrified, he's terrified that his kids will have the same conditions as him and that's why. He said, basically he doesn't want to go through what he's put us through, he doesn't want to have to go through that and it terrifies him. Then when I asked Alec the same question he said, he says he does want kids when he's older but not yet. I said, how would you feel if they had your conditions, and he said, well I would just try and control them and help them through it and stuff, but he wasn't as bothered by his condition, he just thought, oh I'll just get them through it. Whereas Harvey was like… I don't think I'd want kids because if they had my condition, it would ruin my life."*

This quotation illustrates how Imogen's stepsons had different views on the topic of genetics and how their learning disability influences what they both think about having children. The way Imogen says Alec *'wasn't as bothered by his condition'* is also like what Vanessa (pwLD, 40s) described earlier, as like Vanessa, Alec seemed focused on supporting and getting any children he may have *'through it'*.

Fiona (pwLD, 30s) is a mother with a learning disability with a young son who is currently undergoing investigations for learning disability and autism diagnoses. While Fiona described how her own pregnancy was unplanned, she said it might be harder for people with learning disabilities to choose to have children *'because they are scared of it being passed down'*. Fiona suggested the idea of biological destiny was not a view she held herself, but she seemed to think it would impact how other people with learning disabilities might think about having children. What Fiona says can be tied to dominant medical and social discourses that mark disability as a genetic risk and something to be avoided that is shaping individual decisions whether to have children or not. This way that genetic risk is deterring people with learning disabilities from having children connects with wider social discussions about reproduction and stratification as some people are deciding not to have children because society suggests it is undesirable and irresponsible. The idea that the reproduction of people with learning disabilities will be judged as risky and critiqued by others illustrates how decisions can be influenced by social contexts.

Some participants also said the assumption that learning disability will be passed on to the children of parents with learning disabilities is widely held by society (although, as noted earlier most children born to parents with learning disabilities will not be disabled themselves). Sibling participant Conor (30s) for instance said he felt dominant social assumptions about people with learning disabilities having children is that their disability will inevitably be passed on:

> Conor: *"I think people see it as going, well if you've got something, I sound horrible saying it, but saying it from what I think someone would be saying, if you've got something that wrong with you, what are you doing having sex, basically, I think that's what it is. Again, why would you want to try and reproduce and put someone else in the world like it.*
>
> Katrina: *So is that the worry that the disability could be passed on?*
>
> Conor: *Yeah, yeah."*

Support worker Gus (60s) also said, *'there's a feeling isn't there, that if two people with a learning disability have a baby it's inevitably going to be an impaired baby in some way'*. When support worker Huw (40s) was also asked about what he thought the social views of people with learning disabilities having children were he similarly responded by saying, *'I feel* *awful saying it, but I think it's a case of people see it as like well if you let them have sex, then you're going to end up with them having babies… what's going to be wrong with the baby'*.

Michael (pwLD, 70s) talked about how he thinks family members discourage people with learning disabilities from starting a family of their own because of the genetic concerns:

> *"I think they're afraid of what's going to happen to their son or daughter and what kind of child they're going to have, I think they're afraid of that, that's what my possibility is. They're afraid of their next granddaughter or the next grandson, how are they going to turn out, what are they going to turn out like. If a person has a child, is it going to be normal the same as you or any of the members of staff, or is it going to be with a learning disability."*

This quotation from Michael highlights that learning disability can still be considered a risk and something to be avoided and discouraged. It also reinforces discussions from Chapter 4 about the complex relational networks that people with learning disabilities often have as family members' ideas and assumptions can influence and restrict parenthood possibilities. Like Michael, support worker Freya (20s) also suggested family members' ideas and views about genetic risk could prevent people with learning disabilities from thinking about parenting possibilities:

> Freya: *"…they kind of don't want their child to reproduce because it's likely that if they have a learning disability, you know, their children will have one too*
>
> Katrina: *Do you think that's something parents are worried about?*
>
> Freya: *It depends on the parent, but I do think that's something that parents are quite worried about."*

Freya talked further about how she felt family members' concerns about genetic risk were perhaps less about the impairment *per se*, but their reservations were instead related to how society still perceives and treats people with learning disabilities today:

> *"I think you know, a few parents are quite worried that because people with learning disabilities are seen to be kind of almost like inferior to other people, you know, they*

> *probably just don't want their children to have to go through what they did, that kind of struggle you know. Like the 1960s, if you had a child that was like deformed or disabled, it was very much, oh we have to hide them away. Whereas I don't think that's so much of an issue now, I think it's still, you know, a wee bit of a kind of issue as well but not as much obviously, but you know it's still- they're still very kind of excluded from society."*

This quotation from Freya seems to suggest family members not wanting their children to reproduce may come from a sense of protectionism, a theme also highlighted in Chapter 4. If family members hold these views, then it may be difficult for people with learning disabilities to ask questions and learn about reproductive and parenting information. Without opportunities to learn about the topics people with learning disabilities are restricted in their capability to make free and informed decisions about reproduction and parenthood.

While some seemed to think the fatalistic view learning disability would inevitably be passed on in the genes, a few participants however felt it was more dictated by chance. From participants that I spoke with, Michael (pwLD, 70s) for example talked about his own experiences of being *'the only one in my family with a learning disability'*. Michael said it was a myth that because one or both parents have a learning disability then the child will inevitably have a learning disability, instead he suggested that it might miss a generation and *'may miss out on that child, that child may not have a learning disability'.*

In contrast to participants with learning disabilities, many sibling participants said genetic screening and testing was something they had accessed or were thinking about accessing in the future to inform their own reproductive decision making. Sibling participant Stella (40s) for example described how when she became pregnant with her children, she accessed prenatal screening technologies because she was concerned Down's syndrome, the diagnostic label her sister Essie (30s) has, *'could be hereditary so there could be a risk of that'*. Stella also said that throughout both her pregnancies, the idea that *'the girls might have had Down's syndrome was very scary, I even said I don't know if I could have kept 'em'*.

Sibling participant Conor (30s) does not currently have children, and he said he was not sure if genetic screening technologies would be something he would access before having children.

He told me, *'I've always wanted kids, but it is in the back of my head'* that they could have a learning disability like his sister Chloe (20s). When asked how he felt Chloe's learning disability impacted his own parenting decisions he said it was something he and his partner have spoken about before because *'I saw how hard it was from mum'* parenting Chloe. Conor said:

> *"I've had this moral question before and me and my other half spoke about what if you can have the test before the baby is born to see if they're going to have a learning disability or not, and would you want it or not. And in some ways, I'm going I would want to know, but then it's but what actually would I do with that information. Because then you're deciding either to get rid of a child because they might have a learning disability, but they might not, because the test might be wrong. Or you decide I'm going to stick with it anyway because we've decided to have a child, and I will love that child no matter what. It will make life harder, but it's worth it. Like mum loves Chloe more than anything, as much as she can be a bit of a terror, she's also amazing. So yeah, it might make me have less kids, mum wanted another three."*

This example from Conor is important because it highlights how information and access to genetic screening technologies may shape and influence the future decisions he makes about whether, and how many, children he has.

Like Conor, sibling participant Abigail (late-teens) said she recognised how difficult it was for her family raising her brother Luke (mid-teens) because of his learning disability. Abigail described how Luke was diagnosed with a rare chromosome variation that doctors had said was *'genetic and has come from a parent, so both my mum and dad took this genetics test and it come back that dad has it'*. Abigail said it was difficult to believe her father has the same genetic variation as her brother because her father has *'never really had those symptoms, he's gone through life, he's got a job and whatever'*. She went on to say that she was never tested for this genetic variation when she was younger, but as she got older it was something she wanted to know about herself:

> *"I was never given the option to get tested… but I wanted to know for my future and for my kids and I just said, I want to know now, this is the time, you know, I'm getting a bit older, I want to know what my future holds… And yeah, it come back positive."*

When asked how she felt, Abigail said *'I got a bit upset when I found out… it was a massive shock for me'*. Despite having the same genetic variation as her brother, Abigail said that like her father she is *'completely fine, I've gone and got a job you know, I'm quite independent'*, but that is not the same for Luke. Her family are not sure whether Luke's learning disability is the genetic variation *'making him this way or is there another underlying condition'*. Abigail then told me finding out she has the same rare genetic variation as her brother and father *'definitely questions my future'* of having children and becoming a parent. Abigail said because the prenatal screening is not currently advance enough to screen for her and her brother's specific genetic variation, this complicates her decision whether to have children in the future:

> Abigail: *"The testing is just not out there in terms of chromosome disorders, so if I was pregnant, I wouldn't be able to know if I've passed it on, it's a fifty-fifty chance, so I wouldn't know until the baby is here if it's got that chromosome disorder, which is quite a gamble*
>
> Katrina: *If there was a test for it, do you think you'd have it?*
>
> Abigail: *Yeah definitely. It just sounds really bad because I love my brother and he's literally my world, but I just know the struggles that it comes with and mum having to not work… mum always wanted to be a stay at home mum, so it suited her but I have big plans, like I want to go up in my job and I want to work quite a lot, I want to have kids as well… but I know if I did have a child like Luke, that just that wouldn't happen."*

Abigail's situation here shows some of the challenges and complexities around current genetic screening technologies. Accessing genetic screening has shown her that she shares the same rare genetic variation as her brother, but currently there is no way of knowing if any children she has will also have the variation and whether they will have a learning disability or not. Her experiences highlight some of the ongoing tensions between the right to choose to have a baby or not, and the concerns of the disability rights movement that genetic screening technologies are reaffirming previous eugenic social ideas that disability is something that should be avoided (McCarthy 2009a).

Sibling participant Elaine (50s) however differed in her views and experiences of genetic screening and testing technologies as she said she *'made a conscious decision'* not to undergo prenatal testing during her pregnancies. Elaine said because her sister Sheila (60s) has Downs syndrome that medical professionals 't*alked about having extra tests and I said, no because it would make no difference'*. Elaine went on to say:

> *"I didn't have any of the extra tests for spina bifida or anything like that, amniocentesis I said, no, I didn't want it. No. What came, came, and that was that really, so no it didn't affect me… but I know other people that it did, that did fall pregnant that already had people with a learning disability in their family and they had every test under the sun because they didn't want the same for them."*

This section has shown that the range in ideas about genetic screening and testing technologies is varied, and this is particularly the case for participants with learning disabilities. Most sibling participants interviewed described how they had information and opportunities to access genetic screening technologies that they could choose to use to help inform their reproductive decision making. In juxtaposition, while many participants with learning disabilities seemed to have a range of different knowledge and ideas about genetics, no one interviewed with a learning disability said they had accessed, or thought about accessing, genetic screening or testing technologies. I suggest many participants with learning disabilities may not have known what knowledge and technologies could be available to them that might help them know how much a 'risk' there was, which is limiting their opportunities to make meaningful and informed decisions about parenthood. Genetic screening and testing services have also been critiqued for disseminating often complex and overly factual information that can be a barrier for people with learning disabilities to access (McGaw & Candy 2010). It is also possible that participants with learning disabilities did know about these technologies but may not have used them because, like Vanessa (pwLD, 40s) suggested earlier, they may not regard the chance of their disability being passed on as a risk and therefore something that does not require testing for. This is also mirrored in research by Boardman and Hale (2018) as they found a 'mismatch' between the way society negatively views genetic impairment and disability compared with the often more positive perspectives and experiences of some people living with a condition, although these perspectives can vary depending on the genetic impairment (also see Boardman & Hale 2019; Hansson et al 2018).

Ideas that the reproduction of people with learning disabilities is a risk restricts them from accessing information about and using testing technologies to make their own choices about whether to have children. As suggested throughout this thesis, the parenthood imaginaries of people with learning disabilities are influenced by dominant social views that their reproductivity is risky, inappropriate, irresponsible and seen something to be avoided. The ways that some people with learning disabilities internalise this narrative that parenthood is something they should avoid is indicative of the ways the reproductive decisions of people with learning disabilities are controlled, managed and subjugated by wider social contexts and powerful others.

6.5 Conclusion

This chapter has shown that people with learning disabilities are at greater risk of sexual violence, unplanned and unwanted pregnancies by a lack of accessible information and their wider marginalised positions within society. While access to sexual and reproductive health information will not stop abuse from happening, yet without it, people with learning disabilities can find it difficult to recognise instances of sexual violence and make timely choices about responding to pregnancy (see Borawska-Charko et al. 2017; Conder et al. 2011). As this chapter has detailed, participants across all interview groups have called for more opportunities for people with learning disabilities to access and learn about sexual and reproductive health to empower their own decision making.

On the issue of child removal, findings from this research show the ways a culture of risk aversion within contemporary social work practice is further restricting the parenthood experiences and imaginaries of people with learning disabilities (McConnell & Phelan 2022; Callus et al. 2019; Bates et al. 2017; Grieve et al. 2009). Informed by a priori assumptions that people with learning disabilities are unfit and incapable of successfully fulfilling parenting roles, parents with learning disabilities are discriminately targeted by child protection proceedings. Findings in this study have illustrated how parents with learning disabilities feel they are not afforded the same opportunities to learn new skills and prove their parenting capabilities as non-learning-disabled parents. People with learning disabilities, including those who do not yet have children, have an awareness of the ways social service professionals perceive people like them as risky and dangerous parents. For many, the consequences of child removal seem almost inevitable, and this is a barrier to people with learning disabilities fulfilling their own parenting ambitions.

Recent advances in the field of genomic medicine and the development of genetic screening and prenatal testing technologies have changed how society thinks about the topics of reproduction and disability. Participants with learning disabilities held a range of understandings about if, and how, parents with learning disabilities might ‘pass on’ their learning disability to their children and the influence this had on their own parenthood imaginaries and experiences. The dearth of discussion about genetic screening and prenatal testing technologies among people with learning disabilities compared with other participant groups points towards a lack of accessible information they have on the topic. It can be argued that by not knowing the reproductive options that might be available to them, people with learning disabilities endure reproductive injustice and oppression as they are restricted from making informed choices.

Chapter 7. Conclusion

7.1 Introduction

This final chapter presents the conclusions informed by the findings of this research and sets out recommendations for enabling people with learning disabilities to have more choice and autonomy when it comes to making their own decisions about reproduction and parenthood. It looks at some of the limitations of this research and how these can be used to inform future research about the topics of reproduction and parenthood for people with learning disabilities. Finally, I end this thesis writing some concluding remarks reflecting on the research.

7.2 Responding to the research questions

1. What imaginaries and experiences do people with learning disabilities have towards reproduction and parenthood?

Findings from this research show that people with learning disabilities have a range of desires and experiences towards having children and becoming parents. Some people with learning disabilities did not want to have children and parenthood was not a role they ever wanted to fulfil in their lives. It is possible that if they had lived in different contexts where the possibility of them having children was not dismissed so readily by others around them that some people with learning disabilities may have thought differently about parenthood. Despite not wanting to have children, a number of people with learning disabilities talked about the pleasure they got from taking on different familial responsibilities as an aunt or uncle. This value of having opportunities to be involved in the lives of other children in their families was a sentiment also shared by sibling and non-learning-disabled parent participants. For many other participants with learning disabilities, having children was something they desired, and they talked candidly about the challenges and barriers they experienced in trying to fulfil these ambitions. Issues with a lack of sexual and reproductive health information, not knowing whether having children was possible for them, the threat of child removal, and concerns about passing on their learning disabilities if they were to have children were some of the challenges to parenthood participants talked about. The experiences of parents with learning disabilities also varied as some were happy fulfilling parenting roles and felt supported by others around them, whereas other parents with learning disabilities described how family members interfering negatively shaped their parenting experiences. The issue of child removal from parents with learning disabilities is also significant to this research as it shapes the reproductive decisions of people with learning disabilities who have experienced child removal, as well as those who do not yet have children.

2. How are parenting imaginaries and experiences shaped by family members, staff and other professionals in their lives?

While some people with learning disabilities reported feeling supported in their parenting roles by family members, protectionism and infantilisation also emerged as strong themes throughout this thesis. Despite often good intentions of trying to protect people with learning disabilities, this research has shown family members, especially parents, can constrain and oppress the reproductive and parenting possibilities of people with learning disabilities. It is significant that siblings were often critical of their parents' protection towards individuals with learning disabilities that highlights the dynamics of familial relations, roles, and responsibilities. Some family members and support workers can be particularly reluctant to engage in discussions about reproduction and parenthood with people with learning disabilities which reinforces the narrative that parenthood is not for people like them. As well as this silence from family members and staff about the topics, findings from this study also show how contraceptive usage of people with learning disabilities can be controlled by family members and support workers that further restricts parenting possibilities. For instance, findings from this research show how some people with learning disabilities are using contraception because it is what their parents have decided and individuals with learning disabilities are not always aware that it prevents pregnancy. Incidents where staff are confiscating condoms from people with learning disabilities is also exempla of how contraception usage of people with learning disabilities can be controlled by others. Other participants report that opportunities for them to become parents and have children are quashed by family members telling them that they cannot cope with raising a family and they are not allowed to have children. This gatekeeping of parenting possibilities is also shown by staff monitoring and surveilling the intimate lives of people with learning disabilities that makes it difficult for them to think meaningfully about having children. Despite the closure of institutions, the lives of people with learning disabilities are still closely controlled by staff and other professionals around them that continues to limit their reproductive decision making. Findings from this research also illustrate how some people with learning disabilities feel targeted by other professionals, such as social workers, and feel they are not given a chance to parent their children. The threat of social service involvement and child removal processes are important issues in this research that are also shaping how people with learning disabilities who do not yet have children think about their own parenthood possibilities.

3. How are social ideas and assumptions about people with learning disabilities shaping parenting possibilities and experiences?

Findings from this research suggest that social ideas and assumptions about people with learning disabilities are significant in shaping how people with learning disabilities think about reproduction and experience parenthood. Despite advances of the disability rights movement, stereotypical ideas that people with learning disabilities are asexual and child-like persist and these assumptions are still restricting their opportunities for making their own meaningful choices about parenthood. In this study, participants both with and without learning disabilities said these assumptions made it challenging for people with learning disabilities to have opportunities to experience intimate relationships and access sexual and reproduction health education to enable them to make their own decisions. Furthermore, widely held social assumptions that people with learning disabilities will be unable to cope with parenting means that if they do have children, many will come under the surveillance of others, especially social services. Participants with learning disabilities had an awareness of these social ideas but strongly disagreed with this narrative. Instead, some felt that many people with learning disabilities are capable of being good and loving parents while also recognising that, like many parents without learning disabilities, some people with learning disabilities may need support to help raise their children. This research has also shown how social ideas of genetic risk is shaping what people with learning disabilities think about their own parenting possibilities. While some did not see ‘passing on’ their learning disability as the tragedy society often portrays, others felt it was a ‘risk’ they did not wish to take. Ideas about genetic risk also came through from sibling participants as they shared their own reflections about the role their brother or sisters learning disability had in their own reproductive decisions. These discussions around genetic risk resonate with wider disability literature and eugenic ideologies that questions the appropriacy of people with learning disabilities having children and becoming parents as their reproduction is still widely considered something to be avoided. All participant groups in this research were aware of these social ideas and called for change so that people with learning disabilities can access the same reproductive and parenting possibilities as anyone else.

4. How can people with learning disabilities be supported to reflect on the topics of reproduction and parenthood and be empowered to make their own active choices?

This research has shown how the lack of accessible education and information about sexual and reproductive health is a barrier for people with learning disabilities making their own informed choices about the topics. Accurate information needs to be available in a range of different settings (e.g., schools and colleges (mainstream and SEND), advocacy groups, social and living spaces). Family members and staff also need more support to feel confident discussing these issues with people with learning disabilities in ways that empowers them to have autonomy and safeguard themselves. As well as access to information, there needs to be more support in place to assist parents with learning disabilities when they reach out for help. Participants in this research said they were told they would be given parenting lessons and support, but it never materialised, instead child protection proceedings were carried out against them and some parents with learning disabilities had their children taken off them.

7.3 Research contributions

The concepts of stratified reproduction and reproductive justice have been used in feminist literature on the issues of reproductive decision making engaging with non-disabled or physically disabled women, but these frameworks have scarcely been applied to the reproductive imaginaries and experiences of people with learning disabilities. By using these concepts to explore the reproductive possibilities of people with learning disabilities I am addressing a gap within the literature and making contributions to the field. By drawing together understandings from disability studies, stratified reproduction and reproductive justice, this research has shown how the reproductive and parenting possibilities of people with learning disabilities is still limited and restricted by powerful others and the contexts they are positioned within. While most people with learning disabilities are no longer living in institutions, the control and oppression that many people with learning disabilities experience around their reproductivity is indicative of ongoing newgenic ideas and practices. These challenges people with learning disabilities experience with intimacy, reproduction and parenthood reinstate social ideas that their reproductivity is stratified and valued less-than non-disabled people that points towards their general marginalisation.

As indicated in Chapter 2, the topic of reproduction in disability studies is often an area that is dominated by literature on physical disability. By centring the voices and experiences of people with learning disabilities, this study provides new insights on the topics of reproduction and parenthood from a social group often left out of these discussions. Furthermore, hearing the perspectives and views of men with learning disabilities around the topics of reproduction and parenthood is also an area my research adds to as the focus of existing research has predominantly been around women. What male participants with learning disabilities have said in this research helps to illustrate some of the nuances between gendered parenting roles and how these can shape both the parenting imaginaries and experiences of men and women with learning disabilities. This research contributes to wider literature on disability and families by including the voices of siblings of someone with a learning disability. While the views and experiences of siblings are sometimes overshadowed in existing disability literature by parents, this study has shown the important role siblings can play in supporting their brother or sister with learning disabilities to access sex education and how this impacts their parenting imaginaries and experiences. The inclusion of sibling participants has also illustrated how family member perspectives are not monolithic as ideas of care, protectionism, independence, and risk can differ for parents and siblings of someone with a learning disability.

7.4 Research recommendations

The recommendations outlined below have been developed from what participants told me about how people with learning disabilities could be better supported to make choices about parenthood and having children, with a particular focus on access to sexual and reproductive health information and parenting support. It is important to acknowledge while making these recommendations that there are other aspects around the topic of parenthood and learning disability that I have not had scope to explore in this thesis.

- Improved access to sexual and reproductive health information:

This research has described how the reproductive possibilities of people with learning disabilities are still being limited and restricted by a lack of accessible information about sexual and reproductive health. For people with learning disabilities to make their own informed and autonomous decisions about these topics, information needs to be available in easy read and picture formats and feature in a range of different settings such as: schools, colleges, GP surgeries, advocacy groups, supported living accommodations and other social care settings. Better signposting of how and where people with learning disabilities can access sex education is also needed to optimise informed decision making opportunities for people with learning disabilities. This information needs to include content about contraception; especially the different forms of contraception that are available, how these can impact fertility and in what ways. Findings from this study have also highlighted the gaps in what some people with learning disabilities know about reduced fertility and age; resources therefore need to be clearer about these issues so people with learning disabilities are able to make their own informed decisions. The topics of consent and sexual violence also need to be included in this information to enable people with learning disabilities to recognise and report instances of abuse. As mentioned earlier, while this will not necessarily prevent abuse from happening, it will give individuals more opportunities to respond to what has happened to them.

- Supporting family members and support workers as allies:

Ignoring the sexual and reproductive possibilities of people with learning disabilities forms part of the wider oppression and marginalisation many still experience; action needs to be taken by family members, staff and care organisations to tackle this issue. To support the rights of people with learning disabilities there needs to be more support, guidance and resources available to family members and support workers that enables them to feel confident having conversations about sex and reproduction with people with learning disabilities. There is some information and support for families available online, but these could be developed further into more comprehensive toolkits for families and staff to access (see My Family Our Needs (2023); National Autistic Society (2023); Disability Horizons (2020)). Care organisations also need to be providing staff with more training about the topics of sexuality and reproduction so they can communicate this meaningfully to people with learning disabilities. As set out in Chapter 2, whether and what training about sexuality care organisations provide is at their discretion, however it would be more impactful to make staff training around sexuality and reproduction mandatory.

- Parenting support for people with learning disabilities:

Not every parent with a learning disability will need or want to access formal parenting support, but the current dearth of opportunities to access parenting information and skills development groups is failing many parents with learning disabilities. Participants in this research call for there to be more ways for people with learning disabilities to access parenting classes, workshops, skills development courses and mother-baby groups. This research has highlighted some of the tensions between how people with learning disabilities often feel targeted by social services that restricts their parenting possibilities. Social services need to do more to give parents with learning disabilities the chance of developing parenting skills and care for their children. When child protection proceedings do need to be initiated, parents with learning disabilities need to be better supported to help them understand what is happening, they should have it explained to them why their child is being removed and have their rights to legal representation upheld. For example, parents with learning disabilities should have access to advocates who can support them through child removal processes and help them challenge legal proceedings, if that is what parents with learning disabilities want. This research also highlights some of the trauma parents with learning disabilities can experience during child removal processes and more needs to be done to provide ongoing care for these individuals.

- More opportunities for independence, privacy and intimacy:

This research has illustrated how some people with learning disabilities are restricted in their reproductive and parenthood decision making by protective family members limiting opportunities for independence. This protection is often not without grounds as poor treatment and instances of abuse in residential homes and supported living spaces means families are rightly reluctant to trust care authorities to provide safe support for their loved ones with learning disabilities. To enable families to support people with learning disabilities to leave the family home and live more independently, if that is what individuals with learning disabilities want, then social care organisations need to do more to improve the care staff are providing. More effort needs to be directed at improving staff recruitment, training, pay, career progression opportunities, and ongoing staff support and mentoring. With improved quality of care, the possibility of leaving the family home is something people and families of people with learning disabilities can realistically think about.

As well as independence, strict regulations and policies that restrict rights to privacy in supported living organisations are denying people with learning disabilities chances to build and experience intimate relationships. Findings from this research further suggest care organisations need to reconsider how they can do more to train staff to empower and support people with learning disabilities to experience intimate relationships. For example, people with learning disabilities should be afforded opportunities to have other people stay in their rooms over-night and to go out and socialise with other people if they wish.

- Greater positive social representation of parents with learning disabilities:

While many parents with learning disabilities can provide love and care for their children, like anyone else, negative stereotypes and assumptions about people with learning disabilities as incapable and unsuitable for fulfilling the role of parenthood is impacting the parenting possibilities and experiences of people with learning disabilities. People with learning disabilities interviewed in this study had an awareness of the dominant social ideas that they are not fit for parenthood, and some have internalised this negative discourse. There needs to be more positive representations and visibility of people with learning disabilities having intimate relationships and having children in society to challenge dominant social ideas. Positive portrayals and more visibility in the media and community spaces could go some way in starting to challenge some of the negative stereotypes.

7.5 Study limitations and suggestions for further research

The inclusion of only speaking participants can be identified as a limitation of this study. An extension of this research could be to include alternative communication methodologies to provide a space for more marginalised groups of people with learning disabilities, who do not use speech, to contribute to discussions and share their perspectives. As a relatively small-scale study conducted during the Covid-19 pandemic, I did not have access to the skills nor resources to facilitate this effectively but exploring ways to include the perspectives of non-speaking people with learning disabilities is an area researchers should continue to consider and develop further, especially around the topic of parenthood.

Having children and becoming a mother or father are deeply gendered roles with different social experiences linked to them (Malacrida 2020). The inclusion of male participants with learning disabilities has been a refreshing insight into how they experience and think about the topic of parenthood. Having said this, only one father with learning disabilities took part in this study and I suggest that there is much more we can learn by including more fathers and men with learning disabilities in future research. Keeping with the issue of demographics, it is important to highlight that aside from one male participant with learning disabilities who identified as British Pakistani, all other participants in this research said they were white British. An exploration into how race and ethnicity may shape the imaginaries and experiences of parenthood for people with learning disabilities would also be an interesting extension of this research. This would allow for further consideration of cultural nuances about family roles and relationships that is only briefly touched on in this thesis. It was also beyond the scope of this research to explore the parenthood imaginaries and experiences of people with learning disabilities who identify as LGBT+ but it is something future research should consider.

Furthermore, I feel I have only scratched the surface exploring what parent and support worker participants told me and a more in-depth exploration into the views of these participants would be something to take forwards. Dyadic interviews with people known to one another would also provide different opportunities to delve further into some of the relational networks and dynamics that have been highlighted in this thesis.

Another limitation is that the voices of social work professionals were not included in this research. This was partly because in the early design stages of the study I planned on only speaking with younger people with learning disabilities who were not yet parents. However, as the focus expanded in response to Covid-19 to include parents with learning disabilities, some of whom had experienced child removal, the critique of social services became more apparent. Participants with learning disabilities who were parents often described their acrimonious experiences and feelings towards social service professionals. Throughout this thesis I have acknowledged the absence of social service professionals and state here that their inclusion would be an insightful extension of this research. In a similar vein, medical professionals have also been critiqued by participants in this thesis for not doing enough to support people with learning disabilities with accessible information about linkages between menstruation, fertility, reproduction and pregnancy. Their perspectives about whether and how they engage with people with learning disabilities about these issues is something future research should expand upon.

Having so far focused on some of the methodological limitations of this research I will now present some suggestions for ways the topics outlined in this research could be developed and expanded in further studies. For instance, future research should look more closely at the kinds of sexual and reproductive health information that is disseminated in mainstream and SEND schools. With the recent legislative changes to sex education provision in schools in England, it will be important to see what impact this will have on how people with learning disabilities make choices about what they learn about the topics of relationships, sex, reproduction and parenthood. While this is important for future research to consider, I also argue that it must not distract from the importance and urgency of addressing the inadequacies of sex education provided to people with learning disabilities today.

Finally, a significant theme throughout this research has been the ways support staff find it difficult balancing tensions between protection and supporting autonomy that allows people with learning disabilities to make decisions the same as anyone else. I suggest future studies should explore practical ways social care organisations can provide staff with better training and support to help people with learning disabilities navigate the topics of intimate relationships, reproduction and parenthood. Without this support, the reproductive and parenting opportunities of people with learning disabilities will continue to be oppressed and denied.

7.6 Concluding remarks

This thesis has shown that while some family members can be supportive of people with learning disabilities as parents, many family members can find it challenging trying to balance protection with supporting people with learning disabilities to make their own choices around the topics of sexuality, reproduction and parenthood. Support staff can also restrict the reproductive imaginaries and experiences of people with learning disabilities by monitoring and surveiling their intimate lives. Even if individual staff support the reproductive rights of people with learning disabilities, their position as institutional actors within organisational contexts can make it difficult for them to enable people with learning disabilities to make their own choices about reproduction and parenthood. A significant theme throughout this research is how contexts of risks are further shaping the reproductive and parenting possibilities of people with learning disabilities. The risk and threat of child removal is shaping how people with learning disabilities think about parenthood and their future reproductive opportunities. Social ideas and assumptions that people with learning disabilities are incapable of fulfilling parenting duties is a barrier to them accessing parenting support. By drawing on disability studies, reproductive justice, and stratified reproduction, this research has shown that whilst older eugenic ideas and practices have waned, the reproductive and parenting possibilities of people with learning disabilities are still controlled and oppressed through more subtle forms of newgenics. Judgements are still being made by powerful others about the appropriacy and suitability of people with learning disabilities for parenting roles. Society needs to recognise the eugenic ideology restricting who is worthy of reproduction is as significant today as it was during the early twentieth century; it is unjust and unfair that people with learning disabilities are still oppressed and devalued in this way.

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Appendices

Appendix A: Pre-Covid-19 pandemic material

Recruitment email sent to care organisations

Hello [**name**],

My name is Katrina, and I am a PhD student at Newcastle University. I am currently planning a research project on young people with learning disabilities and what they think about parenthood and their futures. I would really like to learn more about the support the [**name of organisation**] provide for people with learning disabilities and to see whether any of the people you work with might be interested in the research.

Before beginning my PhD in Sociology, I worked as a support worker for people with learning disabilities. My PhD research aims to focus on what young people with learning disabilities think about the opportunities and barriers to parenting, and to also explore how families and other social networks might shape the decisions of young people.

A lot of the existing work that has been carried out in this area focuses on the views of medical professionals or family members, very little has been done to find out what young people themselves think about parenting with a learning disability. My research will centralise young people’s voices and I hope it will provide an opportunity for young people with learning disabilities to share their perspectives on parenting and feel heard.

I hope that my research will provide an opportunity for people with learning disabilities to share their perspectives and feel heard. To achieve this, I’m eager to work directly with people with learning disabilities to discuss their views and understand their lives.

It would be great to talk to you more about the work you do, my research and whether this might be something that the people you work with/support might be interested in being involved with? I am very open to exploring ways that the work and my involvement with you could also support and/or develop knowledge that could be useful to you.

I’d be more than happy to call or drop-in to talk more face-to-face about it if that would suit you?

Many thanks and best wishes,

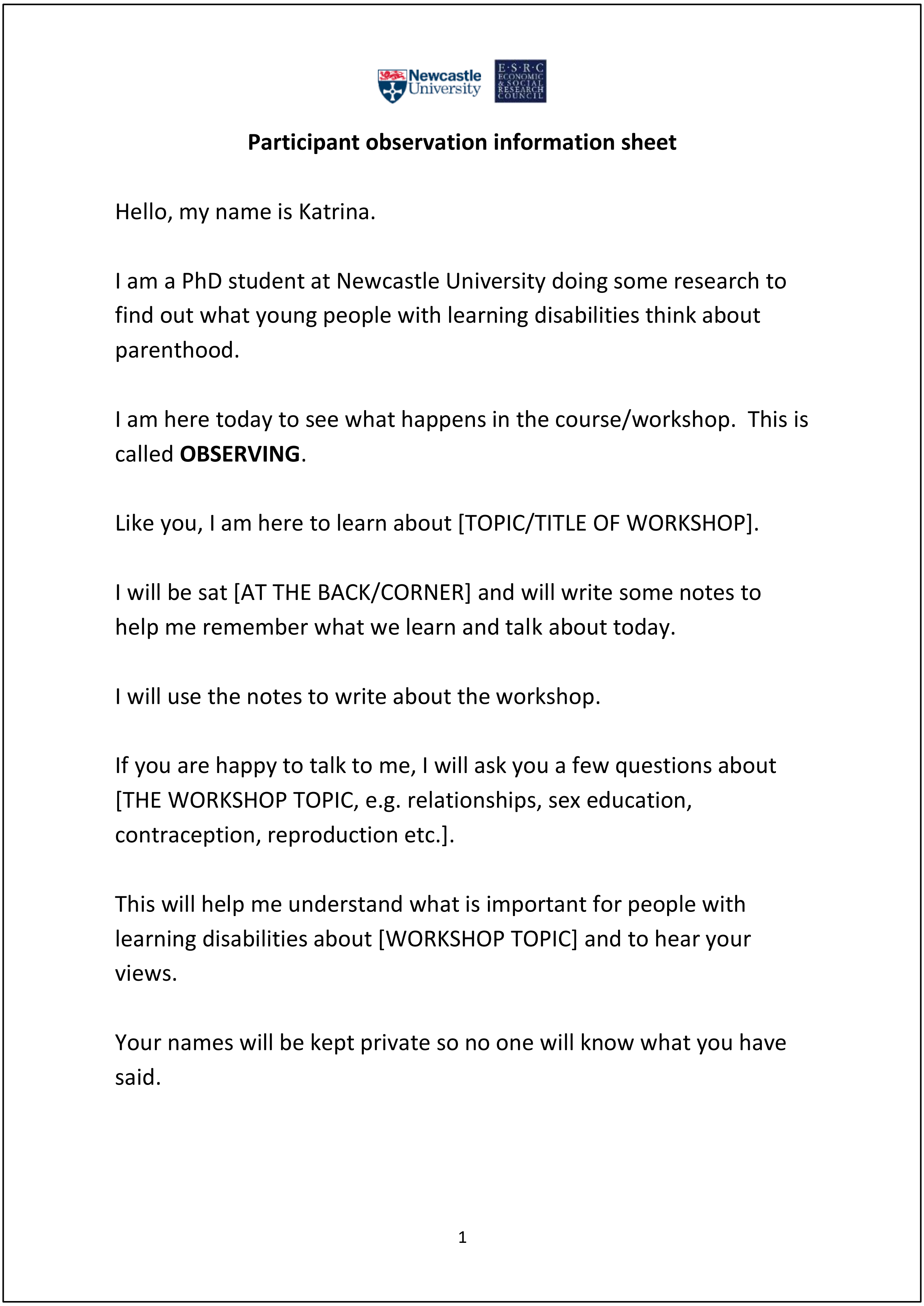
Katrina

Katrina Rose
PhD student researcher
Newcastle University

https://research.ncl.ac.uk/parenthoodstudy/

Newcastle
University

Participant observation sheet



Participant observation information sheet

Hello, my name is Katrina.

I am a PhD student at Newcastle University doing some research to find out what young people with learning disabilities think about parenthood.

I am here today to see what happens in the course/workshop. This is called **OBSERVING**.

Like you, I am here to learn about [TOPIC/TITLE OF WORKSHOP].

I will be sat [AT THE BACK/CORNER] and will write some notes to help me remember what we learn and talk about today.

I will use the notes to write about the workshop.

If you are happy to talk to me, I will ask you a few questions about [THE WORKSHOP TOPIC, e.g. relationships, sex education, contraception, reproduction etc.].

This will help me understand what is important for people with learning disabilities about [WORKSHOP TOPIC] and to hear your views.

Your names will be kept private so no one will know what you have said.

1

If you don’t want me to talk to you just tell me or [WORKSHOP FACILITATOR].

Does anyone have any questions?

If you think of a question later, you can ask me in the break or at the end.

👍

Thank you for letting me observe the [WORKSHOP/COURSE].

If you have questions about my research, you can contact me by email. My email address is parenthoodstudy@newcastle.ac.uk

This research is being supervised by:
Professor Janice McLaughlin
janice.mclaughlin@newcastle.ac.uk

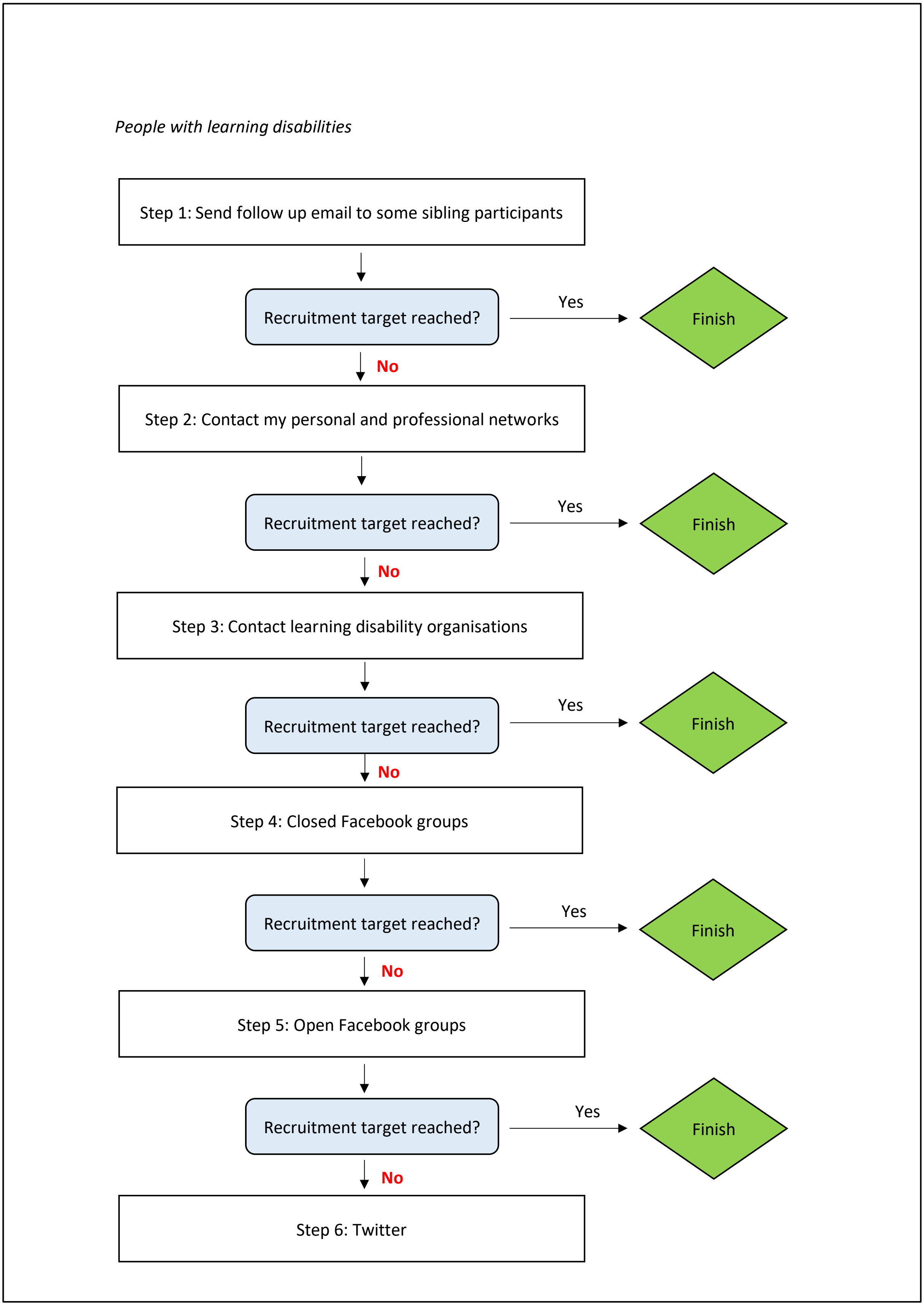
Dr Sarah Winkler-Reid
sarah.winkler-reid@newcastle.ac.uk

Appendix B: Talking Mats

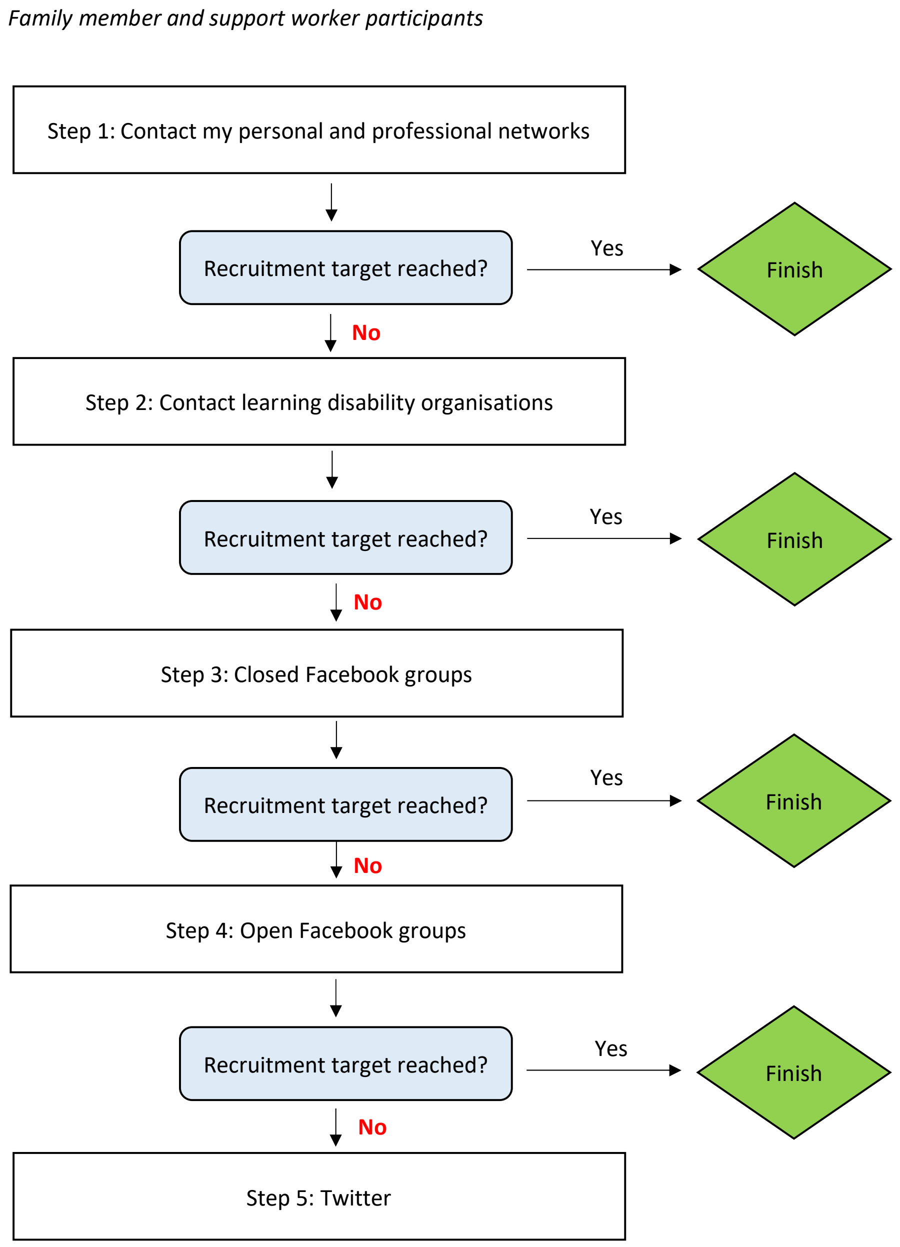
Image examples of Talking Mat picture cards that could have been used in this research pre-Covid-19 pandemic:

Appendix C: Recruitment method guides

People with learning disabilities

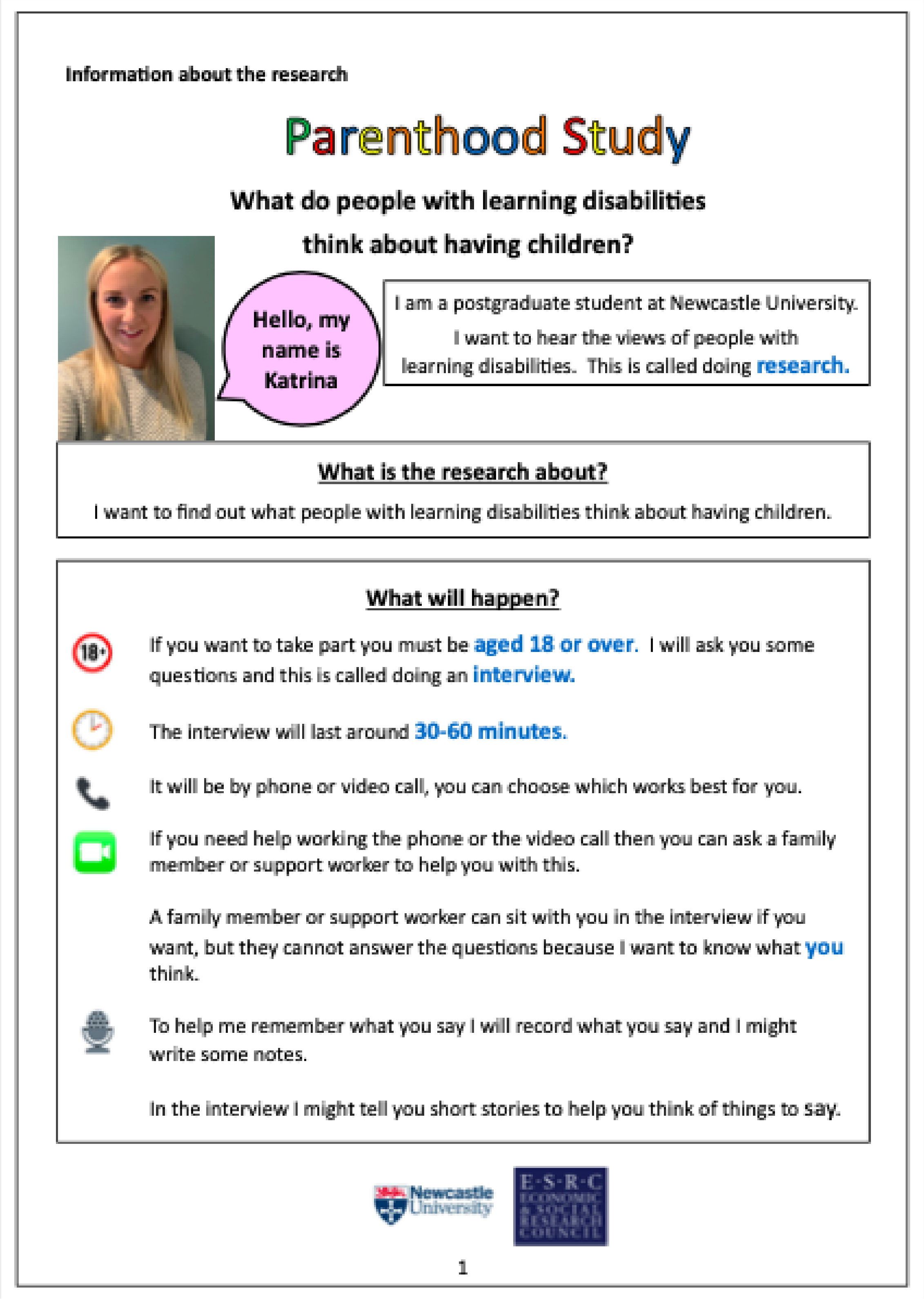


Family member and support worker participants



Appendix D: Participation information sheets

Participation information sheet for people with learning disabilities



Information about the research

Parenthood Study

What do people with learning disabilities think about having children?

Hello, my name is Katrina

I am a postgraduate student at Newcastle University. I want to hear the views of people with learning disabilities. This is called doing **research.**

What is the research about?

I want to find out what people with learning disabilities think about having children.

What will happen?

18+ If you want to take part you must be **aged 18 or over.** I will ask you some questions and this is called doing an **interview.**

The interview will last around **30-60 minutes.**

It will be by phone or video call, you can choose which works best for you.

If you need help working the phone or the video call then you can ask a family member or support worker to help you with this.

A family member or support worker can sit with you in the interview if you want, but they cannot answer the questions because I want to know what **you** think.

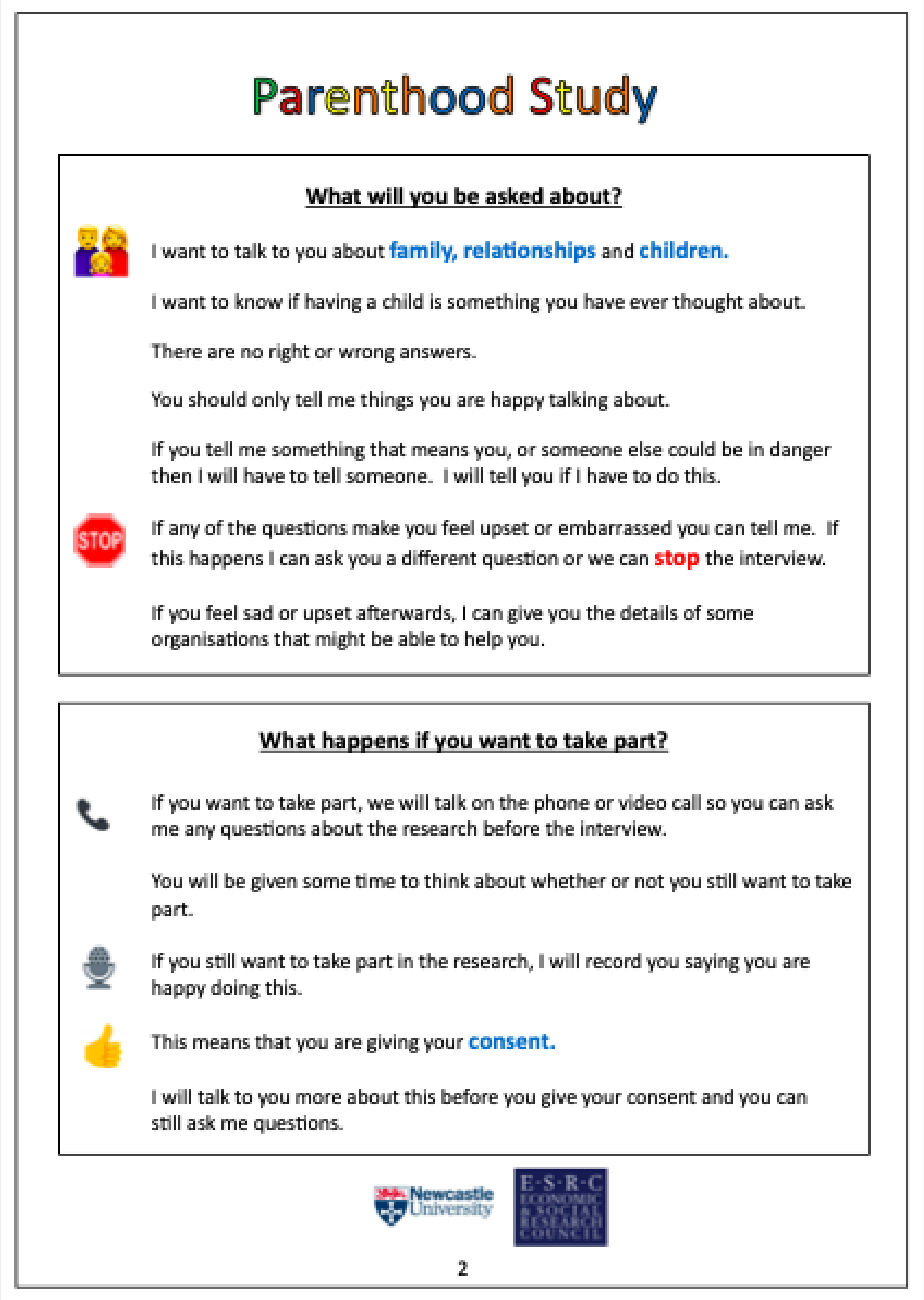
To help me remember what you say I will record what you say and I might write some notes.

In the interview I might tell you short stories to help you think of things to say.

Newcastle University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

1



Parenthood Study

What will you be asked about?

I want to talk to you about **family, relationships** and **children.**

I want to know if having a child is something you have ever thought about.

There are no right or wrong answers.

You should only tell me things you are happy talking about.

If you tell me something that means you, or someone else could be in danger then I will have to tell someone. I will tell you if I have to do this.

If any of the questions make you feel upset or embarrassed you can tell me. If this happens I can ask you a different question or we can **stop** the interview.

If you feel sad or upset afterwards, I can give you the details of some organisations that might be able to help you.

What happens if you want to take part?

If you want to take part, we will talk on the phone or video call so you can ask me any questions about the research before the interview.

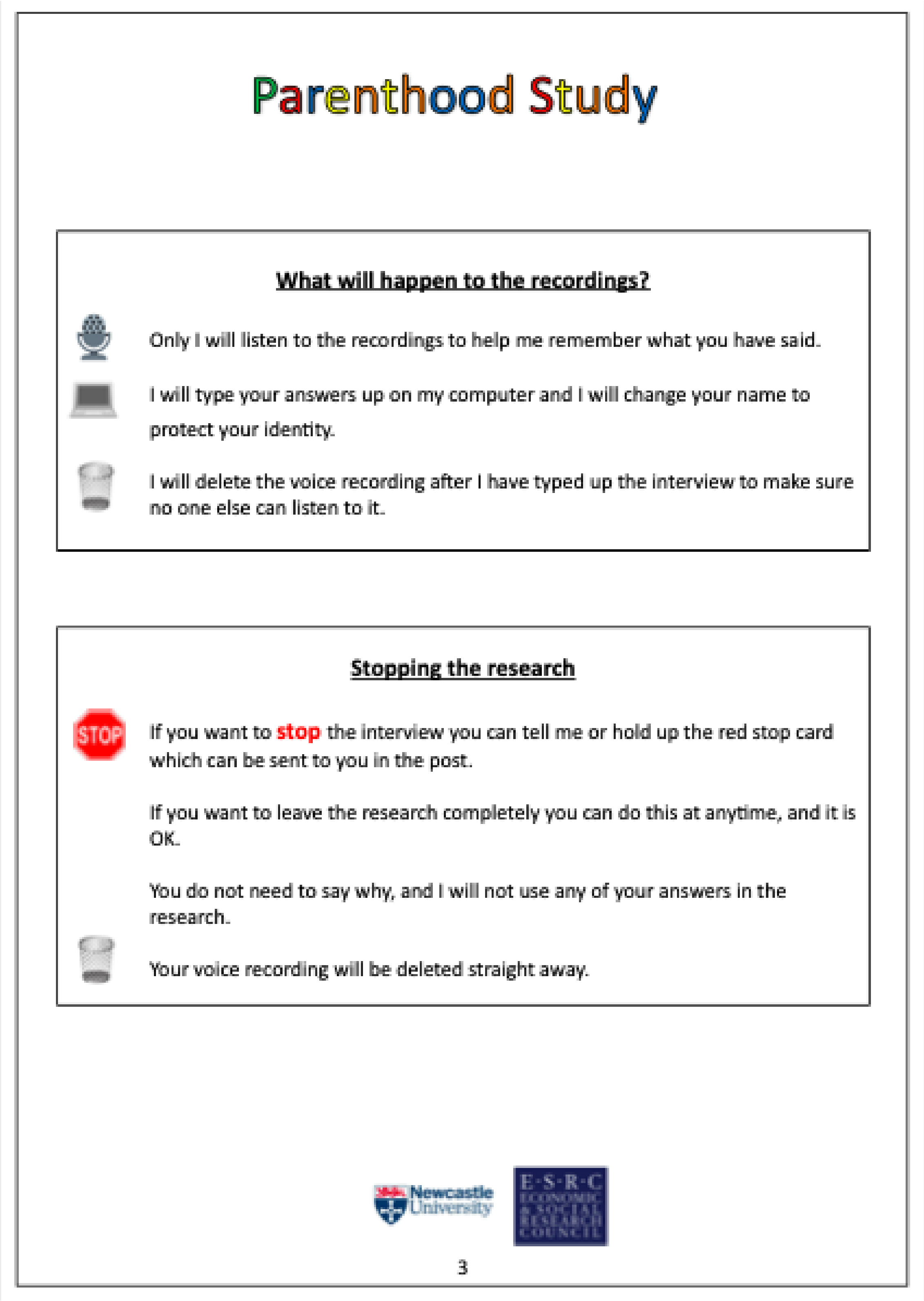
You will be given some time to think about whether or not you still want to take part.

If you still want to take part in the research, I will record you saying you are happy doing this.

This means that you are giving your **consent.**

I will talk to you more about this before you give your consent and you can still ask me questions.

2



Parenthood Study

What will happen to the recordings?

Only I will listen to the recordings to help me remember what you have said.

I will type your answers up on my computer and I will change your name to protect your identity.

I will delete the voice recording after I have typed up the interview to make sure no one else can listen to it.

Stopping the research

If you want to **stop** the interview you can tell me or hold up the red stop card which can be sent to you in the post.

If you want to leave the research completely you can do this at anytime, and it is OK.

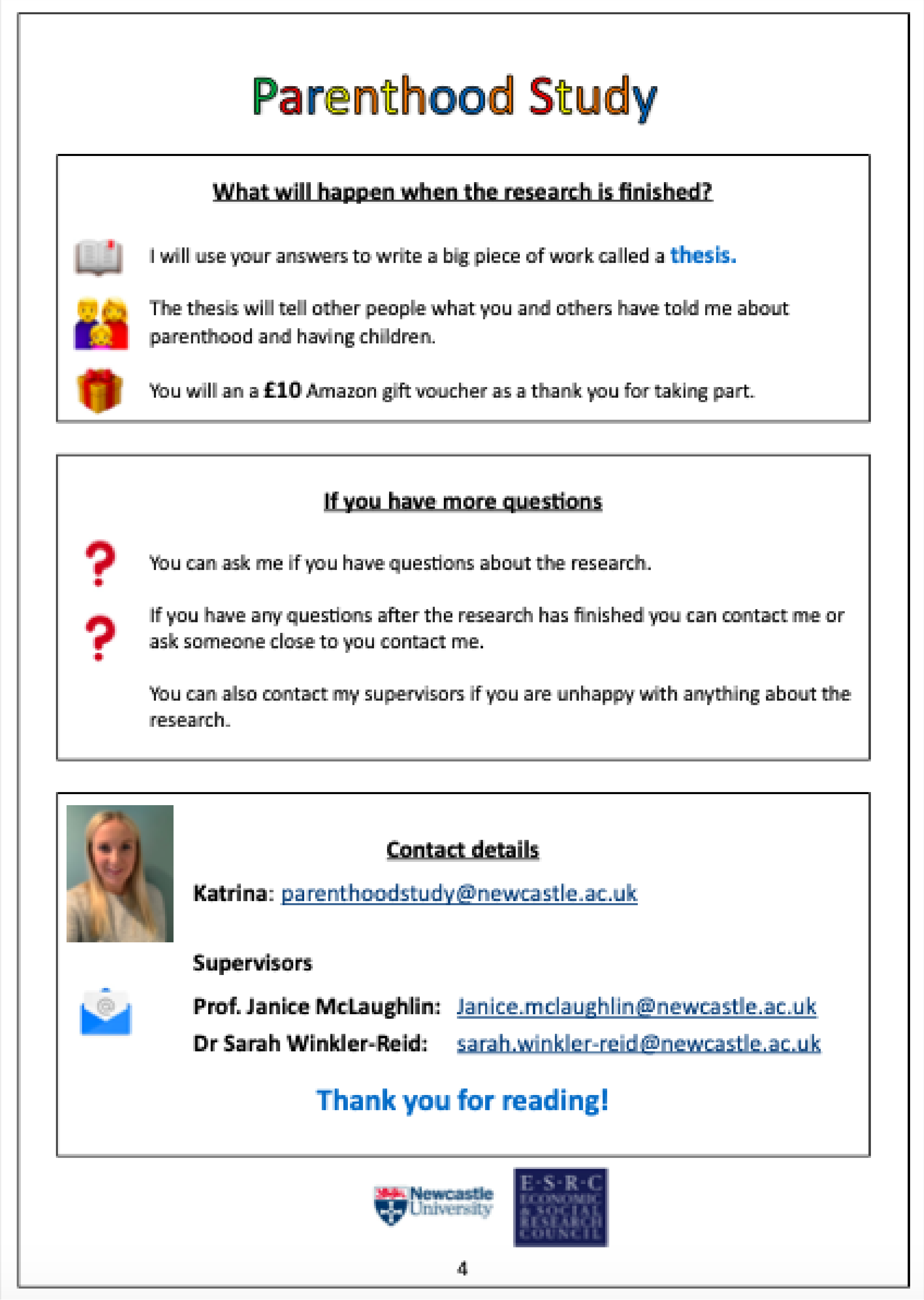
You do not need to say why, and I will not use any of your answers in the research.

Your voice recording will be deleted straight away.

Newcastle University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

3



Parenthood Study

What will happen when the research is finished?

I will use your answers to write a big piece of work called a **thesis.**

The thesis will tell other people what you and others have told me about parenthood and having children.

You will an a **£10** Amazon gift voucher as a thank you for taking part.

If you have more questions

You can ask me if you have questions about the research.

If you have any questions after the research has finished you can contact me or ask someone close to you contact me.

You can also contact my supervisors if you are unhappy with anything about the research.

Contact details

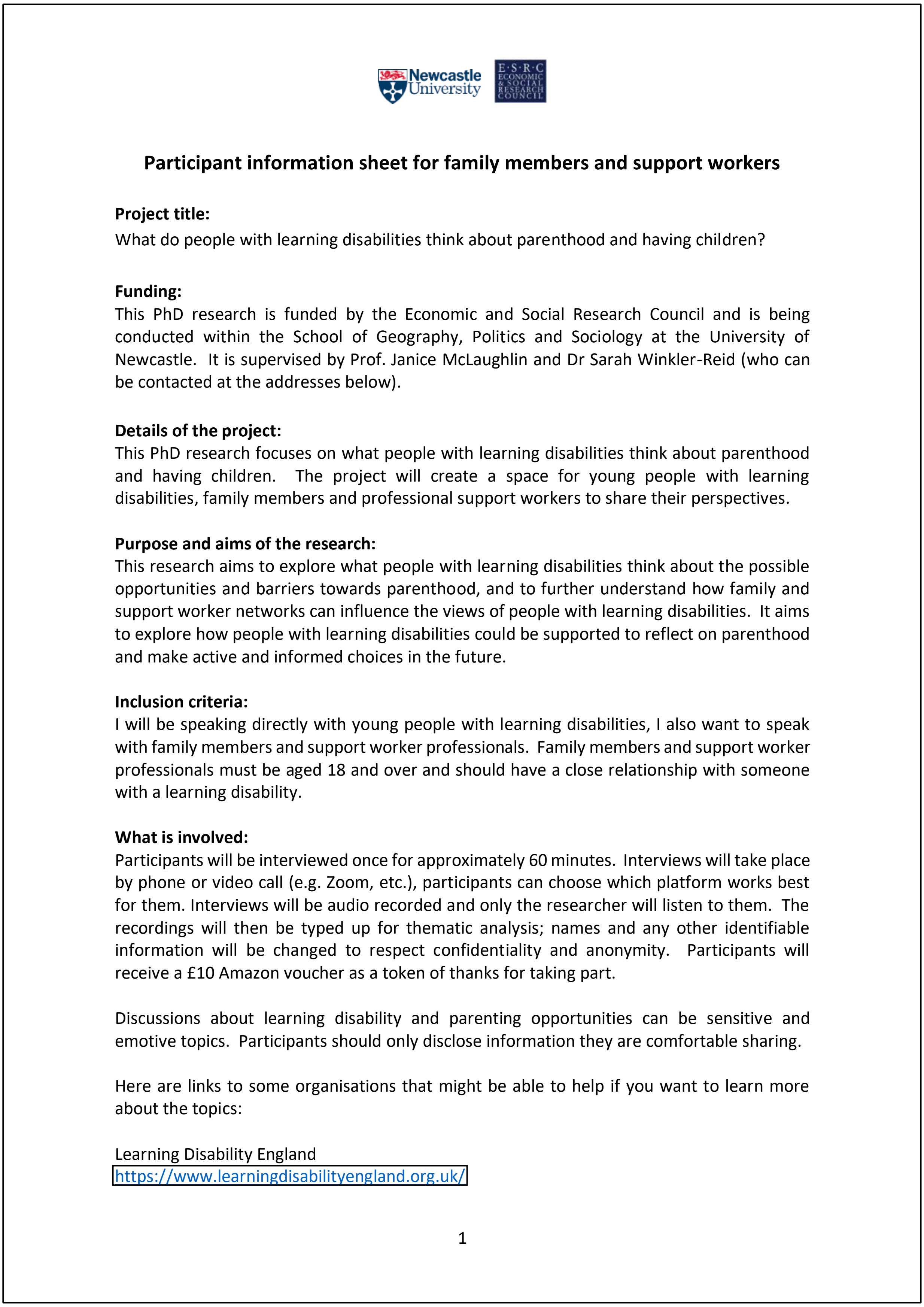
Katrina: parenthoodstudy@newcastle.ac.uk

Supervisors

Prof. Janice McLaughlin: Janice.mclaughlin@newcastle.ac.uk
Dr Sarah Winkler-Reid: sarah.winkler-reid@newcastle.ac.uk

Thank you for reading!

Participation information sheet for family members and support workers



Participant information sheet for family members and support workers

Project title:

What do people with learning disabilities think about parenthood and having children?

Funding:

This PhD research is funded by the Economic and Social Research Council and is being conducted within the School of Geography, Politics and Sociology at the University of Newcastle. It is supervised by Prof. Janice McLaughlin and Dr Sarah Winkler-Reid (who can be contacted at the addresses below).

Details of the project:

This PhD research focuses on what people with learning disabilities think about parenthood and having children. The project will create a space for young people with learning disabilities, family members and professional support workers to share their perspectives.

Purpose and aims of the research:

This research aims to explore what people with learning disabilities think about the possible opportunities and barriers towards parenthood, and to further understand how family and support worker networks can influence the views of people with learning disabilities. It aims to explore how people with learning disabilities could be supported to reflect on parenthood and make active and informed choices in the future.

Inclusion criteria:

I will be speaking directly with young people with learning disabilities, I also want to speak with family members and support worker professionals. Family members and support worker professionals must be aged 18 and over and should have a close relationship with someone with a learning disability.

What is involved:

Participants will be interviewed once for approximately 60 minutes. Interviews will take place by phone or video call (e.g. Zoom, etc.), participants can choose which platform works best for them. Interviews will be audio recorded and only the researcher will listen to them. The recordings will then be typed up for thematic analysis; names and any other identifiable information will be changed to respect confidentiality and anonymity. Participants will receive a £10 Amazon voucher as a token of thanks for taking part.

Discussions about learning disability and parenting opportunities can be sensitive and emotive topics. Participants should only disclose information they are comfortable sharing.

Here are links to some organisations that might be able to help if you want to learn more about the topics:

Learning Disability England
https://www.learningdisabilityengland.org.uk/

Change
https://www.changepeople.org/

Choice Support
https://www.choicesupport.org.uk/

Withdrawing from the research:
Participants can choose to withdraw from the research at any time. Participants do not need to explain their decision to withdraw, and all existing data collected from them will be destroyed.

How the information will be used:
The audio recordings from the interview will be transcribed anonymously onto Word and stored securely on the Newcastle University online secure network. The research will follow Newcastle University Data Protection Policy and GDPR. The information will be used to produce a PhD thesis for examination. The information gathered may also be used to write articles for academic and professional journals and conferences.

Contacts:
Katrina Rose (student researcher)
Parenthoodstudy@newcastle.ac.uk

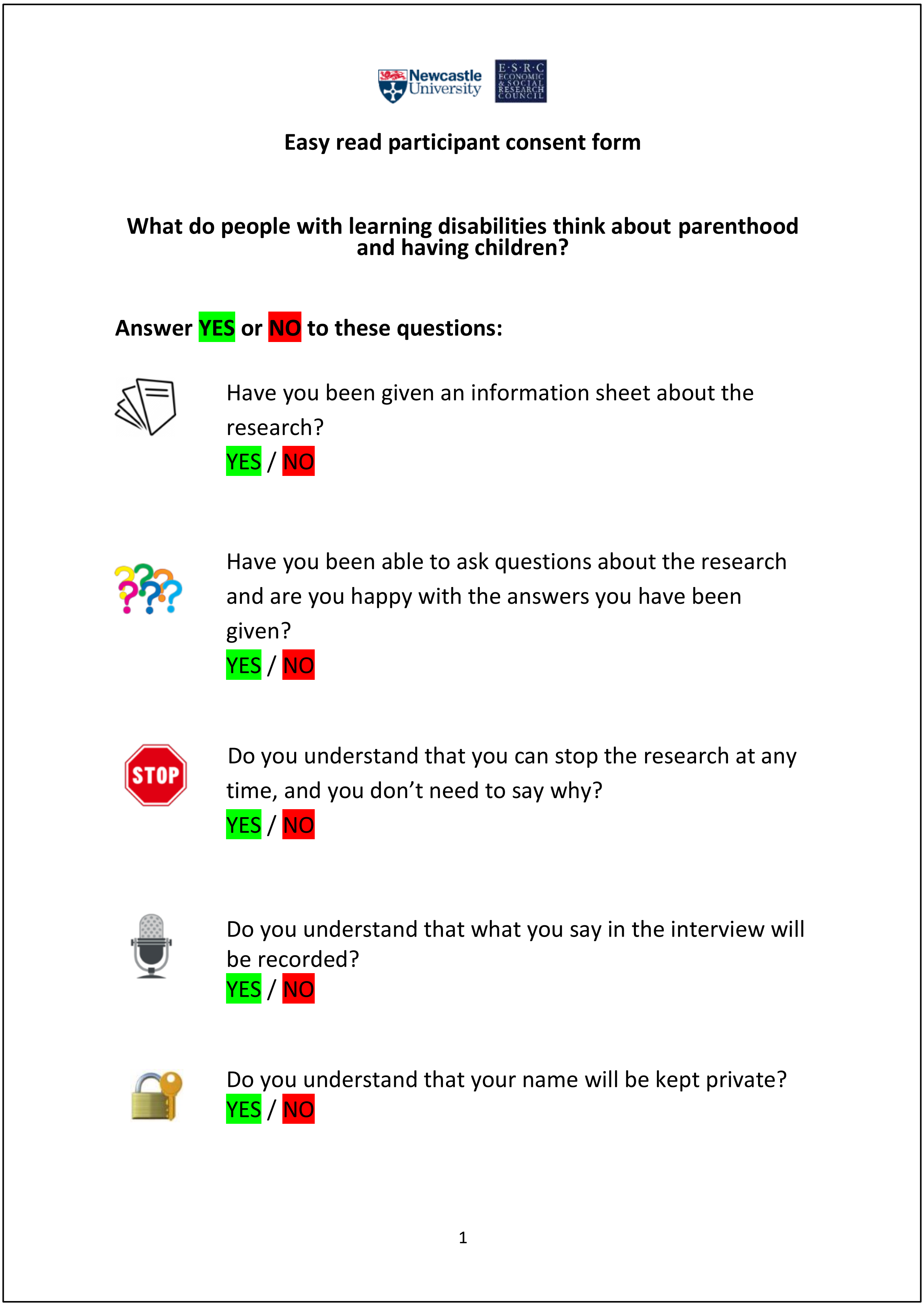
Research supervisors:
Prof. Janice McLaughlin
janice.mclaughlin@newcastle.ac.uk

Dr Sarah Winkler-Reid
Sarah.Winkler-Reid@newcastle.ac.uk

Please contact Katrina if you have any questions about the research. The supervisors should be contacted if you have any concerns about the project or the researcher.

Thank you for your interest in taking part.

Participation consent form for people with learning disabilities



Easy read participant consent form

What do people with learning disabilities think about parenthood and having children?

Answer YES or NO to these questions:

Have you been given an information sheet about the research?
YES / NO

Have you been able to ask questions about the research and are you happy with the answers you have been given?
YES / NO

Do you understand that you can stop the research at any time, and you don't need to say why?
YES / NO

Do you understand that what you say in the interview will be recorded?
YES / NO

Do you understand that your name will be kept private?
YES / NO

✅ Are you happy to take part in the research?
🟩 YES / 🟥 NO

🎙

I will record your answers to these questions before we start the interview.

Participation consent form for family members and support workers

Family member and support worker consent form

Project title: What do people with learning disabilities think about parenthood and having children?

Researcher: Katrina Rose, PhD student at Newcastle University

Please tick where appropriate:

1. I have read and understand the information sheet ☐
2. I have been able to ask questions about the research and I am happy with the answers given ☐
3. I understand that my participation in this research is voluntary ☐
4. I understand that I can withdraw from the research at any time, and that I don’t need to give any explanation for this ☐
5. I agree for the interview to be audio recorded ☐
6. I understand that what I say will be kept confidential and that any personal details (e.g. my name) will be changed to protect my identity ☐
7. I understand how my answers will be used in the research, and the sharing and archiving of the data have been explained to me ☐
8. I understand that I should only share information I am comfortable talking about ☐
9. I understand that relevant safeguarding policies and procedures will be followed if I disclose information indicating risk or harm to any individual(s) ☐
10. I am happy to take part in this research ☐

Participant name: ……………………………………………………………………………

Participant signature: ……………………………………………………………………………

Once completed please return to Katrina and for any further questions please contact parenthoodstudy@newcastle.ac.uk

1

Appendix E: Information pack for people with learning disabilities

Summary page

Information pack

What do people with learning disabilities think about parenthood and having children?

Thank you for your interest in taking part in the Parenthood Study.

This information pack will tell you more about taking part and what will happen next.

It might be helpful to read this information with someone you trust. After you have had chance to read this information, we can talk so you can ask me any questions about the research.

In this pack you will find:

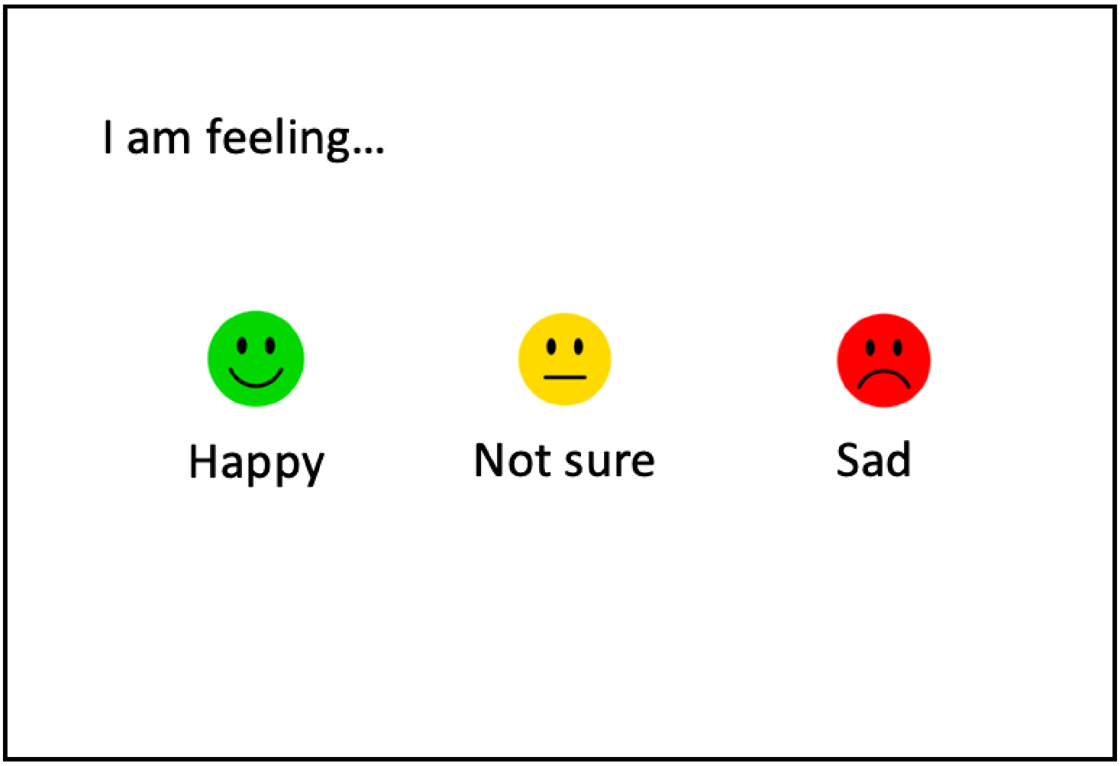
- ☐ 1 Information sheet
- ☐ 1 Consent form
- ☐ 1 'I am feeling…' card
- ☐ 1 'Stop' card

If you are unsure about anything in this pack, you can email me (Katrina) Parenthoodstudy@Newcastle.ac.uk.

Thank you for your interest in taking part.

I am feeling' card

Front:



I am feeling…

Happy

Not sure

Sad

Back:

In the interview I will ask how you feel.

Use this card to tell me if you feel happy, not sure, or sad.

Tell me if you feel sad and we can stop the interview.

'Stop' card

Front:

I want to stop the interview

Back:

Hold this card up if you want to stop the interview.

We can take a short break, or we can stop the interview.

It is ok if you want to stop.

Appendix F: Recruitment calls

Facebook call for sibling participants (text and poster image)

“❓ Do you have a brother or sister with a learning disability?

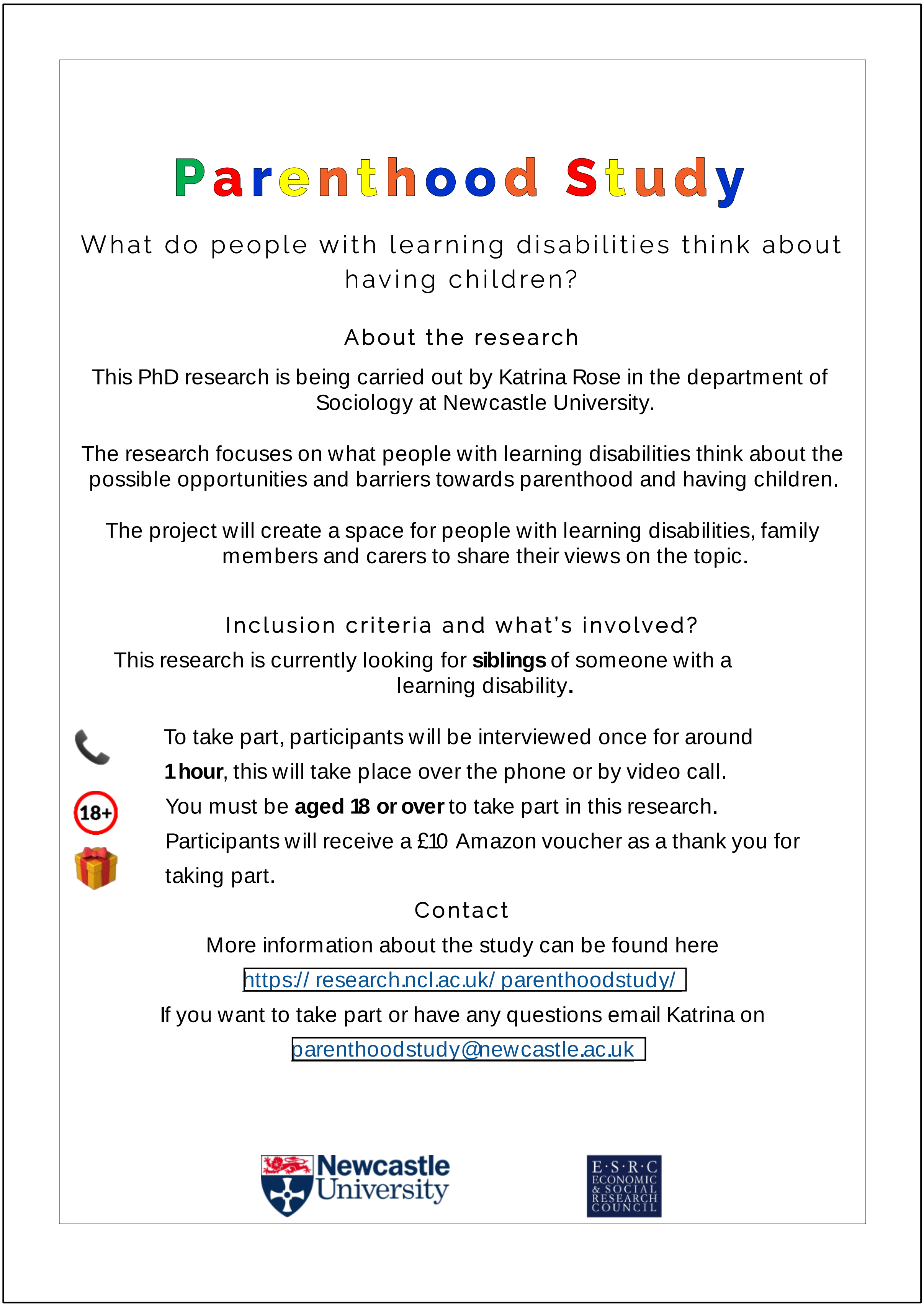
As part of my PhD research, I want to talk to siblings of people with a learning disability.

The research focuses on what people with learning disabilities think about parenting and having children 👶🏻👶🏽👶🏿 There will be a space for young people with learning disabilities, siblings and other family members to share their views.

I’m currently looking for siblings (aged 18+) of someone with a learning disability to take part in a phone/video call interview which will take around 1 hour.

If you think you or someone you know might be interested, then please get in touch 🙏🏻 You can find out more here https://research.ncl.ac.uk/parenthoodstudy/”

Participants will also receive a £10 voucher as a thank you for talking to me 😊”



Parenthood Study

What do people with learning disabilities think about having children?

About the research

This PhD research is being carried out by Katrina Rose in the department of Sociology at Newcastle University.

The research focuses on what people with learning disabilities think about the possible opportunities and barriers towards parenthood and having children.

The project will create a space for people with learning disabilities, family members and carers to share their views on the topic.

Inclusion criteria and what's involved?

This research is currently looking for **siblings** of someone with a learning disability**.**

☎ To take part, participants will be interviewed once for around **1 hour**, this will take place over the phone or by video call.

18+ You must be **aged 18 or over** to take part in this research.

🎁 Participants will receive a £10 Amazon voucher as a thank you for taking part.

Contact

More information about the study can be found here

https:// research.ncl.ac.uk/ parenthoodstudy/

If you want to take part or have any questions email Katrina on

parenthoodstudy@newcastle.ac.uk

Newcastle University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Facebook call for people with learning disabilities (text and poster image)

“❓ Do you have a learning disability or know someone who does?

As part of my PhD research, I want to talk to people with learning disabilities. I want to hear what people with learning disabilities think about having children 👶🏻👶🏽👶🏿

If you want to take part, you must be aged 18 or over.

I will ask you some questions about family, relationships and children. I want to know if having a child is something you have ever thought about.

You can talk to me by phone or video call and it will last around 30-60 minutes.

If you think you or someone you know might be interested please get in touch 🙏🏻

You can find more information about the study here
https://research.ncl.ac.uk/parenthoodstudy/

Participants will also receive a £10 voucher as a thank you for talking to me 😊”

Parenthood Study

What do people with learning disabilities think about having children?

👶🏻 👶🏼 👶🏽 👶🏾 👶🏿

What is the study about?

My name is Katrina, I’m a student at Newcastle University.

I want to hear the views of people with learning disabilities.

I want to talk to you about **family**, **relationships** and **children**. I want to know if having a child is something you have ever thought about.

What will happen?

I will ask you some questions, this is called an interview.

📞 You can talk to me over the phone or by video call.

The interview will last around **30-60 minutes**.

18+ If you want to take part, you must be **aged 18 or over**.

You will get a £10 Amazon gift voucher to thank you for taking part.

Contact

You can find more information about the study here https://research.ncl.ac.uk/parenthoodstudy/

Or email Katrina on Parenthoodstudy@newcastle.ac.uk

Newcastle University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Facebook call for parents and support workers (text and poster image)

"❓ Are you a support worker or parent/guardian of an adult with a learning disability?

As part of my PhD, this study focuses on what people with learning disabilities think about having children and parenthood 👶🏻👶🏽👶🏿There will be a space for people with learning disabilities, family members and carers to share their views on this topic.

I am now looking for parents/guardians and support workers (aged 18+) of someone with a learning disability to take part in a phone/video call which will take around 1 hour (sorry, I'm no longer recruiting siblings).

If you think you or someone you know might be interested, please get in touch on here or at parenthoodstudy@newcastle.ac.uk

You can find out more here https://research.ncl.ac.uk/parenthoodstudy/familyandcarers/

Participants will also receive a £10 voucher as a thank you for talking to me 😊

Parenthood Study

What do people with learning disabilities think about having children?

About the research

This PhD research is being carried out by Katrina Rose in the department of Sociology at Newcastle University.

The research focuses on what people with learning disabilities think about the possible opportunities and barriers towards parenthood and having children.

The project will create a space for people with learning disabilities, family members and carers to share their views on the topic.

Inclusion criteria and what's involved?

This research is currently looking for **parents/ guardians and support workers** of someone with a learning disability**.**

☎ To take part, participants will be interviewed once for around **1 hour**, this will take place over the phone or by video call.

18+ You must be **aged 18 or over** to take part in this research.

Participants will receive a £10 Amazon voucher as a thank you for taking part.

Contact

More information about the study can be found here

https://research.ncl.ac.uk/parenthoodstudy/

If you want to take part or have any questions email Katrina on

parenthoodstudy@newcastle.ac.uk

Covid-19 redesign recruitment email sent to learning disability organisations

Hello [**name**],

My name is Katrina, I am a Sociology PhD student at Newcastle University. I am currently doing a research project focusing on what people with learning disabilities think about parenthood and having children. I would like to know whether any of the people you work with at [**name of organisation**] might be interested in learning more about the study and potentially take part?

Before beginning my PhD in Sociology, I worked as a support worker for people with learning disabilities. My PhD research aims to focus on what people with learning disabilities think about the opportunities and barriers to parenting, and to also explore how families and other social networks might shape the decisions of people with learning disabilities.

Due to Covid I've had to redesign a lot of my work, but I am now looking to speak to people with learning disabilities either by phone or video call to hear what they think about the topic of parenthood and learning disability. This should take around 30-60 minutes and participants will receive a £10 Amazon gift voucher to thank them for their time.

I have created a website with more information on the study and an audio recording of the information sheet for people with learning disabilities to access:
https://research.ncl.ac.uk/parenthoodstudy/peoplewithalearningdisability/

It would be great to hear if you think the people you work with might be interested in talking to me.

I've attached a copy of a call for participants to this email and an easy read information sheet explaining more about the study.

If you want to arrange a quick call to talk about any of this, please just let me know.

Many thanks and best wishes,

Katrina

Katrina Rose
PhD Student
Newcastle University

https://research.ncl.ac.uk/parenthoodstudy/

Appendix G: Interview questions

Interview questions for sibling participants

Introductions

- Could you tell me what interested you in taking part in this study?
    - Is it a topic that is important to you?
- How do you feel about the topic? Is it something that you think is important?

Opening questions

- Can you tell me a little about your brother/sister?
    - What sorts of things do they enjoy doing?
    - Do they work/volunteer/go to a day centre etc.?
    - Can you describe their personality and interests?
    - What kinds of support (if any) do they get?

- How has your brother/sister been coping with Covid and lockdown?

- How do you describe your brother's/sister's learning disability?

- How would you describe the relationship between you and your brother/sister?

- What was it like growing up with a brother/sister with a learning disability?

- Do you think your life is different because you have a brother/sister with a learning disability?
    - In what ways?

Family expectations

- Thinking about growing up and now, are there times when you think your family might have had different expectations for you and your brother/sister?
    - Could you tell me more about these expectations?

        - What were the similarities and differences?
        - Did you notice these most growing up or when you reached adulthood?
        - What do you think fuelled these expectations?

- Do you think there is an expectation that you will support your brother/sister throughout adulthood?
    - How might this care responsibility affect you?
        - Does it affect your own choices about where you live or having a family etc.?

Broader expectations and attitudes

- What attitudes and expectations do you think society has for people like your brother/sister?
    - Have you and your brother/sister experienced these views personally? *(Be careful here, this question could lead to distressing accounts of bullying)*

- What do you think are some of the social attitudes towards people with learning disabilities having serious relationships? (e.g. sexual relationships, marriage etc.)
    - What do you think about these views? As a sibling how does it affect you?
    - Where do you think these kinds of views might come from?
    - Do you think these views are changing? Why?

- What about general social attitudes towards people with learning disabilities having sex?

- What social attitudes do you think there are towards people with learning disabilities having children?
    - Might these views impact the choices people with learning disabilities make about having children over time?
    - Do you think these attitudes are the same for both men and women with learning disabilities?

Starting a family

Broad views

- How do you think people in general might react to people with learning disabilities having and raising children?
    - Why might they think that?

- What about support services, what do you think their attitude or attitudes might be?

- Do you think there's much help and support for people with learning disabilities who might want to start a family?

Family views

- From your experience, do you think families are generally supportive of people with learning disabilities thinking about parenthood?
    - What concerns might they have?

- Is this something you and your family have talked much about? What has been said?
    - Is it the sort of thing you feel comfortable talking about with them?

- Has your brother/sister ever spoken about wanting or not wanting children?
    - What did they say?
    - What was your reaction to this?
    - How did your other family members respond to this?
    - Has anything happened due to those conversations?

Having children

- Do you think people with learning disabilities have much choice about parenthood?
    - Are these choices the same for men and women? Or are there differences?
    - Who and what might influence these choices?

- How is this different compared to people without a learning disability?

- What do you think might be the main challenges for someone with a learning disability having and raising children?

- Is there anything that they might struggle with more than someone without a learning disability?

- Do you think these challenges would be felt by both mothers and fathers? Or are these experienced more by one side?

- Are there some things that you think someone with a learning disability might do really well as a parent?

- What are the sorts of things that can help support people with learning disabilities to make decisions about having children?

Close

- That's the end of the interview questions, is there anything that you think I've missed? Or anything you'd like to add?

- Do you think this study might be something that your brother or sister might like to learn more about?

Interview questions for people with learning disabilities who already have children

Introduction

- Why did you want to take part in this study?

- Can you tell me a bit about [name of advocacy group]?
    - What do you do with them?
    - What do you like about [name of advocacy group]?
    - How has it helped you?

- How has Covid and lockdown affected you?

About you

- Can you tell me a bit about yourself? (what sorts of things do you enjoy doing?)

- Do you see yourself as having a learning disability?
    - What does this mean to you?
    - Are there good things about having a learning disability?
    - Are there some things you struggle with or need help with?
    - How do other people treat you because of your learning disability?

Family and living

- Can you tell me about the people you live with?
    - What's it like living together?

- Do you have support workers helping you sometimes?
    - What sorts of things do they help you with?

- Can you tell me a bit about your family?
    - Who is in your family? Do they live with/near you?

Adulthood and life choices

- Have you got/had a girlfriend/boyfriend?
    - YES
        - What is/was that like?
    - NO
        - Would you like to have a girlfriend/boyfriend?

- Are there enough opportunities for people with learning disabilities to look for a partner?

- Do you want to get married one day?
    - Why/why not?

- Do you think many other people with learning disabilities think about getting married?

Choosing to start a family

- What do you think being a family means? (what do family do for each other?)

- Do you think anyone can have children? (anyone who shouldn't?)

Already have children

- Did you always want to have children?
    - Why did you want to have a baby?
    - What did you think it would be like?

- Did you talk to anyone about wanting kids before you had them?
    - Who? What did you say? What did they say?

- Did you plan to get pregnant?

- How did find out you were pregnant?
    - What was your reaction? (scared, happy, sad?)

- How did your partner/family react to you being pregnant?

- What was it like when you had your baby?

- What do/did you like about being a mum/dad?

- Is there anything that you find hard about being a mum/dad?

- Does your learning disability affect what you do as a mum/dad?
    - Any good things about being a mum/dad with a learning disability?
    - Any bad things about being a mum/dad with a learning disability?

- Do you wish anything was different? What?

- Do you think there's much support for other people with a learning disability who might want to start a family?

If children have been removed

- What was it like when your child got taken into care?

- Do you think this happens a lot for people with learning disabilities?

- Do you think having children taken into care might make other people with learning disabilities not want to have children?

- What do you think other people think about parents with learning disabilities?

General parenthood questions

- What are some of the things people need to think about before having children?
    - How do people think this through?
    - Who makes the decision? Or who might help people to decide? (e.g. family, carers, social workers, doctors etc.)

- Why do you think someone might **not** want to have children?

- Do you think having a learning disability might make it harder for people to choose to have children? Why? (e.g. living situation? money/cost?)

- Are there times when people might not have a choice? When might this be?

- What do you think makes someone a good parent?

- What might mean that someone is a bad parent?

- Do mums and dads have the same roles? Or do they do different things?

- Did you get any help with your baby/child?
    - Who did you get help from?
    - Did you want/need more help?

- What kind of help might someone with a learning disability need to help raise a child? (who might help out?)

Societal attitudes

- What do other people think about people with learning disabilities having children?
    - What are some of the positive/negative things people might think?
    - Might these views affect the decisions people with learning disabilities make about having children? (how?)

- Do you think parents with learning disabilities are treated the same or different as parents without learning disabilities?
    - What makes them get treated the same/differently?

- Has anyone ever said you can't or shouldn't have children?
    - What did they say?
        - Why do you think they said that?
        - How did that make you feel?
        - Has that affected what you think about having children?

Looking ahead

- In the future, what could help people make choices about having children? (e.g. more accessible information?)

Sex education

- Is there enough sex education for people with learning disabilities?

- How did you learn about sex education?

- Is there enough information about contraception for people with learning disabilities?
    - Do you think people with learning disabilities are able to make well informed choices about sex and contraception?

Close

- That's the end of the interview questions, is there anything that you think I've missed? Or anything you would like to add?

Interview questions for people with learning disabilities who do not yet have children

Introduction

- Why did you want to take part in this study?

- Can you tell me a bit about [name of advocacy group]?
    - What do you do with them?
    - What do you like about [name of advocacy group]?
    - How has it helped you?
    - How has Covid and lockdown affected you?

About you

- Can you tell me a bit about yourself? (what sorts of things do you enjoy doing?)

- Do you see yourself as having a learning disability?
    - What does this mean to you?
    - Are there good things about having a learning disability?
    - Are there some things you struggle with or need help with?
    - How do other people treat you because of your learning disability?

Family and living

- Can you tell me about the people you live with?
    - What's it like living together?

- Do you have support workers helping you sometimes?
    - What sorts of things do they help you with?

- Can you tell me a bit about your family?
    - Who is in your family? Do they live with/near you?

Adulthood and life choices

- Have you got/had a girlfriend/boyfriend?
    - YES
        - What is/was that like?
    - NO
        - Would you like to have a girlfriend/boyfriend?

- Are there enough opportunities for people with learning disabilities to look for a partner?

- Do you want to get married one day?
    - Why/why not?

- Do you think many other people with learning disabilities think about getting married?

Choosing to start a family

- What do you think being a family means? (what do family do for each other?)

- Do you think anyone can have children? (anyone who shouldn't?)

Choosing to start a family – what do you think?

- Have you thought about having children?

  YES

    - Tell me a little about that
    - Is it something you think about a lot?
    - What do you think it might be like?
    - What would be good/hard about being a mum/dad?
    - Have you talked to anyone about this? (who?)

  NO: "I don't want children"

    - What made you decide that?
    - Did you decide that on your own? Or with someone else?
    - What sorts of things put you off from having children? (e.g. the cost? practical task? education? don't like children? medical – can't have children?)
    - Has your learning disability played a part in you deciding you don't want/can't have children?
    - Are there any good/bad things about not having children?

Not sure: "I've never thought about it" or "not yet"

  - Why do you think you've not thought about it?
  - Is it something you might think more about in the future?

- Do any of your friends/people you know have children or talk about wanting children?
    - What sorts of things do they say?
    - Do they have a learning disability?

- Have any of your friends/people you know said that they **<u>do not</u>** want children?
    - What sorts of things do they say?
    - Do they have a learning disability?

General parenthood questions

- What are some of the things people need to think about before having children?
    - How do people think this through?
    - Who makes the decision? Or who might help people to decide? (e.g. family, support workers, social workers, doctors etc.)

- Why do you think someone might **<u>not</u>** want to have children?

- Do you think having a learning disability might make it harder for people to choose to have children? Why? (e.g. living situation? money/cost?)

- Are there times when people might not have a choice? When might this be?

- What do you think makes someone a good parent?

- What might mean that someone is a bad parent?

- Do mums and dads have the same roles? Or do they do different things?

- What kind of help might someone with a learning disability need to help raise a child? (who might help out?)

- Do you think there's much support for other people with a learning disability who might want to start a family?

Societal attitudes

- What do other people think about people with learning disabilities having children?
    - What are some of the positive/negative things people might think?
    - Might these views affect the decisions people with learning disabilities make about having children? (how?)

- Do you think parents with learning disabilities are treated the same or different as parents without learning disabilities?
    - What makes them get treated the same/differently?

- Has anyone ever said you can't or shouldn't have children?
    - What did they say?
        - Why do you think they said that?
        - How did that make you feel?

        - Has that affected what you think about having children?

Looking ahead

- In the future, what could help couples make choices about having children? (e.g. more accessible information?)

Sex education

- Is there enough sex education for people with learning disabilities?

- How did you learn about sex education?

- Is there enough information about contraception for people with learning disabilities?
    - Do you think people with learning disabilities are able to make well informed choices about sex and contraception?

Close

- That’s the end of the interview questions, is there anything that you think I’ve missed? Or anything you would like to add?

Interview questions for parents of someone with a learning disability

Introductions

- Could you tell me what interested you in taking part in this study?

- How do you feel about the topic?
    - Is it a topic that is important to you?

Opening questions

- How have you and your son/daughter been coping with Covid and lockdown?

- Do you want to tell me a bit about your son/daughter?
    - What are they like? What do they enjoy doing?
    - What does their learning disability mean?
    - How does their learning disability affect you and your family?

- Can you tell me about the relationship between you and your son/daughter?
    - What's it like being the parent to [name of son/daughter]
    - Tell me about the good things, are there things that are difficult?

- Do you want to tell me a bit more about where your son/daughter lives?
    - Tell me about the care and support they receive (if any)?

- Do you have other children?
    - What's their sibling relationship like?
    - What impact has [name of son/daughter] learning disability had on your other children?
        - Positive/negative
        - Do siblings take on care responsibilities? What does that involve?

- What role do you think the sibling might play in the life of your son/daughter with learning disabilities in the future?

Relationships

- Is your son/daughter with learning disabilities in a relationship? Have they been in a relationship?
    - Do you want to tell me more about their relationship(s)?
        - What did they like/dislike about being in a relationship?
    - Is it important to you that people like your son/daughter with learning disabilities have the opportunity of being in a relationship?
    - Is being in a relationship something you think other people with learning disabilities might want to have?
    - Do you think there are enough opportunities for people with learning disabilities to have romantic and intimate relationships?
        - Do you think there are any barriers to people with learning disabilities having relationships? (e.g. living in care settings?)

- What do you think other people think about people like your son/daughter with learning disabilities having relationships and sex?
    - What do you think about these views? As a parent how does it affect you?
    - Where do you think these kinds of views might come from? Are these views changing?
    - How do you think these views might affect people with learning disabilities?
        - Is it something you think they're aware of or care about?

Having children

- Has your son/daughter with learning disabilities ever spoken about wanting or not wanting children?
    - What did they say?
    - What was your reaction to this?
    - How did you feel about having those kinds of conversations?
    - How did your other family members respond to this?
    - Has anything happened due to those conversations?

    - Do you think it's something that other parents discuss with their children with learning disabilities?

- Who or what else might influence what people with learning disabilities think about having children?
    - As a parent, do you think your views play a role in shaping what your son/daughter thinks about having children?
    - Do their siblings play a role in shaping some of these views? Or other family members (e.g. cousins etc.)
    - If/how might support workers and care settings affect what people with learning disabilities think about having/not having children?

- Are there any barriers to becoming parents and raising children that you think people with learning disabilities might face?
    - Do you think there are times/situations where people with learning disabilities should be discouraged/stopped from having children?
        - Can you think of any examples?

- Do you think there's much help and support for people with learning disabilities who might want to start a family?
    - What kinds of support can you see being helpful to people who may be thinking about or wanting to have children?

- How does society think about people with learning disabilities having children?
    - As a parent, how do you feel about these views? Where might these views come from?
    - Might these views impact the choices people with learning disabilities make about having children?
    - Are these attitudes the same towards both men and women?
        - Do you think mothers and fathers with learning disabilities are viewed the same? Are there differences?
        - What do you think about these differences/similarities?

Sex education

- What kind of sex education, if any did your son/daughter with learning disabilities get?
    - What do you think about this level of sex education?
    - Is it something you've talked about with your son/daughter?
    - Do you think it's something other families discuss with people with learning disabilities? Why/why not?

- Do you think people with learning disabilities get information about contraception?
    - Do you think people with learning disabilities are able to make informed choices about contraception?
    - Is this a conversation you've had with your son/daughter with learning disabilities?
        - What sorts of things did you talk about?

- Is sex and contraception information something that people with learning disabilities should be supported to access?
    - Who should support if needed? E.g. parents, teachers, support workers, internet?

Looking ahead

- What kinds of views do you think other people have towards your son/daughter and people with learning disabilities like them?
    - Do you think attitudes towards people with learning disabilities are changing?
        - How do you think these views have changed?

- What do you hope to see in the future for your son/daughter and other people with learning disabilities and the topic of parenthood? And the future generally?

Close

- That’s the end of the interview questions, is there anything that you think I’ve missed? Or anything you would like to add?

Interview questions for support workers

Introduction

- What interested you in taking part in this study?

- Can you tell me a bit about the support work you do? What types of people do you support?
    - What's a typical day in your care job/role like? Can you talk me through the sorts of things you do?
    - How long have you been doing this kind of role?

- How has Covid and lockdown affected your work and the people you support?
    - How are you, your colleagues, and the people you support managing with lockdown?

- What status do you think support workers like yourself have in society?
    - Do you think this is changing? E.g. Covid?

Relationships

- Do any of the people you support have girlfriends/boyfriends?
    - Can you tell me a bit about some of these relationships?
        - Do you as a support worker have a role in supporting their relationships? How?
        - How do you find families' attitudes are toward them having relationships and sex?

- Do you think the people you support have opportunities to meet others and have romantic and sexual relationships?
    - Are there certain kinds of things you might do to support them with this?
        - Is there resistance from other staff, family or other people about this?

    - What sorts of barriers (if any) might they face to having these kinds of relationships?

- What do you think the general view towards people with learning disabilities having relationships and sex might be?
    - Are these views and attitudes changing in any way?
    - How do you feel about these views? Where might some of these views and attitudes stem from?

Having children

- Do you think people with learning disabilities have much choice about parenthood?
    - Do you think they have the same opportunities to be parents as everyone else?
    - Are these choices the same for men and women? Or are there differences?
    - How is this different compared to people without a learning disability?
    - Who and what might influence these choices?

- What role do you think families have in shaping the views people with learning disabilities have about parenthood and having children?
    - From your experience, do you think families are generally supportive of people with learning disabilities thinking about parenthood? What concerns might they have?

- Is the topic of parenthood something that gets talked about much between support worker staff and people with learning disabilities?
    - What kinds of views do the other support workers you work with have towards people with learning disabilities and parenthood?

- How do you think support workers' own personal views and experiences might shape what people with learning disabilities think about parenthood and having children?

- Is wanting children something that any of the people you support ever talk about?
    - What sorts of things do they say? How do you respond to this?
    - How do your colleagues feel about discussing the topic of learning disability and parenthood?

- Have you ever supported someone with a learning disability who was or became a parent?
    - Do you want to talk more about this? What happened, people's reactions etc.?

- Do you think there are any groups/kinds of people that might experience the same barriers?

- Are there any barriers to becoming parents and raising children that you think people with learning disabilities might face?
    - Do you think there are times/situations where people with learning disabilities should be discouraged/stopped from having children?
        - Can you think of any examples?

Support

- What kinds of help and support do you think people with learning disabilities get with making choices about having children?
    - Do you think this support is enough?
    - What support do you think people with learning disabilities might need to make choices about parenthood?
- What kinds of support might be useful to new parents with learning disabilities to help them raise their child?

- What do you think might be the main challenges for someone with a learning disability having and raising children?

- What sorts of things do you think parents with learning disabilities might be good at?

Sex education and contraception

- Is there enough sex education for people with learning disabilities?
  - If no, why do you think they aren't given more information about sex?

- Where do you think they find out about sex? (e.g. family, carers, TV, schools, direct experience, including abuse etc.)

- Is sex something you talk about with the people you work with?
  - What sorts of things do you say?
  - Would you feel comfortable talking about this with them?
  - Do you think there are some support workers that might not feel comfortable talking about this?

- Is contraception something you think people with learning disabilities get much education around?
  - Do you think they get much choice about contraception?
    - Who, if anyone, might influence these choices? (e.g. support workers, family, doctors etc.)
    - What do you think about these kinds of discussions?

- What do you think about the use of long-term contraception for women with learning disabilities?

General views and expectations

- What kinds of views do you think others have towards the people you support? (E.g. positive/negative)
  - Why might they have these views?

    - Do you think attitudes towards people with learning disabilities are changing? How do you think these views have changed?

Close

- That’s the end of the interview questions, is there anything that you think I’ve missed? Or anything you would like to add?

List of interview questions emailed to participant with learning disabilities (who already had children) that asked to see the questions before the interview

Introduction

- Why did you want to take part in this study?

- Can you tell me a bit about [name of advocacy organisation]?

- How has Covid and lockdown affected you?

About you

- Can you tell me a bit about yourself?

- Do you see yourself as having a learning disability?
  - Are there good things about having a learning disability?
  - Are there some things you struggle with or need help with?
  - How do other people treat you because of your learning disability?

Family and living

- Can you tell me about the people you live with?

- Do you have support workers helping you sometimes?

- Can you tell me a bit about your family?
    - Who is in your family? Do they live with/near you?

Adulthood and life choices

- Are you married? Or are you in a relationship?

- Are there enough opportunities for people with learning disabilities to look for a partner (girlfriend/boyfriend)?

- Do you think anyone can have children? (Anyone who shouldn't?)

Already have children

- Did you always want to have children?
    - Why did you want to have a baby?
    - What did you think it would be like?

- Did you talk to anyone about wanting children before you had them? Who?

- Did you plan to have a baby?

- How did find out you were going to have a baby?
    - What was your reaction? (scared, happy, sad?)

- How did your family react to you having a baby?

- What was it like when you had your baby?

- What do you like about being a dad?

- Is there anything that you find hard about being a dad?

- Does your learning disability affect what you do as a dad?

- Do you wish anything was different? What?

- Do you think there's much support for other people with a learning disability who might want to start a family?

Child being removed

- Do you think children being taken into care happens a lot for people with learning disabilities?

- Do you think having children taken into care might make other people with learning disabilities not want to have children?

- What do you think other people think about parents with learning disabilities?

General

- What are some of the things people need to think about before having children?

- Why do you think someone might <u>not</u> want to have children?

- Do you think having a learning disability might make it harder for people to choose to have children?

- Are there times when people might not have a choice? When might this be?

- What do you think makes someone a good parent?

- What might mean that someone is a bad parent?

- Do mums and dads have the same roles? Or do they do different things?

- Did you get any help with your baby/child?
    - Who did you get help from?
    - Did you want/need more help?

- What kind of help might someone with a learning disability need to help raise a child? (Who might help out?)

Societal attitudes

- What do other people think about people with learning disabilities having children?
    - What are some of the good/bad things people might think?
    - Might these views affect the decisions people with learning disabilities make about having children? How?

- Do you think parents with learning disabilities are treated the same or different as parents without learning disabilities?

- Has anyone ever said you can't or shouldn't have children?
    - What did they say?

Sex education

- Is there enough sex education for people with learning disabilities?

- How did you learn about sex education?

- Is there enough information about contraception for people with learning disabilities?

- Do you think people with learning disabilities are able to make well informed choices about sex and contraception?

Looking ahead

- In the future, what could help couples make choices about having children? (e.g. more accessible information?)

End of interview questions.

Appendix H: Demographic questions

Sibling participants

To start, I am going to ask you a few questions about yourself and your brother/sister to help me understand and analyse the data in a bit more detail. If there's anything you don't feel comfortable answering, then just say and we can move on.

Questions about you

1. What gender do you identify as?
2. How old are you?
3. How would you define your ethnicity?
4. Where are you from?

Questions about your brother/sister

1. What's your brother/sister's name?
2. What gender do they identify as?
3. How old are they?
4. Are they the same ethnicity as you? (if not please say)
5. What town/city do they live in?
6. What sort of home do they live in now? (e.g. family home, supported living, care home etc.)
7. What type of schools/colleges did your brother/sister go to?
8. Do you know their relationship status? (e.g. are they single, with a partner, married etc.)
9. Do they have children?

Participants with learning disabilities

To start, I am going to ask you some questions about you. This will help me understand what you say in the interview better.

These questions are personal, so if you don’t feel happy answering them then just tell me and I’ll ask you something different.

If you don’t understand the question, let me know and I can try and ask it a different way.

Questions about you

1. What is your gender?
2. How old are you?
3. How would you describe your ethnicity?
4. Where are you from?
5. What type of home do you live in now?
6. What type of schools/colleges did you go to?
7. What is your sexual orientation? This means who you are attracted to (e.g. do you like men, women, both, or non?)
8. Are you in a relationship at the minute? (e.g. do you have a girlfriend/boyfriend or are you married?)
9. Do you have children?

Parents of someone with learning disabilities

To start, I am going to ask you a few questions about yourself and your son/daughter with learning disabilities to help me understand and analyse the data in a bit more detail. If there's anything you don't feel comfortable answering, then just say and we can move on.

Questions about you

1. What gender do you identify as?
2. How old are you?
3. How would you define your ethnicity?
4. Where are you from?

Questions about your son/daughter

1. What's your son/daughter's name?
2. What gender do they identify as?
3. How old are they?
4. Are they the same ethnicity as you? (if not please say)
5. What town/city do they live in?
6. What sort of home do they live in now? (e.g. family home, supported living, care home etc.)
7. What type of schools/colleges did your son/daughter go to?
8. Do you know their relationship status? (e.g. are they single, with a partner, married etc.)
9. Do they have children?

Support workers

To start, I am going to ask you a few questions about yourself to help me understand and analyse the data in a bit more detail. If there's anything you don't feel comfortable answering, then just say and we can move on.

Questions about you

1. What gender do you identify as?
2. How old are you?
3. How would you define your ethnicity?
4. Where are you from?
5. What type of setting do you work in? (e.g. Residential, supported living, day centre, community, hospital etc.)
6. What's the age range of the people you support? (e.g. Under 18's, over 18)
7. Do any of the people you support for have children?

Appendix I: Participant debrief documents

Participants with learning disabilities

Thank you for taking part in the interview

Your answers will help me write up a big piece of work called a thesis. The thesis will describe how some people with learning disabilities make choices about parenthood and having children.

I will try to share lots of what you have said to help people understand your views and know what is important to you.

I will not use your name, so no one will be able to tell it was you. You can still withdraw from the research if you change your mind, and your answers will not be used.

Here is a list of some services that can give you more information:
Learning Disability England
https://www.learningdisabilityengland.org.uk/

Change
https://www.changepeople.org/

Choice Support
https://www.choicesupport.org.uk/

If you think of anything else that you want to tell me, or if you have any other questions about the research, you can email me. My email address is parenthoodstudy@newcastle.ac.uk

The research is being supervised by Professor Janice McLaughlin and Dr Sarah Winkler-Reid. They are helping me to make sure I do everything right. If you have any issues or concerns about the project you can email them: Janice.Mclaughlin@newcastle.ac.uk and Sarah.Winkler-Reid@newcastle.ac.uk

Thank you, Katrina

Family member and support workers

Thank you for taking part in the interview

For some people this can be quite an emotive and sensitive subject to talk about, so I really appreciate you taking the time to share your thoughts and views with me.

I will now type up the interview recordings, and your responses will help me to explore key themes around the topic of learning disability and parenthood. This will become part of my PhD thesis that I'll be writing up over the next year or so. Remember your name and any other identifiable information will be changed to protect your identity, and you can still withdraw from the research if you change your mind.

If you have any further comments or questions about the research, or how the data will be used then please email me on parenthoodstudy@newcastle.ac.uk

Here are links to some organisations that might be able to help if you want to learn more about the topics discussed in the interview:

Learning Disability England
https://www.learningdisabilityengland.org.uk/

Change
https://www.changepeople.org/

Choice Support
https://www.choicesupport.org.uk/

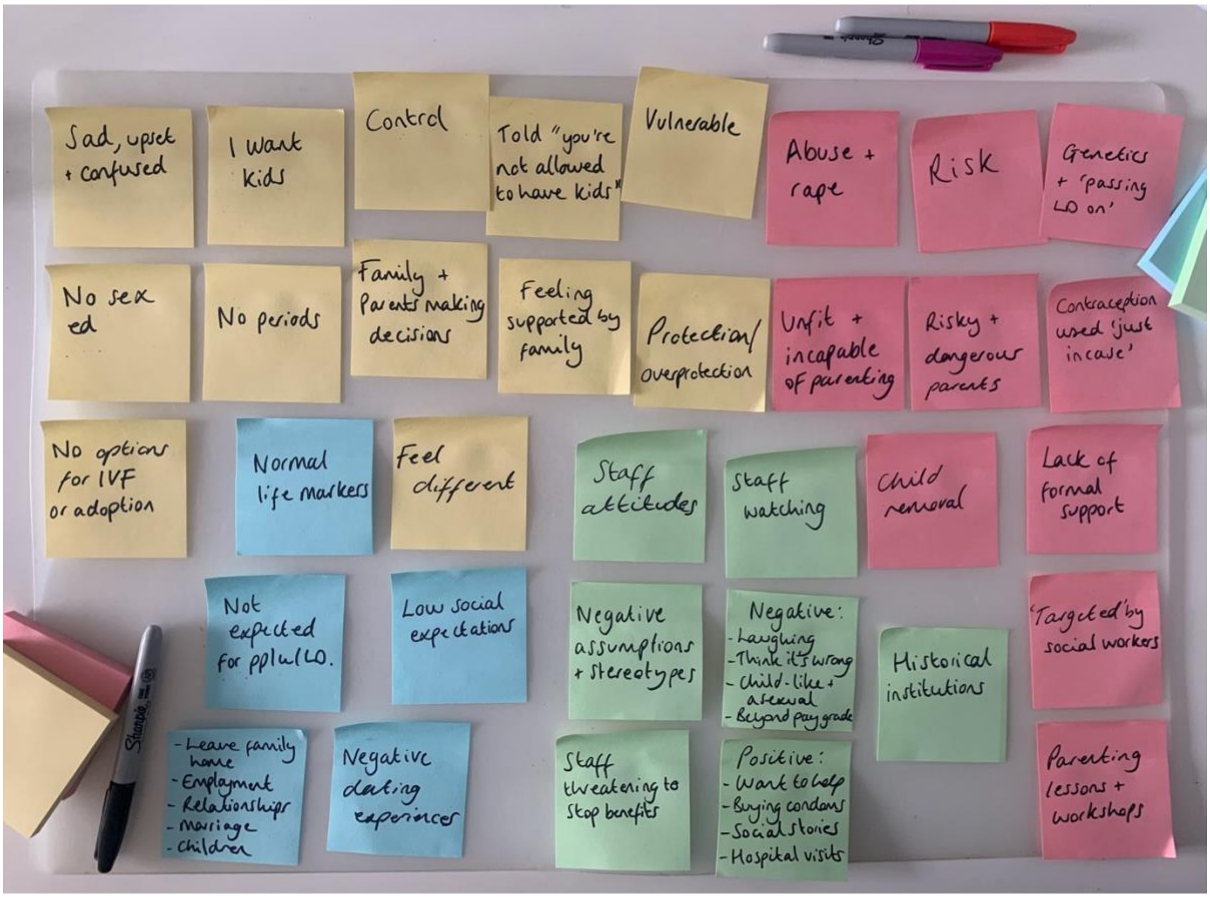
The research is being supervised by:
Prof. Janice McLaughlin
janice.mclaughlin@newcastle.ac.uk

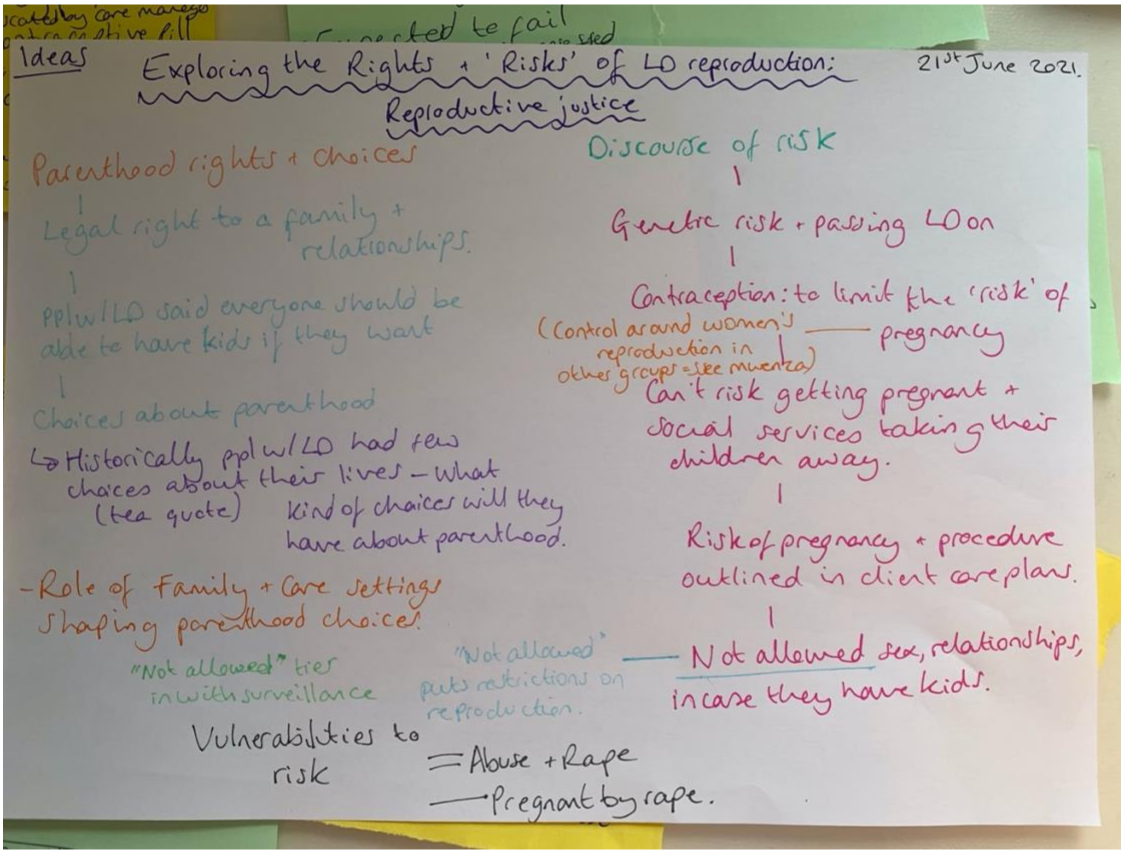
Dr Sarah Winkler-Reid
Sarah.Winkler-Reid@newcastle.ac.uk

Thanks again

Katrina

Appendix J: Analysis notes





Ideas

Exploring the Rights + 'Risks' of LD reproduction:
Reproductive justice

21st June 2021.

Parenthood rights + choices

Legal right to a family + relationships.

ppl w/LD said everyone should be able to have kids if they want

Choices about parenthood

↳ Historically ppl w/LD had few choices about their lives – What kind of choices will they have about parenthood.
(tea quote)

- Role of Family + Care settings shaping parenthood choices.

"Not allowed" ties in with surveillance

"Not allowed" puts restrictions on reproduction.

Discourse of risk

Genetic risk + passing LD on

Contraception: to limit the 'risk' of pregnancy

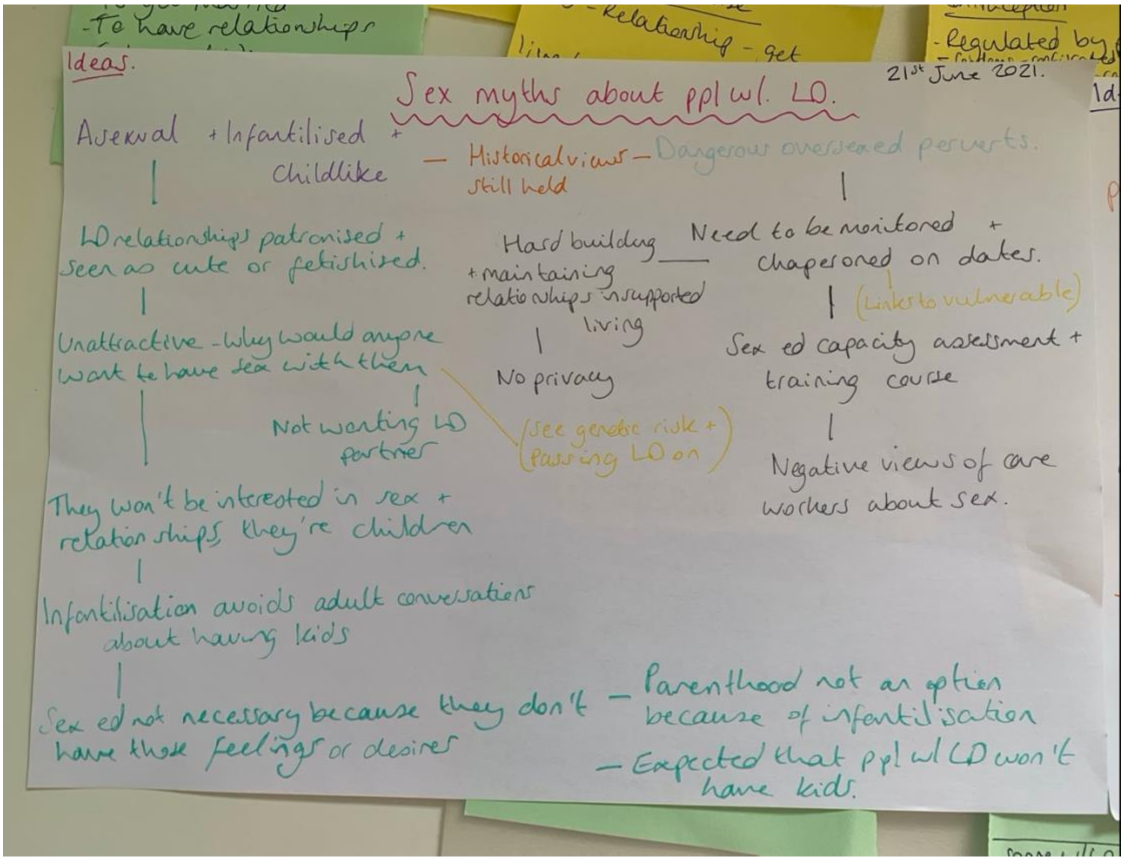
(Control around women's reproduction in other groups = see mwenza)

Can't risk getting pregnant + social services taking their children away.

Risk of pregnancy + procedure outlined in client careplans.

Not allowed sex, relationships, incase they have kids.

Vulnerabilities to risk = Abuse + Rape
— Pregnant by rape.



Ideas.

Sex myths about ppl w/. LD.

21st June 2021.

Asexual + Infantilised + Childlike – Historical views – Dangerous oversexed perverts.
still held

LD relationships patronised + seen as cute or fetishised.

Unattractive – Why would anyone want to have sex with them

Not wanting LD partner

(see genetic risk + passing LD on)

They won't be interested in sex + relationships, they're children

Infantilisation avoids adult conversations about having kids

Sex ed not necessary because they don't have those feelings or desires – Parenthood not an option because of infantilisation

– Expected that ppl w/ LD won't have kids.

Hard building + maintaining relationships in supported living — Need to be monitored + chaperoned on dates.

No privacy

(Links to vulnerable)

Sex ed capacity assessment + training course

Negative views of care workers about sex.