"If she wanted to go to Hawaii, then yeah... I want her to live life as much as I can." Families with Learning-Disabled Children: Exerting Choice and Control For Quality of Life.

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"If she wanted to go to Hawaii, then yeah... I want her to live life as much as I can."

Families with Learning-Disabled Children: Exerting Choice and Control For Quality of Life.

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Photo of play equipment for research with children.
Picture used for family information leaflets.

This Thesis is submitted for the Degree of Doctor of Philosophy

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Abstract

The enactment of The Children and Families Act in 2014 represented a significant attempt to create equity for disabled children in England; supporting special educational needs and disabilities (SEND); and promoting family rights to choice and control. This thesis explores the impact of this and other legislation, policies and professional systems on the experiences of disability; specifically for learning disabled-children with complex support needs and their families. It investigates whether families believe they can exercise sufficient choice and control when working with professional agencies to achieve a good quality of life. It also explores whether disability activism founded in theoretical perspectives about embodied disability have been able to challenge successfully societal barriers in progressing the rights of learning-disabled children.

Using a social constructionist framework, this qualitative study investigates how families navigate complex professional systems to obtain support to achieve independence, agency and a good quality of life for their learning-disabled children. Family narratives are explored to understand family lifeworld and experiences of, and perspectives on relationships with professionals within the system. Data is analysed using the UK Government wellbeing framework and Nussbaum's central capabilites framework. Analyses of individual Education Health and Care Plans are undertaken to analyse whether they support the best possible outcomes for children. Additionally, the impact of societal constructs of childhood, parenthood and disability are considered.

The findings evidence some good, compassionate professional practice, but suggest that families may lack opportunities for co-production with professionals. Families did not believe that they have sufficient choice and control in working with professionals. Consequently, they have learned to develop strategies to better influence the quality of life outcomes they seek. Findings also point towards an increasing dominance of the SEND system within England. This has shifted focus to education outcomes rather than social outcomes; possibly disadvantaging learning-disabled children with complex support needs. Family narratives additionally provide evidence that, despite the rhetoric of human rights legislation and policies, learning-disabled children experience disability discrimination and ableism within professional and societal contexts. Highlighted is how disability theories have been mostly developed in an adult context which does not sufficiently recognise the lack of agency afforded by society to children, or the symbiotic nature of child/parent relationships. To begin to address this, a preliminary child and family disability contextual framework is offered. It is suggested that this provides the basis for future work to build a model that provides understanding of disability in the context of childhood, parenthood and family.

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Abbreviations

The following abbreviations are used throughout this thesis.

BASW	British Association of Social Workers
CA 89	The Children Act 1989
CA 04	The Children Act 2004
CDS	Critical Disability Studies
CFA 2014	The Children and families Act 2014
CSDPA 1970	Chronically Sick and Disabled Persons Act 1970
CQC	Care Quality Commission
DfE	Department for Education
DoHSC	Department of Health and Social Care
D.S.	Down syndrome
EHCP	Education Health and Care Plan

IRISS	The Institute for Research and Innovation in Social Services
LGA	Local Government Association
NICE	National Institute for Care and Clinical Excellence
NSPCC	National Society for the Prevention of Cruelty to Children
ONS	Office for National Statistics
QoL	Quality of Life
SMART	Specific, Measurable, Achievable, Relevant, Time-bound
SCIE	Social Care Institute for Excellence
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
UNCRC	United Nations Convention on the Rights of the Child
UPIAS	The Union of the Physically Impaired Against Segregation

Terminology

Throughout this thesis the terms parent/s, sibling/s, families and learning-disabled child/ren are used. The use of the term “families” when discussing data is not used interchangeably; its use is specific and applied where similar points have been made in narratives by a combination of parent, sibling, and/or learning-disabled child participants. Where points are specific to parents then the term parent/s is used. Similarly, where points are specific to siblings then sibling/s is used, and equally for learning-disabled children.

The term Down syndrome is mostly used throughout this thesis as this was the preferred terminology for most families; although where direct quotations are given and participants use the terminology, Downs syndrome, this is not changed.

Declaration:

The contents of this thesis are produced solely for the qualification of Doctor of Philosophy at Durham University and consist of the author’s original contributions with appropriate recognition of any references indicated throughout

Statement of Copyright:

Acknowledgements

Whilst PhD study is often equated with the fabled loneliness of the long distance runner the reality is that the journey is not alone. So many people are involved and deserve thanks.

The inspiration for this thesis came from working professionally with many learning-disabled children and their families. They all faced many challenges in their lives, and professional systems did not always serve them well; but could also be transformative. Working with families was joyful and a privilege; hearing their stories led me to believe that more family stories should be recorded and better understood. Ben O wisely advised me to never stop listening to families. This sowed the seeds for my research. Thank you to all those children and families who inspired me.

A PhD can only scratch at the surface in telling the myriad of family stories about disability. The stories of the nine families who contributed to this study tells us much about what can make a difference in professional practice, and even more so about what kinship means. Huge thanks go to all of these wonderful families for their preparedness to be involved, for their openness and for continuing to inspire me.

Huge thanks go to my supervisors Professor Simon Hackett and Dr. Josie Phillips. They make a great team. They've supported me in developing my ideas, kept me on track and challenged me when I needed pointing in the right direction. Their wisdom, expertise, kindness and constancy have helped me to navigate the course. Thanks also to Professor Nicole Westmarland who brilliantly supported me mid-way through my studies.

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Finally for a family who taught me a lot about wisdom, love and compassion. The K family who lost their beautiful, precious son. My work is dedicated to his memory.

Thomas 1992-2016

Main Text of Thesis

Chapter 1. Thesis Introduction

1.0. Introduction

In 2018, when this research started, there were over 300,000 learning-disabled children and young people in England who were being supported by their families, friends, and in partnerships with multidisciplinary groups of professionals. These partnerships are primarily intended to enable disabled children and young people to live high-quality lives that are as fulfilling as possible. This is a human right.

Of these children and young people 67,765 had more complex needs and had an Education, Health and Care Plan (EHCP) in place (Department for Education, 2018b). These plans make provisions to meet the special educational needs (SENs) of the young person; securing the best possible outcomes for them in education, health and social care; and prepare them for adulthood as they grow older.

This research is a phenomenological study of the lived experiences of nine nuclear families that are all accessing services through the English special educational needs and disability system (SEND). Each family cares for a learning-disabled child with complex support needs that warrants an EHCP under the provisions of the Children and Families Act 2014. All of these children also have physical disabilities. Although this study uses a small sample, the insights that these families provide are important and contribute valuable knowledge about a very heterogeneous population of disabled children that is not always fully recognised as such.

Through family narratives and analysing EHCPs, this study seeks to increase the understanding of the challenges inherent to achieving a good quality of life for learning-disabled children with complex needs; and how families seek to overcome these challenges. It recognises that children do not grow up in isolation; and explores how the health of the entire family system affects an individual child's well-being. This research considers the dynamics of whole nuclear families ('nuclear' was defined for this study as two generations, parents or step-parents who are not necessarily married and their offspring, usually but not always residing in the same household). It explores how services and professional relationships both support and frustrate families in achieving the best life possible not only for their disabled family member; but for the family group overall. Family life tends to be about balancing the needs of all members. When this is impossible, the whole family's quality of life can be affected. Living with complex disabilities creates additional challenges in family dynamics, although these challenges can also foster stronger familial bonds.

To use regulatory and professional terminology, the families involved in this study are 'experts by experience'. This research seeks to contribute to the understanding of what families who care for learning-disabled children believe that professionals and society need to know and understand about learning disabilities; and how policy and practice work together. Family views remain underrepresented in research about learning disabilities. By interacting directly with families, this study offers insights that can ultimately help to improve service systems and challenge attitudes and stigma. In understanding these families' perspectives, a deeper understanding of their unique experiences and the support needs of individuals can be achieved. Cultural issues and contexts related to professional practice are also highlighted, contributing to the body of work that seeks to reduce prejudice and discrimination in the context of learning disabilities, including within professional systems.

I approached this research from the perspective of a professionally qualified social worker of over three decades. Given this professional background and my positionality, there is a strong slant in this research towards the social aspects of learning-disabled children's experiences. This research explores the SEND system in the round and recognises the system's focus on supporting children's education. However, key interests within the research are in understanding the holistic and social context of learning-disabled children's and their families' overall quality of life (QoL). This includes the choice and control they can exert to achieve desired outcomes .

This chapter reviews the thesis structure and research aims; and introduces the main constructs supporting the thesis. It also explains my professional context and personal interest in the subject.

1.1. Contextual background

This study focuses on families with learning-disabled children who have some of the most complex support needs. Learning disability itself is a social construct.

Internationally, different definitions and terminology are used in relation to learning disability. In the UK, the Department of Health formally defines it as:

> *A significantly reduced ability to understand new or complex information (impaired intelligence), to learn new skills with reduced ability to cope independently (impaired social functioning) which started before adulthood with lasting effect on development*. (Department of Health, 2001, p. 14)

This governmental definition provides a starting point for this research. As previously stated there are 67,765 children and young people aged 25 years or younger in England who have an EHCP associated with their learning disability; entitling them to statutory provisions to support their needs (Department for Education, 2018b). The Learning Disabilities Observatory (Hatton *et al.*, 2016) found that 56% of children with these specialist plans have severe or profound learning disabilities. This study considers these more complex needs.

Having complex learning disabilities entails additional challenges across many aspects of family life, which can result in both financial and emotional impacts. Disabled children and young people are generally more likely to live in poverty than those without a disability (Emerson, 2012). Contact a Family (2018) found that over one-third of families with children with SEND, experience extra costs averaging an additional £300 per month to support their disabled children. Only 56% of these families reported that disability benefits covered these additional costs.

There is also strong evidence that the parents of learning-disabled children experience a higher likelihood of depression or other mental health diagnoses than the parents of non-disabled children (Marquis, McGrail and Hayes, 2020; Baker *et al.*, 2021). Parents, particularly mothers, are also likely to experience employment effects; often giving up working life to be full-time carers (Saunders *et al.*, 2015).

The siblings of learning-disabled children often experience more complex family life, although overall, the research evidence focused on learning-disabled children's siblings is limited and there are considerable gaps in understanding (Hastings, 2014).

It is therefore important to explore and better understand families' individual experiences and the effects of disability both on children and family life. Disability is often considered homogeneously, an attitude that this study seeks to counter by understanding differences in experience as well as commonalities.

1.2. A case for change

This research has evolved from both my professional background in social work; and personal interest. One of the original motivations for undertaking the study arose whilst working with learning-disabled children who also had complex epilepsies. Having worked with families for several years, I came to recognise that they constantly face real dilemmas and challenges while operating within a system that is theoretically designed to meet their learning-disabled children's needs; but often fails in doing so. The relatively new Children and Families Act 2014 (CFA, 2014) sought to radically reform the SEND system, but after a couple of years, concerns that it was not achieving the government's intent were already emerging.

In 2017, the Conservative Government commissioned Dame Christine Lenehan, the Director of the Council for Disabled Children (CDC), to undertake what became two separate reviews. These focused on why SEND policy was insufficiently preventing the institutionalisation within special residential schools, of many learning-disabled children with complex support needs. Institutionalisation is not only expensive for the public purse but also contrary to national and international care policies for children.

The 2009 United Nations General Assembly supported the reduction of institutional care as an important principle; and argued for family and community-based solutions to be prioritised (UNGA, 2009). It has been argued that care within large institutions is an abrogation of children's rights (Davidson *et al.,* 2017). If consideration is being given to children living away from parents for whatever reason then two important principles require consideration; necessity and suitability (Cantwell *et al*. 2012).

The necessity principle involves preventing situations and conditions that can lead to alternative care being required. The suitability principle requires that if a child does need alternative care it should be provided in an appropriate way, meet the child's need and protect their wellbeing (Cantwell *et al*., 2012). Both of these principles are highly applicable to learning-disabled children who have complex needs.

Lenehan, and then Lenehan and Geraghty, produced two reports, respectively, *These Are Our Children* (2017) and *Good Intentions, Good Enough?* (2017). Their reports summarised the environment and the challenges faced and identified a lack of societal ownership of the needs of learning-disabled children, hence the title of the first report. They also highlighted several professional system issues and broadly concluded that more multiagency work could contribute to ultimately solving the problem.

My professional response to these reports at the time was that decades of professional activity in multi-disciplinary and multi-agency contexts had not had the desired effect for disabled children to date; so why would these reports change the outcomes? Continually doing the same things tends to offer the same results. Sometimes, multi-agency work can focus on structural design that is convenient to the agencies involved rather than their service users. My frustrations with the conclusions of the two Lenehan reports partially piqued my interest in this doctoral research.

In 2019, the UK government-commissioned review into the SEND reforms found that whilst the CFA 2014 reforms were correct for children, poor implementation and pressured local authorities, left schools struggling to cope; and, ultimately, threw families into crisis (House of Commons Education Committee, 2019). The government response to these findings was that a child-centred system was required, highlighting, as Lenehan had, joint work between agencies as well as co-production with families. This theme of co-production is further highlighted in the long-awaited 2022 green paper on SEND reforms following the 2019 SEND review, in which, once again, ministers promoted the importance of co-productive relationships with families (Hansard, 2022).

The CFA 2014 offers opportunities for good plans for children that can make a real difference. I was interested in exploring families' assessments of how the system works and understanding their realities; not only assessing policy or service rhetoric. The strengths and weaknesses of the system are explored with families in this research. It is as important to learn from what families report they have valued and why, as it is to learn from the things that have been problematic for them. When elements work well, life can be transformed not only for a disabled child but also for their family. Ryan (2021) argues that professional systems still fail to sufficiently understand the needs of families living with learning disabilities. She asks what do professionals need to know about the families of learning-disabled children. This study seeks answers to that question by talking directly with families.

1.3. A constructionist study

This research is a constructionist study. It explores the nature of family experiences; their social construction of reality in the context of legislation; and societal and policy understandings of childhood, parenthood, disability and quality of life. Families' experiences are greatly influenced by societal constructs; the ideas that are shaped and defined by our cultural beliefs, structural arrangements, policies and practices; and which have become institutionalised within society (Buchmann, 1989). How these intersect is considered in this work, including the contradictions of this intersectionality. Conceptualisations of how power is exercised to achieve (or prevent) choice and control are also incorporated. The study focuses on investigating the social influences on communal and individual lives within families (Galbin, 2014).

Families as kinship groups are constructed and, whatever their size and composition, become key social institutions or 'micro-cultures' in the context of family decision-making (Bertaux and Delcroix, 2000; Langellier and Peterson, 1993). They operate within a unique lifeworld; with tacit understandings of shared meanings. Day-to-day actions are generally communicative about what is important to the family. This lifeworld interacts with 'the system'; the strategic actions of institutions and organisations, including those designed to support learning-disabled children (Habermas, 1981). Insights into how family lifeworlds interact with the system, provide valuable knowledge about how the best outcomes can be achieved for learning-disabled children and their families; as well as what is working well within disability services and wider support systems; what needs to change and how power within the system is constructed and maintained.

The dynamics of these interactions influence how families navigate often complex and sensitive issues within the private family sphere and the broader public services system. Academics in the field of learning-disabilities point to a misalignment between the political and policy rhetoric about supporting families; and the families' understanding of how the system actually supports them (Goodley and Runswick-Cole, 2010a; Ryan, 2021). That many families voice frustration with the system is evident even from a cursory look at public-domain social media, as the three tweets below demonstrate (Redacted to maintain authors' anonymity).

[redacted]

most of my time is spent hearing stories of parents on their last vestiges of mental strength. Stories that are growing, lives that are breaking. WHAT WILL IT TAKE for the system to recognise & support us? Parents of disabled children are fracturing NOW LISTEN, LOOK [redacted]

[redacted] [redacted]

This week I've been bitten, punched & kicked by the daughter I love more than anything because there was no learning disability nurses in a children's hospital. Parenting a disabled child is unnecessarily stressful because of lack of support. #GiveItBack #WorldMentalHealthDay2019

[redacted] · 1h

We were founded from [redacted] experience. Forced to resort to 3 tribunals & 1 high court case in order to gain her daughter an education after being refused one for almost 18 months. This is why we are marching on Thursday. #SENDNationalCrisis @SendCrisis #SENDamessage

The families of disabled children comment regularly on their experiences of the system on social media. The distinctions between online and offline worlds are increasingly blurred in society and online groups have become rich sources of social commentary (Garcia *et al*., 2009, cited in Caliandro, 2018). Online interaction has become a regular part of daily life for demographically diverse populations (Golder and Macy, 2014). This enables dialogue amongst groups of people that previously would have struggled to be heard beyond their immediate local communities. Families can now share their frustrations with much wider audiences.

Childhood is also a societal construct; in navigating childhood, all children grow and develop. The speed at which they develop varies and their growing up is a constantly evolving process. Whilst childhood is societally constructed, psychology has predominated as the arbiter of correct or normal development (Burman, 2008), taking a more scientific approach (Sorin and Torzillo, 2018) including within health, social and educational contexts Understanding this is important in understanding learning-disabled children, because it creates challenges both for the child and their family when they deviate from so-called norms. More recently new sociologies of childhood which develop ideas of agency and autonomy (James, Jenks and Prout 1998; Sorin and Galloway 2006) have encouraged different understandings of childhood and the agentic child. However, learning disabled children continue to be marginalised (Wells 2018). Underwood *et al*. (2020) argue the social oppression of disability means that medicalised discourses still dominate in understanding childhood in the contexts of disability with a focus maintained on development, rehabilitation and clinical interventions.

The early 20th century saw developmental psychology's establishment as the dominant paradigm for studying young children and influencing professional practice in care and education (Woodhead, 2003, cited in Gabriel, 2020, p. 49). Discourses about ages and stages became linked to developmental norms, encoded in milestones that highlight 'developmental delays'. There is an expectation within this paradigm that disabled children should actively work to meet developmental norms, whatever the barriers. Where they fail to achieve 'normal development', at worst, they can be segregated, institutionalised, and cut off from their families and communities, becoming labelled and discriminated against (Adams and Leshone, 2016, p. 174).

All families engage in a constant process of navigating different life events, stages and transitions while bringing up their children. Some happen biologically and some are imposed by societal structures, such as starting school, preparing for adulthood or moving into an independent home. Sometimes these life events progress smoothly and sometimes not. There are peaks and troughs of both calm and crisis. Barriers to a good life can be created when professionals see a child's 'slower' development as a deficit and respond in ways that seem to place blame, particularly on the parents. Notions of what childhood is, how it intersects with parenting roles and what it means for attitudes towards learning-disabled children are explored with parents in this research. This includes whether notions of a normal childhood within societal discourse become a way to 'other' disabled children and label them as different; thereby seeking to somehow 'cure' them (Goodley and Runswick-Cole, 2010b).

In Chapter 3, several relevant social constructs are explored in greater detail, and how these affect learning-disabled children is discussed. In critiquing these, disability theorists and activists agree that disabled people continue to be undervalued and discriminated against. To challenge this, new forms of knowledge are needed that value disabled people's experiences as experts, to address their marginalisation and exclusion (Egilson *et al*., 2021). The narratives of society need to better understand the intersectionality of constructs of childhood, parenthood and disability.

1.4. Why this research matters

Academics frequently comment on the lack of research in disability studies (Abbott, Morris and Ward, 2001; Arthur, 2003; Grue, 2011; Fletcher, Flood and Hare, 2016; Santoro, Shear and Haber, 2018). Nevertheless, the academic sphere that considers the constructs and human experiences of disability has widened and evolved over the past century; and this work continues to successfully, albeit incrementally, develop disability awareness. Disability activism continues to challenge societal stigmas and stereotyping. Where academic study and debate have occurred, government agencies and professionals have gained the insights and knowledge required to plan for and develop adequate services for both physically and learning-disabled people (Bolt, 2015; Kuper, Haran and White, 2018, World Health Organization, 2011).

The complexity of the system that families must navigate however is recognised in this study. My professional observations over some decades are that the majority of parents of learning-disabled children are likely to be very engaged with their children’s plans; they work hard to achieve the best for and from them. I, therefore, wanted to explore what these children, their parents and their siblings perceive as important for a good quality of life; and how helpful they find the available services and support in meeting their needs. I also wanted to research how much choice and control they have in achieving their goals.

Disability studies have become more established, with a body of academic knowledge in the UK following the formation of the Union of the Physically Impaired Against Segregation (UPIAS) in 1974. The UPIAS actively campaigned for the inclusion of physically disabled people in mainstream society. This activism was highly influential and has catalysed further change in the UK since the 1970s, opening up new fields of enquiry and research. Reforming the system to achieve the best outcomes for disabled people remains a work in progress, and this is particularly true for learning-disabled people. There is still a general lack of research to understand learning disabilities, and this is particularly true of research with learning-disabled children and with those who have lived experience with learning disabilities (Durell, 2016). I aim to understand the historical and contemporary context and develop a further understanding of the experiences of learning-disabled children as citizens in the third decade of the 21st century.

In reality, there is no clear-cut single model of care that suits all children, as there is no single ‘normal’ or optimum model of family life. Learning disabilities represent a wide spectrum. To date little research has been undertaken that directly explores quality of life within whole family units where they are caring for a learning-disabled child who has particularly complex support needs. This research seeks therefore, to gather families’ insights about navigating the system and, particularly, the main statutory systems that are designed to support the well-being of learning-disabled children. This study is particularly concerned with the experiences of specific families with children who have complex support needs. It argues that their experiences should be understood holistically, and so, it explores family perspectives about education, health and social care, as well as professional and societal attitudes.

This study focuses on how two key pieces of legislation holistically support learning-disabled children: the Children and Families Act 2014, which establishes principles of family choice and control, as well as EHCPs; and the Children Act 1989, which applies the concept of ‘child in need’ in relation to disability. These two pieces of legislation have been enacted for a sufficient period of time to enable families’ lived experiences regarding the system’s success in supporting learning-disabled children’s holistic quality of life; and families’ ability to exercise choice and control, to be assessed.

1.5. Families’ agency

A critical part of the research design lies in recognising the individual agency of every family member to exercise choice and control in their lives. This includes hearing the views of learning-disabled children, their parents and their siblings; this latter group within families, professionals often characterise as young carers.

Reports from regulatory agencies, such as Ofsted and CQC, and associate bodies, like the Local Government Association, provide plenty of material in the public domain related to professional assessments of how the system works. A lack of real engagement with families however may be skewing this narrative. Families, when consulted, can provide a fuller understanding of the reality of how social policy, legislation and societal attitudes come together to either support or create barriers to a good quality of life and individuals’ choices. This is why I believe this research is crucial.

Family insights informing policy development are not universally evident; even reports that claim to have consulted families can be quite superficial. Such consultations often involve talking to one umbrella parenting body; a sometimes-homogeneous group of parents that can obscure the granularity of the issues that different families face. For instance, there can be significant differences between the experiences of autistic children and children with Down syndrome, or those with complex epilepsy or other learning disabilities. The involvement of learning-disabled young people, particularly those with more complex support needs in decision-making about their own lives is even more superficial.

This research, therefore, focuses on how families' perspectives vary in making life decisions, developing life paths for all family members; maintaining family bonds; and maintaining kinship commitments, when they have a family member with a complex learning disability. It seeks insights into the relationships that family members must navigate within societal systems, particularly in professional relationships.

1.6. Starting points

"Human beings, who are almost unique in having the ability to learn from the experience of others, are also remarkable for their apparent disinclination to do so." Douglas Adams (undated).

That there is a crisis in SEND policies and service delivery at the start of the third decade of the 21st century is easily confirmed (Education Committee on SEND 2019; HM. Gov. Green Paper 2022; Bryant, Parish and Kulawik, 2022). This thesis has sought in part to understand, from families' perspectives, what might have caused this crisis. That children's support needs are inconsistently met most of the time is apparent from the number of SEND tribunals that find in favour of parents (96% in 2021).

Within society, disability tends to be referenced as an all-encompassing construct; however, this attitude fails to recognise the heterogeneity of experiences that result from different types of disability. This homogeneity is a particular problem in research about disabled children, where children's voices have sometimes been conceptualised into one overall body of knowledge (James, Jenks and Prout, 1998; Levin, 1994, cited in Davis, 1998). McLaughlin *et al.* (2008b) point to more recent work that has explored the varied meanings given to 'disability' and 'impairment' within childhood (e.g., Connors and Stalker, 2007) and within families (e.g., Ryan and Runswick-Cole, 2008). This study, in acknowledging the complex and multiple conditions of the children and young people involved, seeks to recognise the heterogeneous nature of the experiences of disability.

Families interact with a range of legislation and policy. A grey literature review reveals that currently social policy to assess the needs of learning-disabled children tends to move families through a predominantly educationally focused SEND system that is delivered through schools and colleges. This is overseen by Special Educational Needs Coordinators (SENCOs), educational psychologists, head teachers and local authority SEND officers.

A strong emphasis on a neo-liberal model of delivering education during childhood to prepare for employment is consistent across the population. This is linked to a general social policy imperative that focuses on education as the route to enable citizens to become economically productive in adulthood. This imperative was equally emphasised for learning-disabled children in the policy reforms of the UK's Labour Government in the early part of the 21st Century; it has been maintained by subsequent governments; including the Coalition and Conservative administrations from 2010 onwards. The Coalition Government asserted:

> '*If more effective support of disabled children and children with SEN prompted greater achievement, it could result in higher productivity gains and growth for the economy, thereby benefiting both the individual and society' (DfE, 2011a).*

This statement suggests that learning-disabled children are perceived as a drain on productive society (Runswick-Cole, 2011).

1.7. Finding purpose

A further line of enquiry that is explored with families within this research lies with seeking purpose. All humans seek purpose, regardless of the challenges they face. Frankl's (1946) seminal work on meaning and purpose cites Nietzsche, 'He who has a *why* to live for can bear with almost any *how*'. Frankl argues that no individual's situation repeats, so each situation calls for a different response and that purpose matters. It is important to explore how families' children achieve purpose in life and how parents support their children in this goal to achieve a good quality of life. Social context and how it is applied within families and supported by professionals is important to this process as well.

UK societal expectations are that adults generally achieve day-to-day purpose through paid employment, thereby contributing economically in a capitalist democracy. These principles are apparent in SEND policies that seek to provide young people with education that is focused on employability. Might this focus be disabling to young people who, due to the complexity of their conditions, cannot achieve paid employment? The percentage of adults with complex learning disabilities in paid employment is minuscule; 5.1% (NHS Digital, 2021). How do young learning-disabled people fully participate in life when the policy model of paid employment excludes them and may be to their detriment? What alternatives do they have? Additionally, what pressures does this place on parents who seek to achieve the right outcomes for their children into early adulthood and beyond, when they as parents will no longer be present? To recognise the complexity of these children's situations, should there be a stronger emphasis on developing aspects of their social worlds to fulfil other types of purpose?

The SEND system runs predominantly through education structures, which are, arguably, less focused on wider health and social needs, although EHCPs are intended to be holistic. The Children Act 1989 provides for assessing the needs of children with disabilities (Section 17(1), CA1989), requiring local authorities to provide services for disabled children that minimise the effects of their disabilities and permit them to lead lives that are as normal as possible. Whilst UK government data indicates an increase in the overall number of children with special educational needs (UK Government, 2020) and a corresponding increase in EHCP assessments, national data also indicates that Child in Need (CIN) assessments for reasons of disability through the Children Act 1989 have actually decreased in the same period. Are EHCPs replacing CIN assessments as the preferred way to assess disability needs? Families' reported experiences can provide insights into this possibility.

In some respects, the assessment of learning-disabled children's needs has been negatively affected by changes to children's social care, with its focus on risk and safeguarding. The 2022 SEND review green paper reports that some families with disabled children are put off from seeking support from children's social care programmes because they fear being blamed for the challenges their children face and being treated as a safeguarding concern; rather than receiving the support they need. The difficulties of navigating children's social care assessments can mean that support is often provided only after families reach crisis points (Special Needs Jungle Online, 2022).

Historically, in assessing children in need, the DfE enacted the 'Every Child Matters' (ECM) outcomes (DfE, 2003, p. 19), setting out a structure that professionals working with children should strive to achieve. The five outcomes were:

- Being healthy
- Staying safe
- Enjoying and achieving
- Making a positive contribution
- Achieving economic well-being

Whilst it is no longer a recognised framework for the delivery of children's services, ECM recognises wider outcomes and implicitly recognises purpose. Aynsley-Green (2019), previously the Children's Commissioner for England, bemoans the loss of the framework, which he argues is built from deep academic knowledge and professional understanding of children. The framework supported the Children Act 1989 in considering children's wider needs and well-being. This research, therefore, also explores families' social contexts, the provisions of the Children Act 1989 and its conceptualisation of a 'child in need' (CIN) because of disability. How these wider needs are assessed alongside the specific assessments of special educational needs (SEN) through the CFA 2014 is investigated.

In literature review Chapter 2, the legislative frameworks of education, health and care services for children are summarised and briefly explained. This identifies more than a dozen key pieces of legislation that can apply to meeting the needs of learning-disabled children. Whilst criticisms of the Children and Family Act 2014 have been made nationally through various government reviews, this research explores with families how the provisions of the Act function for them alongside other relevant children's legislation. This provides insights into the success or failure of integrating children's legislation. Some professionals argue that what is perceived as the current 'SEND crisis', originates from a failure to comply with the law at even the most basic level (Fiddy, 2019). Policy and legislation per se may not be the issue then but that it is in how professionals apply these.

1.8. Developing the research questions

Whilst disability activism and advocacy has achieved many positive changes in the wider societal understanding of disability; and in the development of helpful theoretical models of how disability is understood; there is evidence that families' perspectives are still not properly heard by government, professionals or society. However, service users' understandings of the strengths and weaknesses of the system can be valuable in reshaping that system. Family experiences can provide important knowledge about the current systems' successes and failures in relation to learning-disabled children.

A key part of Part III of the CFA 2014 is that families should be able to exercise choice and control in the plans made for their children. Lenehan's (2017) review discussed better multi-agency partnerships and, presumably, saw parents as active partners in these arrangements. This research recognises the current policy narrative of co-production with service users and their families as a means for the effective planning and delivery of services. It explores families' experiences and how they feel able to exert choice and control to achieve the best quality of life for the whole family. This is explored against the current backdrop of neoliberal systems of consumer choice promoted by successive Governments since the start of the new millennium.

A further area of exploration is whether, within professional discourses, practice dynamics are constructed from both conscious and unconscious ableist frames of reference that question disabled children's perceived worth. Notions of normative development or the stages of development that the majority of children of a specific age are expected to achieve are linked to this (Meggit, 2006). The perceptions and experiences of stigma and discrimination and how these affect the quality of life are also explored with families.

The questions that are considered in this thesis emerged from both personal professional experiences and a wide review of academic and grey disability literature.

This study aims, overall, to enhance knowledge about family perspectives on children’s embodied experiences of disability. It is intended to inform practice and improve the delivery of Human Rights for a specific section of the population: learning-disabled children who have complex and multiple support needs.

1.9. Research questions

There are many gaps in disability research and not least in the involvement of families in research studies. This study recognises that families of learning-disabled children become ‘experts by experience’ and can contribute valuable knowledge which informs our contextual understanding of disability. It provides insights about how families interact with services to seek better outcomes for their learning-disabled children.

The main research question explored is:

How do parents and learning-disabled children and young people exert choice and control in decisions about the support they receive to achieve a good quality of life?

In exploring this, I also consider:

- *What are parents and siblings’ aspirations for learning-disabled children?*
- *How are decisions made for and with the child, and by whom?*
- *What are the key tensions within the decision-making process?*
- *How has Part III of the Children and Families Act 2014 affected families’ choices?*
- *What are the families’ professional power relationships and how do they navigate them?*

1.10. Positionality statement

McManus Holroyd (2007), citing Weinsheimer (1985, p. 11), comments, ‘We understand the world before we begin to think about it’. She argues that a researcher must first reflect on their pre-understandings and the meanings within them to evaluate and determine their legitimacy, as they influence new understandings. I reflect on this in my approach to this research as a professionally qualified and registered social worker. In this respect, I recognise my insider positionality and my personal and professional interest in the subject and reasons for choosing the investigative methods I have applied. My long career in children's social care means that I bring an integrated practitioner's understanding of public sector services to this study. I recognise that I have been on a heuristic journey in undertaking this research.

I would describe myself as a therapeutic social worker; I have sought to emulate 'emotionally intelligent relationship-based understandings to practice' (Ferguson, 2010, cited in Garrett, 2013, p. 4; Garrett 2013; Ingram and Smith, 2018). My professional knowledge, training, values, and background have shaped my approach and influenced my research design; as have the ethical codes that underpin social work practice (BASW and Social Work England codes).

This research is a qualitative phenomenological study that focuses on understanding families' perspectives. It is built from individual case studies to understand individuals' life stories and recognises families as relationship-based units. The use of narrative methods explores what for participants, constitutes the families' lifeworlds and how these interact with societal systems. Past professional experience influenced these methodological choices.

During my social work career, I worked with children who were in the care of the local authority under the Children Act 1989. An aspect of my work was developing life story books with and for children. These books help children know and understand about their birth families, family histories, events and people who have been important to them during childhood, supporting their sense of identity. Biographical accounts in the form of life story work can be used to provide a continuity of experiences to individuals and support identity regarding relationships (Middleton and Hewitt, 1999).

Narrative storytelling and oral histories were natural choices for me in the design of this research and influenced my approach to exploring meaning with the families involved. I wanted to achieve a deeper understanding of families' direct experiences, giving voice to individual family members and the whole unit.

1.11. Expanding professional knowledge

I have directly observed, in working as a professional with learning-disabled children, that professional expectations of what can reasonably be achieved with and for disabled children sometimes seem much lower than those of more typically developing children. A disabled child's inability to meet milestones as quickly as other children can influence what is then accepted by professionals as 'good enough' for them in terms of a good childhood. Disabled children can miss out on many experiences, such as the ability to develop friendships or extra-curricular participation in school life because the school transport system for disabled children cannot support their participation. Some children cannot go on education trips because their health and safety needs are seen as too onerous or too risky to manage. These assessments of 'good enough' would be seen as limiting for a typically developing child. This is discriminatory.

It is equally apparent to me professionally, that families sometimes believe that what practitioners view as an acceptable quality of life for their child results in segregation, which parents refuse to accept as 'good enough'. They argue that their children deserve better, and that differential treatment is to their children's detriment.

A typical example that reflects my experience arose early in the course of this research. I informally met by invitation with a senior local authority director who was responsible for commissioning services. They were positively interested in the work I was undertaking. During the discussion, they commented that the problem with disabled children is that the costs involved in their support means that for every disabled child funded, probably two non-disabled children could be supported (2019; not referenced to maintain anonymity). This raises questions regarding understanding of differential intrinsic worth, which appears to be underpinned by unconscious ableism and discrimination.

I wanted to explore the dissonance between family and professional expectations and understandings in this research. Navigating this dynamic is something parents I have worked with have sometimes referred to as 'a dance' while trying to access suitable provisions. Families exist within a professional hegemony that they must learn to navigate if they are to access support, but family needs sometimes seem to be poorly understood. Ryan (2021, p. 110), an academic and parent of an autistic child comments, 'I've always been struck how many health and social care professionals are blinkered to some of the demands families face… the lack of recognition or acknowledgement of the sometimes physical and medical labour undertaken by families.'

1.12. A heuristic journey

In considering my research design, I applied principles of heuristic inquiry, finding this framework helpful. Sultan (2019) argues that starting with our early experiences of learning, we are constantly assessing what and how we feel about things and then checking others' perceptions of different experiences; and whether these are the same or different. These individual insights are integrated into a whole that seeks to describe a more cohesive understanding of a phenomenon or our world.

This research involves such a heuristic journey; my understanding of the stories that families tell me will be influenced by my own experiences and perceptions as a researcher (Moustakas, 1990; Sultan, 2019). Also, as a social work professional, I am situated within a certain dominant perspective of social care. My knowledge is predominantly based on my training, learned practice theories and orthodoxies, along with work-based experiences. This certainly provides useful knowledge that both constructs and frames my understanding of social work discourse, but as it also shapes my analysis, it creates the risk of bias. Family perceptions will inevitably challenge my understanding of the system, and I recognised that I must be open-minded, curious, and prepared to be challenged.

Learning from families directly, outside the context of my previous professional power-based relationships of authority, and instead taking on the role of a researcher, creates a different power dynamic. In becoming familiar with the 'being of another' (McManus Holroyd, 2007), this will happen in a different and more collaborative way. The role of the researcher is not about asserting professional and sometimes interventionist authority, as the professional social work role is.

Dominant professional discourses can divorce experience from meaning for individuals; stories are impacted by the hegemonic nature of political and sociological norms. Others in hearing them may not understand context or how the individual feels (Ewick and Silbey 1995). A more collaborative 'researching with' context is applied to this study, I hope to have opened up dialogue in a way that is more inviting and personal without encroaching on the families' desire for privacy.

I recognised from the outset that during this study, families would need to find me authentic as I would be asking them to share personal and often difficult experiences, as well as the joys and successes of family life. My social work practice draws on the principles of authenticity in relationship-building that Carl Rogers (1951) describes. I sought to further draw upon this practice during the research.

1.13. Researching during Covid-19

This study began during the first 18 months of the Covid-19 pandemic. The pandemic provided some stark evidence within professional and societal contexts of stalled progress in the proper consideration of disabled children's rights. This feeds into the research through what families reported.

Both national reports and research participants reveal that people with learning disabilities were disproportionately affected by the pandemic. In the UK, the number of learning-disabled people who died from the virus per 100,000 was higher than for any other part of the population including all other vulnerable groups (Office for National Statistics, 2021; Mencap 2021).

Learning-disabled children and adults were initially considered a lower priority for treatment if the health system could not cope during Covid-19 (NICE, 2020). This was successfully challenged through the courts, but it raises important questions about the rights of learning-disabled people when a whole population is threatened by something like a pandemic. This is discussed further in the main body of this thesis.

Conducting this research during a national lockdown affected the research design and methodology. Changes that were required are reflected upon later in this thesis. What Covid-19 meant for the families and their circumstances is also discussed.

1.14. Overview of the thesis structure

This introductory chapter has outlined the context of the research, setting out its rationale and the questions about quality of life and families' choices and control that this study seeks to answer.

It gives a brief overview of the territory being explored and the interface between families and their lifeworlds with wider societal and professional systems. It sets the scene for exploring family experiences through constructs of childhood, parenthood, disability and quality of life.

Chapter 2 considers what is already known about the experience of disability and seeks to understand the network of relationships, structures and legislation, alongside the historical and contemporary context of disability, that families must navigate.

Chapter 3 considers the theoretical constructs and conceptualisations of disability, quality of life, childhood, parenthood, power and control. These are considered through their intersectionality, as well as how they affect family life and the experiences of learning-disabled children.

Chapter 4 describes the methodological approach applied in this research, restating the research questions regarding how families exert choice and control in seeking a good quality of life. The epistemological and ontological positioning is explained and background information is provided on each participating family. Detail is provided on the different methods applied and why, as well as the data plan.

Chapter 5 presents the data analysis and explores the findings in relation to families' perceptions of life experiences and the services they receive to achieve a good quality of life. It explores two relevant quality of life frameworks and analyses Education, Health and Care plans. The validity, reliability and generalisability of the study is reflected upon.

Chapter 6 discusses family perceptions regarding quality of life and how the system supports them. It recognises that, overall, families want their learning-disabled children to have fulfilling and purposeful lives and to be recognised as full citizens.

Chapter 7 discusses the findings on the importance of relationships to families. Parental and sibling critiques of significant relationships, including personal, community and professional relationships, are discussed. Family and professional co-production is explored, and how it can provide opportunities to develop different types of collaborations to achieve better outcomes. Challenges and barriers are discussed and the need for a shift in professional/parent power dynamics is explored.

Chapter 8 discusses parents' and siblings' reflections on how disability is understood by society and professionals; and recognises how ableist cultures can affect service approaches. It discusses families' views about an often-problematic lack of professional knowledge and training in this context. How different understandings of disability influence practice is also discussed; recognising that no model specifically explores children's experiences of disability. It argues that further work is required in this respect.

Chapter 9 addresses the research questions directly, summarising conclusions and recommendations. A contextual framework for better understanding family interactions with the system is offered with a recommendation for further development. The benefits and the limitations of this study and its implications for practice are recognised. This study's unique contributions to knowledge and areas for future potential research are discussed.

Chapter 2: Literature review: Legislative, historical and contemporary context

‘There is very little mention of disabled children within the childcare literature so that this group is in some ways ‘invisible’ … this represents a significant gap in the knowledge needed to plan services appropriately.’ Borland et al. (1998, p. 35)

2.0. Introduction

Whilst the quotation above is decades old, in many respects, the ‘invisibility’ of disabled children, and learning-disabled children, in particular, remains a challenge that many families who love and care for a disabled child experience.

This chapter contains the first part of the literature review. It considers the legislative frameworks, service structures and historical and contemporary contexts; and how these affect learning-disabled children in England. It explains the system that families must navigate when seeking the best outcomes for their learning-disabled children. The professional context is recognised because it is inextricably linked to the system families navigate; where strategies employed by professionals dominate and control the parent/professional ‘partnership’ (Hodge and Runswick-Cole 2008; Dale, 1996; Seligman and Darling, 1989).

The historical context of disability is explored because of its continued relevance as past beliefs and attitudes can still, and do, echo within contemporary practice. Key features of contemporary understanding are highlighted and potential gaps in current knowledge are identified as well.

In reviewing both academic and grey literature, I have sought to understand how legislative, policy, historical and contemporary context may influence professional practice regarding learning-disabled children’s needs.

2.1. Background

Numerous authors have commented on how little research is undertaken specifically to understand the needs of learning-disabled children. This lack of research has been identified across models of care, residential care, emotional well-being, concepts of disability and children’s voices (Abbott, Morris and Ward, 2001; Arthur, 2003; McLaughlin, 2006; Scior, 2011; Goodley, 2013; Fletcher, Flood and Hare, 2016;

Santoro, Shear and Haber 2018). This paucity of research may be partially attributed to the particular challenges of research design in relation to a very heterogeneous group of individuals. Additionally, the meaningful involvement of learning-disabled children can be difficult because of the communication challenges they can face, although these can be mostly overcome.

Disability studies within the UK has gained a much more established body of academic knowledge since the formation of the Union of the Physically Impaired Against Segregation (UPIAS) in 1974. Its campaigning for inclusion catalysed further change. Academic research and theorising, combined with activism have evolved, leading to the establishment of academic disability studies and critical disability studies. Over the past five decades, new and challenging fields of enquiry and disability research have arisen. However, whilst disability has emerged as an increasingly significant area of academic enquiry, the lack of specific learning disability research remains apparent (Durell, 2016).

Whilst the practical challenges for research design previously alluded to have affected learning disability studies, it is equally important to consider whether stigma about learning disabilities has also contributed. An analysis of historical attitudes affirms that ableist and outdated beliefs about sentience and personhood continue to influence how learning disability is understood (Goodley, Runswick-Cole and Liddiard, 2016; Fletcher, Flood, and Hare 2016; Campbell, 2019). Understanding this historical context is important. Nevertheless, the academic sphere surrounding constructs and the human embodiment of disability has broadened and evolved. This work continues to develop incrementally and can challenge societal stigma and stereotyping.

2.2. Planning the literature review

Many factors influence how children and families experience learning disabilities. These must be considered holistically to reveal the day-to-day context of their lives. Subjective experiences of disability are integral to each disabled person’s everyday lived reality. Crow (1996) argues that this is what theoretical models of disability seek to explain, and the layers of complexity in how disability and impairment work together must be peeled away.

Figure 1, below, presents the areas that were explored and considered in the context of the literature review. The diagram represents key areas of enquiry, shown as a system map. This was drafted at the beginning of the research and built upon as the review progressed. It reflects the complex nature of the environment that learning-disabled children and their families must navigate.

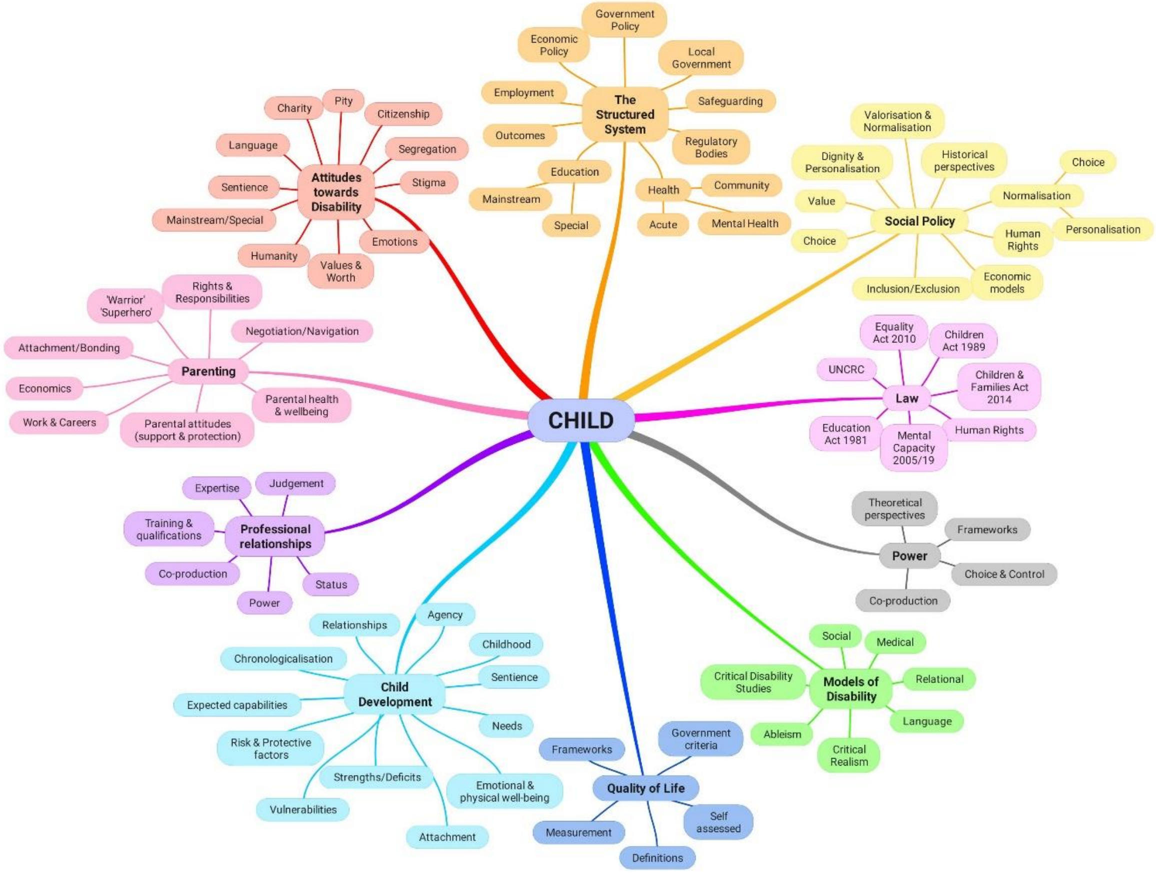


Figure 1. System Map showing context for the literature review.

In reviewing the literature, I used a mostly desk based methodology and included academic and grey literature searches. Some prior professional knowledge of the literature provided a starting point. This included analysing national legislative documents, governmental policy documents and reports, and codes of practice. Where these cited other literature I followed up to identify relevance. I was also aware of a number of seminal works in the field of disability, and children (e.g., Bowlby, Goffman, Oliver).

Electronic data base searches in Durham University's library catalogue alongside Google scholar, Taylor and Francis online, and Sage Journals proved useful. Keyword searches were applied initially. The main keywords were disabilities, learning disabilities, childhood, models of disability, institutionalisation, quality of life, power, and choice.

Journals related to my areas of interest and initially utilised included: British Journal of Social Work; Journal of Intellectual Disabilities; Children and Society; Journal of Applied Research in Intellectual Disabilities; and British Journal of Special Education. I subsequently broadened out into other discipline's journals as my knowledge increased. These included the Journal of Applied Philosophy and Journal of Child Psychology and Psychiatry .

Inclusion criteria for the review comprised material based in qualitative and/or quantitative research; literature of any publication status; and literature derived from peer-reviewed journal articles, books, book chapters, and reports. I did not apply any particular exclusion criteria initially, keeping my approach broad and applying curiosity. Age of publication exclusion criteria were not initially applied as the historical context of how disability has been understood was important throughout.

I kept notes on the literature read and used these to synthesise my understanding; linking themes as I developed my questions and applying a chronological and thematic approach. I kept a reflective log with ideas for follow up. I authored five think pieces which I used to test out arguments, key theories and concepts as well as ontological and epistemological grounds for discussion. These were shared with my supervisors who challenged my thinking at times. I continued to read academic literature throughout the development of my thesis, seeking publications that might highlight new thinking and ideas as well as scanning for new grey literature that flagged changes in policies and legislation.

The literature provided context to family narratives and my subsequent analysis. In the early stages of my research, I found some ideas challenging and radical but these became more familiar over the course of the study which modified my perspectives. The literature in relation to learning disabilities highlighted the systemic professional hegemony that families must learn to navigate to access support. Also, that parents' views can be minimised and children's even more so (Runswick-Cole and Ryan, 2019; Ryan, 2021). How this environment has developed is explored in the context of the extant literature.

2.3. Defining learning disability and understanding its prevalence

Whilst a general definition of learning disability is provided by the UK Department of Health (see Chapter 1), learning-disabled children are not a homogeneous group, although they are often labelled so. The Special Education Needs (SEN) Code of Practice stresses the importance of not assuming fixed categories of disability. Learning disabilities exist on a spectrum from mild to complex needs, which affect children in different ways; there is also a range of different conditions that can affect children differently.

Around 2.5% of the general UK population has a learning disability that will require specialist services at some point during childhood (Emerson and Hatton, 2007). The children involved in this research have some of the most complex needs in the context of disability; they are categorised within education, health and social care as having 'severe or profound learning disabilities' on the NHS continuum of learning needs; although this label is potentially problematic, as will be discussed later. In the UK, around 16% of learning-disabled children are categorised as having severe needs and around 5% are categorised as having profound needs.

Learning-disabled children will have additional support needs and requirements that may fall into one or more of four areas:

- Cognition and learning needs
- Behavioural, emotional and social needs
- Communication and interaction needs and
- Sensory and physical needs

(DCSF, 2014)

It is generally understood that many disabled children will experience a complex mix of social, behavioural, medical, educational and psychological challenges. Many will have interrelated needs. Needs that are poorly met can lead to behaviours that indicate distress or mental stress. This can be worsened if day-to-day routines are disrupted or restrictions are placed on activities that these children enjoy (Christie and Tirraoro, 2022). A poor response to children's support needs directly affects their quality of life.

2.4. Legislative context and children's services structures

To understand the professional environment that families with learning-disabled children must navigate, it is important to understand the legislative context that informs practice and service delivery.

UK children's legislation is underpinned by Human Rights Acts that are supported through regulations and statutory guidance. The European Convention on Human Rights (ECHR) is particularly significant because it has been incorporated into UK domestic law. The United Nations Convention on the Rights of the Child (UNCRC) 1989, ratified by the UK Government in 1991, is also significant in its application of key principles. Whilst these are not formally part of UK domestic law, meaning children cannot rely on them in court hearings, their spirit is woven through legislation that is related to children.

The UN Convention on the Rights of Persons with Disabilities (Disability Convention) 2009 (UNCRPD, 2009) establishes principles such as 'respect for inherent dignity' and 'full and effective participation and inclusion in society'. It clarifies that all necessary measures should be taken to ensure the full enjoyment of all human rights and fundamental freedoms on an equal basis by people with disabilities, including accessibility, independent living and inclusion in the community (Articles 3,7,9 and19).

The policy and legislative environment for learning disabilities is complex but it is critical to how we approach caring for disabled children in the UK. Four of the most essential pieces of legislation that apply to learning-disabled children in England are the:

- Children and Families Act 2014
- Children Act 1989
- Education Act 1996
- National Health Service Act 2006

The Children and Families Act 2014 (CFA 2014). Section III; described as landmark legislation that, when enacted, sought to fully reform services for children with special educational needs and disabilities (SEND); and to support parents and the family as a whole. Before this legislation, the government had determined that the existing system was insufficient for disabled children and a new approach was required. The major changes revolve around giving families better control over their children's welfare, stipulating that local authorities must involve families and children in discussions and decisions surrounding their care and education (Section 19, CFA 2014); and provide impartial advice, support and mediation services. This legislation underpins and promotes principles of co-production.

The Children Act 1989 (CA 1989). This Act establishes that organisations working with children have a responsibility to help safeguard them and promote their welfare. The welfare of the child is paramount.

Section 17 of the Act establishes the principle of a 'child in need', defined as a child who is unlikely to achieve or maintain a reasonable level of health or development, or whose health and development is likely to be significantly or further impaired without the provision of services; *a child who is disabled* (Children Act, 1989; emphasis added) Under this provision, parents can seek an assessment of their child's needs because of their disability. This entitlement to assessment is important.

Section 47 requires the local authority to make enquiries where it has reasonable cause to suspect that a child is suffering or likely to suffer significant harm. This applies to all children. The NSPCC report that disabled children and young people are at an increased risk of being abused compared with their non-disabled peers (Jones *et al.*, 2012).

The Education Act 1996. This Act establishes that all children, regardless of their circumstances, are entitled to education. It generally confirms that a child will be educated in accordance with their parents' wishes, affirming choice and control. A parent who wants their learning-disabled child to attend mainstream or special schools can refer to this Act in the assessment of the child's education needs. This Act requires local authorities to provide a suitable education for children whether they have SENs or not. The education provided must also be full-time unless the local authority determines that it would not be in the child's best interests due to their physical or mental health.

The National Health Service Act 2006. This Act consolidated all previous legislation about health provider organisations into a single Act. It is the pivotal piece of legislation establishing a right to and the provision of health services for all.

Whilst these four Acts are key, further legislation establishes some important principles in relation to disabled children. This is set out in Figure 2, which, while not exhaustive, offers insights into the legislative and procedural environment that the parents of learning-disabled children must navigate; and is relevant to this research.

Figure 2: Key children's legislative principles discussed within this research

Legislation	Key Principles	Summary of key provisions
Children and Families Act 2014	Part III	Places duties on local authorities regarding children with special educational needs and disabilities (SEND).
	Section 19, involvement of children and families	Local authorities must consider the views, wishes and feelings of the child and their parent, enabling them to participate as fully as possible in decisions relating to the child and providing the information and support necessary to enable participation in those decisions to support the child and their parent, to help them achieve the best possible education and other outcomes.
	Sections 36 and 27, assessment of special needs and disabilities	Establishes statutory education assessments and whether an Education, Health and Care Plan (EHCP) is needed to define short- and long-term outcomes.
Children Act 1989	Section 1, paramountcy principle	The welfare of the child is paramount.
	Section 17, child in need	The child's health and development are likely to be significantly or further impaired without the provision of services or a child who is disabled.
	Section 20, duty to accommodate	Every local authority must provide accommodation for any child in need within their area when the person who has been caring for them is prevented from continuing to do so.
	Section 47, duty to investigate	Local authorities must make enquiries when they have reasonable cause to suspect that a child or children are suffering or likely to suffer significant harm.
Children Act 2004	Section 11, duty to safeguard and	Requires all agencies with responsibilities towards children to discharge their functions to support the need to safeguard and promote the welfare of children.

	promote the welfare of children	
Working Together to Safeguard Children Regulations 2018	Safeguarding and promoting the welfare of children	Statutory partnership regulations intended to protect children from maltreatment and act to enable all children to have the best outcomes for their mental and physical health or development, ensuring that children grow up in circumstances consistent with the provision of safe and effective care.
Chronically Sick and Disabled Persons Act 1970 (CSDPA 1970)	Section 2, provision of welfare services	Supports the provision of equipment and adaptations that can maximise health and well-being. Applies to home adaptations and the provision of wheelchairs and other equipment.
Care Act 2014	Promoting well-being; this is mostly an adult provision	Considers principles of dignity, protection from abuse and neglect, control over one’s daily life and choices, and being able to participate in education and training. Impels local authorities to ensure the provision or arrangement of services for care and support. Considers the needs of carers, including young carers. Includes provisions for direct payments or personal budgets to enable service users to purchase services themselves.
Mental Capacity Act 2005 (amended 2019)	Protecting and empowering people (aged 16+) who may lack the mental capacity to make decisions about their care and treatment	Applies both to day-to-day decisions and serious life-changing decisions, such as those about where the person lives and what medical treatment they receive, e.g., decisions about fertility.
Education Act 1996	Section 9, all children, regardless of their circumstances, are entitled to education	Free state education for all children or, if a parent chooses the option to educate their child themselves (providing the education given is ‘efficient’).
The Health and Social Care Act 2012	Access to NHS services on the	Health and well-being boards integrate local commissioners of health and social care, elected representatives and

basis of need, not the ability to pay	representatives of Healthwatch to agree on a cohesive way to improve local health and well-being. Most NHS care is commissioned by clinical commissioning groups, giving GPs and other clinicians the responsibility to use resources to secure high-quality services.

The legal frameworks addressing children’s rights have broadly developed in three core areas: education, care and disability discrimination. These legislative frameworks can sometimes seem divergent. For instance, the law as it applies to education appears less concerned with the affordability of resources than the consistent application of the law (Booth, Bush and Scott, 2011). If a child is assessed as having a need under Education Acts, provision is generally made. If provision is denied, there is a legal appeal process for families through an Education Tribunal service. In 2020, parents lodged 7,917 SEN appeals and 95% of these were successful (Gov.UK SEND Tribunal Tables 2019/20).

For social care however, entitlement to services assessed under the CA 1989 can be balanced against pressures on local care budgets and what the local authority finds affordable; gatekeeping is permissible. There is little right to formal appeal against decisions to refuse services other than through formal, but internal complaint procedures or democratic processes, including via councillors and MPs.

In addition to the legislative context, families seeking integrated and co-ordinated support plans for their disabled children generally have two main agency partnership systems to understand and navigate: the Special Educational Needs and Disability system (SEND); and children’s social care services under the Children Act 1989 and the Children Act 2004, supported by the Working Together to Safeguard Children procedures. The SEND system is arguably dominant for disabled children, but both systems reside within and are co-ordinated by the Local Authority Children’s Services Departments created by the Children Act 2004. They are managed as two parallel processes by most local authorities in England.

In summary:

- Children’s social care services are underpinned by the Children Acts of 1989 and 2004 and Working Together to Safeguard Children 2018 guidelines. The routes to entry include a request for a Section 17 Child in Need assessment under the Children Act 1989 or Section 47 Duty to Investigate. Section 47 focuses on risk and harm. There is a tendency to push children through the social care system rather than to engage long-term.

- The SEND system, introduced through the Education Act 1981, is underpinned by the Children and Families Act 2014 and the SEND Code of Practice. Routes to entry include a request for assessment from the young person, parent, educational setting or a professional working with the family. Children who require additional support to access education may be eligible for an EHCP.

Both systems have eligibility criteria and are intended to utilise multiagency partnerships, integrating the work of education, health and social care through statutory agencies to achieve the right outcomes for children. Health services are mostly structurally separate, although local authorities have some responsibilities for public health. There is a health structure that includes GPs working with Clinical Commissioning Groups (as of 2022, Integrated Care Boards, ICBs) and community and acute health trusts. Figure 3, below, provides a simple diagrammatic overview of the key systems

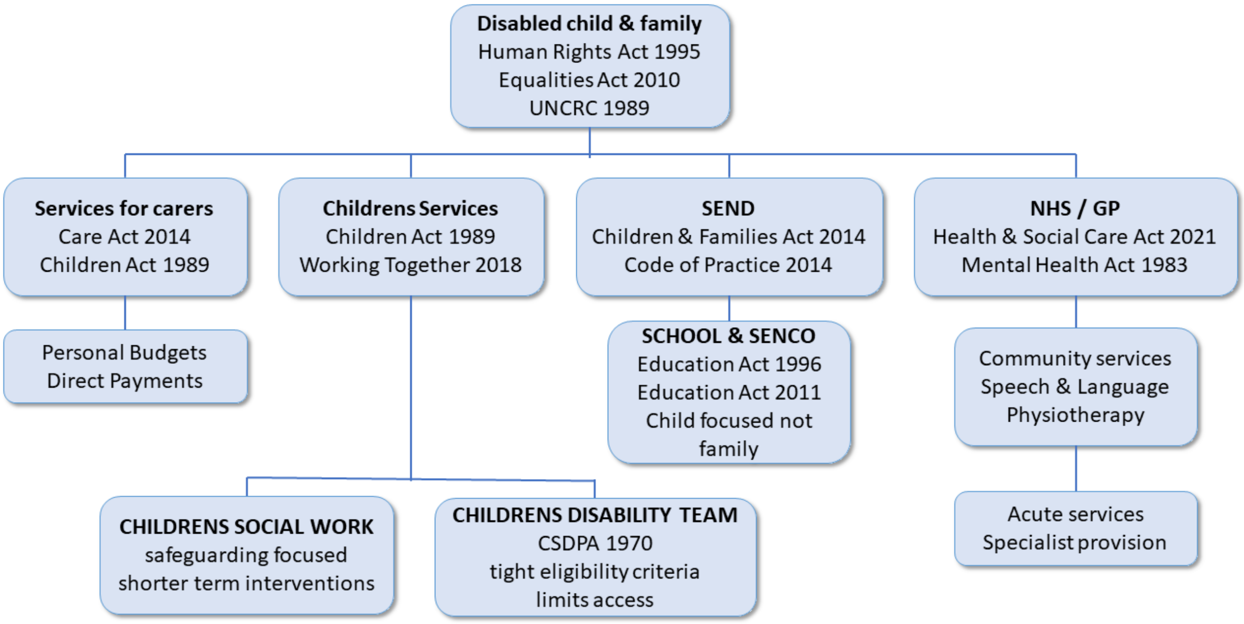


Figure 3: Service access structures and legislative context

2.5. Navigating the system

The above summary of the legislative and structural environment reveals the complexity of the system that families can be involved in. Political and societal rhetoric argues that this system is founded on human rights principles of inclusion, dignity and equality; and properly considers learning-disabled children's needs. Divergent emphases in how the law is applied however, can create challenges for families seeking to achieve the right plans for their desired outcomes.

Professional approaches can also diverge. The three main agencies of education, health and social care emphasise different outcomes. For example,

- Education services are likely to focus on a skills-based approach to enable future employability and independence, although a personal, social and health education curriculum is taught with varying degrees of success.
- Health services tend to focus on health outcomes and well-being, alongside the reduction of impairment through medical treatment models.
- Local authority statutory social care services tend to focus on risk and harm but should also plan for holistic outcomes by promoting health, education, family life, citizenship, employment and independence.

Booth, Bush and Scott (2011, p. 14) summarise the overall complexity of this environment well when they say:

> '*The current divergence of education and care law creates inherent conflict, frustration and uncertainty for disabled children and their families…… it places all parties in undesirable positions; with parents fighting for access to appropriate services, local authorities fighting for protection of their resources and children fighting for an equal position at the decision-making table.'*

The truth of this is apparent; in 2019, the Parliamentary Select Committee report about SEND concluded unequivocally that professional systems have failed to achieve the cultural change that the CFA 2014 intended. Families have been let down, resulting in:

> '*confusion and at times unlawful practice, bureaucratic nightmares, buck-passing and a lack of accountability, strained resources and adversarial*

> *experiences, and ultimately dashed the hopes of many.'* (Parliamentary Select Committee Report SEND, 2019, p. 3).

This is the context in which this thesis has been researched. This study seeks to understand what families would like to see done differently, learning directly from families.

2.6. Understanding policy through its historical context

Understanding the history of learning disabilities and how social policy has evolved is vital. It provides insights into why the contemporary environment is the way it is; and how power is held and by whom. Over the past 50 years, there have been many improvements in the lives of learning-disabled children, with more compassionate and humane understandings of disability, driven by societal change that disabled people have spearheaded through activism. The historically negative and disquieting perceptions of learning disability have become deeply problematic by contemporary standards.

In the academic literature, arguments are made though that this historical context continues to cast shadows on service delivery and societal perceptions of disabled people's value (Carlson, 2010; Campbell, 2011; Goodley and Runswick-Cole, 2011; Ryan, 2021). Contemporary ableist frames of reference still exert power over disabled people. Foucault (1972) observes how knowledge can be applied to control others. He points to the subtle way that power can be exerted through societal discourse and can structure our sense of self, thus defining the reality of our social worlds. In this sense, our understanding of disability becomes significant. Foucault notes that the understanding of constructs of being can change with time, and knowledge becomes inextricably linked to the power then exercised over us. Systemic power wielded through institutional apparatuses, such as laws, regulations, philosophical positions and morality, can be applied to regulate social conduct (Foucault, 1972). Understanding the nature of power relationships within the context and history of learning disabilities is important and relevant to contemporary family life.

Habermas (1987) explores how power affects the relationships between an individual's 'lifeworld' and 'the system'; the former is the experience of everyday life in the informal domains of social life, family and household, creating meaning and understanding in the social world; the latter is patterns of strategic action that serve the interests of institutions and organisations, which are dually driven by money and power. He argues that the system can encroach, displace and even destroy the lifeworld (Habermas, 1987 cited in Garrett, 2013). This thesis explores the context of lifeworlds and the system as families engage with them.

It is important to understand the history of disability, which provides a baseline that enables reflection on the reality of any changes achieved and how they have evolved into contemporary practice. This supports positive challenges about where change is still needed. Numerous historical overviews setting out the context of how policy about learning disabilities has shifted, changed and been successfully drawn into human rights legislation are available (O'Brien and Tyne, 1981; Walmsley, 2001; Historic England, 2012; Open University, 2016; Ryan, 2021).

Generally speaking, few academics or laypeople are likely to disagree that the understanding of and attitudes towards learning disability have improved over time, but continuing changes are needed. Indisputably, learning-disabled people have suffered the impact of stigma, segregation, othering, institutionalisation, bullying and abuse over many centuries. They have been given little choice and control over their own lives. Whilst recognising the long history of disability predating the 1900s, this literature review concentrates on developments from the late 19th century and into the 20th and 21st centuries.

The five main themes explored include:

- The use of language and terminology
- Segregation and institutionalisation
- Education
- Employment
- Eugenics

Overall, quality of life (QoL) for many learning-disabled people has improved since the 19th century, when learning disability was feared and addressed through the Lunacy Act 2013. Individuals were institutionalised, subjected to inhumane standards of care and perceived as burdens on society (Open University, 2016). Whilst improvements have occurred, there is still evidence that learning-disabled people experience institutional abuse, as the 2011 Winterbourne View and 2019 Whorlton Hall scandals indicate. The modern narrative also retains more subtle perceptions of disability as a burden on society. For instance, a 2022 Local Government Association report discusses the 'disproportionate' effect of disabled children with SENs on local authority budgets. This speaks to continuing problematic professional attitudes (Bryant, Parish and Kulawik 2022).

Research indicates that learning-disabled children experience numerous challenges. They remain isolated by social systems that are poorly tailored to their needs. They participate in fewer social activities, engaging in leisure less frequently than their non-disabled peers. One in three learning-disabled young people spend less than 1 hour outside their homes on a typical Saturday (Mencap, 2019). They tend to have fewer friends (Solish *et al.,* 2010; Taheri *et al.,* 2016), and as they get older, they can be prevented from having and enjoying sexual relationships and opportunities to parent. Liddiard (2013, p. 1), citing Brown (1994), comments on ableist cultures where learning-disabled people are assigned the paradoxical social categories of 'asexual, oversexed, innocents or perverts'. The language used speaks to continued discrimination.

2.7. Language and terminology

N.B. Some of the language described below in relation to learning disability is now considered offensive. It is used only to illustrate the discrimination that learning-disabled people have historically experienced and sometimes continue to experience.

Foucault (1972) described how the production of knowledge occurs through language and that this, in turn, can become constructional. Discourse creates meaning that then reinforces belief systems and attitudes. These can shift and change and, with historical context, evolve (Potter and Wetherell, 2004). The language used about learning disability has changed significantly over the last century.

The 1913 Mental Deficiency Act defined early 20th-century conceptions of learning disabilities. The four main categories and their descriptors indicate attitudes and perceptions of deficit. (Mental Deficiency Act 1913, Chapter 28 pp.1-2).

- The idiot, ‘so deeply defective as to be unable to guard themselves against common physical dangers’.
- The imbecile, incapable of managing themselves or their affairs, or, in the case of children, of being taught to do so.
- The feeble-minded person, requiring care, supervision, or control. In the case of children, incapable of receiving benefit from instruction in ordinary schools.
- Moral imbeciles, persons displaying mental weakness coupled with strong vicious or criminal propensities, on whom punishment has little or no deterrent effect.

People with Down syndrome were known as Mongoloids, a term coined by Langdon Down, after whom the syndrome is named. This term described the facial characteristics of some people with the condition. By the 1950s, general categorisations had changed to ‘the subnormal’ and ‘severely subnormal’, and colloquial terms such as ‘backward’ were frequently used.

With shifts in attitudes came changes in language and terminology; the descriptors of the early 20th century became offensive. By the 1980s, ‘people with mental handicaps’ became the preferred term and ‘people with learning difficulties’ was adopted by self-advocacy groups. By 1990, the Department of Health officially adopted ‘people with learning disabilities’. Other terminology now in use includes ‘intellectual and cognitive disabilities’.

Language is significant, and whilst terms such as learning disability are intended to reduce stigma and engender respect, discriminatory language about learning disabilities is still used in society. Terminology is not intended to be offensive when it is initially coined; but to offer a basic understanding and meaning of conditions. However, as this language becomes connected to underlying ableist attitudes about ‘types of people’, the language becomes loaded and, ultimately, offensive.

Historical terminology is still used more generally within contemporary society to insult, including words such as ‘retard’, ‘idiot’ and ‘cretin’. These words are casually used to denigrate others, evidencing attitudes of discrimination and othering. Unlike other terminology connected to discrimination for protected characteristics under the Equalities Act 2010, such as race and gender; the societal use of these terms is barely acknowledged or recognised as causing offence. ‘Idiot’ is used frequently and in many contexts in modern life. The continued language of ableism indicates systemic discrimination and provides insights into learning-disabled people’s contemporary experiences of stigma; as they are still perceived by sections of society as somehow nonhuman/DisHuman and lacking sentience (Braidotti, 2013; Goodley, 2021; Goodley, Runswick-Cole and Liddiard, 2016).

Recognising language is important. Van Dijk (1993) describes how dominant narratives can be established through even subtle, routine language and communication, creating a seemingly natural social order. A 2011 Crown Prosecution Service report on hate crime raised concerns about the increasing number of cases targeting disabled people. This included insults and offensive language. Equality policies have sought to change attitudes towards learning disabilities via language changes and terminology such as social inclusion, personalisation, and normalisation. Research providing insight into the success of these policies is sparse. Rees, Spreen and Harnadek (1991) suggest that attitudes towards learning disability have improved, but a large-scale study by Mencap in 2008 concluded that the general population’s understanding remains limited. Scior (2011, p. 2165) questions the extent of continued discriminatory attitudes and behaviour towards learning disability and whether they arise from ‘general low levels of awareness and more widely held negative attitudes, or rather from extreme prejudices held by a small minority?’ She argues that this is an under researched area.

Another factor to consider is that whilst the attitudes conveyed by language can change over time, new attitudes that replace them can be as discriminatory as previous constructs. Smith and Smith (2021) discuss this, pointing to underlying cultural assumptions about Down syndrome. They explore the idea of the simulacrum as a distorted representation of a person, pointing to new modern tropes of Down syndrome that replace previous ideas of being non-human and suitable for segregation in institutions (Sandino, 2003; Pace *et al.*, 2010) with new condescending attitudes. These include individuals being ‘always happy’ in a state of perpetual childhood.’ Individuals are dismissed, minimised and reduced as citizens and condemned to an existence of permanent dependence’ (Smith and Smith, 2021, p. 292). So, whilst contemporary attitudes towards Down syndrome seem more positive, they still reflect perceptions of deficit.

2.7.1 Disability labels

The National Association of Disability Practitioners (NADP) challenges the current language of disability and the continued practice of categorising people into groups by learning disability, such as mild, moderate, severe and profound learning disabilities. They argue that these groupings are convenient for planning and delivering services but do not benefit the people in the group who, via labelling, become stigmatised. Categories are constructs of how society has sought to identify and plan for particular groups of citizens. Although the language may have changed, new labels can become new discriminatory methods. Goodley (2021), contends, that some people are allowed to be considered human whilst others continue to be denied access to what he describes as an elusive category.

2.7.2. The language of family

Another aspect of language that is considered in this research is the language used about family life. Attitudes towards parents and their roles in the plans for their disabled children's lives have shifted over time. The language applied to parents in policy documents can illuminate professional attitudes towards them. A clear example of how language conveys attitudes appears within the three codes of practice for SEND published in 1994, 2001 and 2015:

- The 1994 Code refers to parents becoming anxious and defensive and recommends giving parents sufficient time and information to discuss their anxieties. Professionals need to ensure that 'parents are happy' (DfE, 1994, p.52, p.106).

- The 2001 Code refers to stress and confusion in the context of SEN and states that partnerships with professionals can be challenging; and professionals must understand how parents' needs can limit effective communication (DfE, 2001). Such views undermine the commitment to equal partnership (Mann *et al*., 2020).

- The 2015 Code discusses parents being able to participate effectively and states that there should be a sense of co-ownership with an emphasis on customer satisfaction and supporting aspirations (DfE, 2015).

2.7.3. The language of co-production

Current language about parents and young people includes describing them as ‘experts by experience’. This concept is increasingly applied in social work and by health professionals to people with direct experience using or caring for someone who uses health or social care services. This terminology is intended to enact an important reclassification from ‘service users’ denoting a less equal relationship. Recognising and affirming expertise helps to engender more equality within the working partnership between families and professionals (McLaughlin, 2009).

Co-production is linked to this language of family expertise. Co-production suggests that parents and children are included ‘not only to illustrate their experiences as service users; but also, to take responsibility for shaping their future experiences and actively participating in delivering the solutions’ (Britton and Taylor, 2013, p. 4). Family expertise is part of the rhetoric of co-production, but there are less positive descriptors of parents who speak up and seek to shape their children’s plans. This includes the narrative of the ‘difficult parent’, the ‘warrior parent’ and the ‘superhero parent’. The language of ‘the fight’ is linked to this. These tropes can lead to parents being minimised and perceived as problematic in professional systems. Being perceived as ‘difficult’ was evidenced in the 2022 SEND report *Agreeing to Disagree*, commissioned by the LGA. Within this report, a local authority leader is quoted as saying ‘If the system is set up to allow the white middle class population to challenge LA decisions, what is the point?’ (Bryant, Parish and Kulawik, 2022, p. 35). Hodge and Runswick-Cole (2008) describe how parents still fear that questioning professionals or asking for additional support or information will lead to them being perceived as difficult. In this sense, co-production does not seem to have been professionally accepted.

2.8. Segregation and institutionalisation

Historical analysis across centuries demonstrates learning-disabled people’s experiences of segregation and institutionalisation. In Victorian England, after the Industrial Revolution, disabled people were perceived as economic and social drains on society. The Christian Church sought to provide positive solutions (by the standards of the time), playing a significant role in developing the Colony Movement; a regional network of self-contained segregated ‘villages’ across the country, intended to provide often-small farm settlements:

> *'The 1913 Mental Deficiency Act specified that 'Mental Defectives' should either be closely supervised in the community or maintained in a new type of institution, the 'mental deficiency colony', providing permanent settlement for both children and adults in an isolated 'scattered village' environment.' Historic England (2012, p. 36)*

Disabled children and adults in colonies lived and were taught work-based skills to make them into useful citizens. There was little focus on their quality of life:

> *'The land our ultimate source of wealth, is largely uncultivated and tens of thousands …are sinking into degradation and despair for want of the opportunity and guidance to enable them to win a modest living.'* Turner (1997), citing the Christian Social Services Union.

Mary Dendy's Sandlebridge Colony opened in 1902 as one of the first colonies (Open University, 2016), and by 1929, the Wood Committee advocated for the formation of additional self-sufficient institutional 'colonies' to cater to 100,000 'mental defectives', regardless of age or level of disability. The NHS Act 1946 replaced the term 'colony' with 'hospital' and responsibility was transferred from local councils to Regional Hospital Boards. Although now medicalised, the system regimes remained institutional and restrictive. They offered residents little choice and control over their lives and QoL was generally poor. There was little privacy; 'patients' often slept in large dormitories and wore institutional clothing.

This shift to a hospital regime also created the focus on what came to be known as the medical model of disability, where impairment was seen as something to be both cured and pitied. Some of these institutions for children eventually became residential special schools for complex special educational needs. Several exist in 2022. Whilst regimes have dramatically changed and are better regulated, these are large institutions where 200 or more children and young people live and are educated and institutionally cared for.

Alongside these hospitals, a few therapeutic and small-group models were developed. The Camphill Movement in the 1940s and the Brooklands Experiment in 1958 are examples of more therapeutic but still institutional provisions. The Camphill Movement still exists today.

Historical context should also consider family policies. Before the 1950s, medical dominance was apparent and parents of children with the most complex disabilities were advised to institutionalise their children and get on with their lives. Parents were then minimally involved in decisions about their children, particularly their education, and were advised that their children were ineducable. Parents began to lobby the government in the 1950s to challenge these notions of ineducability.

2.8.1. Moving away from institutional care

Erving Goffman's seminal 1961 research on asylums sparked debate about institutions and their negative impact on those incarcerated within them. In the UK, the Ely hospital scandal in 1967 proved the ill-treatment of patients, identifying impoverished and squalid living conditions and an emphasis on custodial attitudes among staff (Howe Report, 1969). The Howe Report highlighted the need for fundamental structural change. Its recommendations are credited with accelerating the policy of community care and hospital closures. The de-institutionalisation narrative shifted further with the publication of the 1971 White Paper *Better Services for the Mentally Handicapped*. This laid out a 50% reduction in hospitals by 1991. Progress was slow however, which speaks to the lack of societal interest: The last NHS learning disability hospital was closed in 2010, almost 40 years after the 1971 White Paper.

The focus during the latter half of the 20th century moved towards enabling a better QoL for learning-disabled people, advocating more self-directed care, choice and control. Nirje' s (1969) and Wolfensberger's (1972) work on normalisation made 'social valorisation' influential. Wolfensberger argued that learning-disabled people should be able to experience 'normal patterns' of everyday life, living in normal, ordinary places, and undertaking 'normal' everyday activities. He recognised societal stigma towards learning disability and argued that this could be addressed through inclusion policies, creating opportunities for learning-disabled people to adopt valued social roles.

The narrative of 21st-century policies for learning disability continues to prioritise reducing institutional care and offering more mainstream community provisions. Learning-disabled children and young adults are still placed though in residential institutions in the form of special schools and colleges, Assessment and Treatment Units (ATUs) and residential group homes. This involves separation and segregation from their families and local communities; it places them at risk due to institutional practices.

Despite policies of inclusion, the number of learning-disabled children being moved into ‘specialist institutional provision’ for their education increased by 27% in 2019 (ACL, LGA, AOL and NatSpec, 2020). The 2022 UK Government green paper *Right Support – Right Place-Right Time,* argues that outcomes related to attainment are consistently poorer for children in alternative specialist provisions than for their peers; and there should be a continued push towards mainstream services for all.

In England, the use of residential institutions to care for the general population of children in public care has declined (Narey, 2016). It is difficult to assess whether the situation for learning-disabled children is the same, due to how data are collected. An unspecified number of learning-disabled children (probably in the very low thousands) live in children’s homes linked to special schools. Two government reviews commissioned in 2017 and later published as *These are our Children* (Lenehan, 2017) and *Good Intentions, Good Enough* (Lenehan and Geraghty, 2017) found that the population of children who have a recognised complex learning disability do not always fare well in planning; that there is too much reliance on residential institutions; and insufficient community support. Lenehan (2017, p. 4) comments that we have:

> ‘*followed a path which institutionalised them during their teenage years and condemned them to a life hidden from society, away from their families, at huge financial cost to the taxpayer and with very poor outcomes.’*

Residential school and college placements in England cost an estimated £500m per annum and typically cater for those with the highest needs (Lenehan, 2017). She further identified several problems with the current system.

- Vulnerable children are removed from support networks at overly young ages.
- The need for support could be predicted considerably earlier, offering greater opportunities for intervention.
- Despite this knowledge, the path to a potentially poor placement outcome is not avoided.
- Children can, therefore, become socially isolated.
- These are not economically wise decisions.

Children can reside in a school for 39–52 weeks per year. These are very significant periods of institutional care for a child. CA 1989's Section 20 'looked after' provisions to safeguard children apply to residential special schools but are not always recognised by placing authorities. Local authorities are required to report Section 20 accommodation to the government. The government regretfully recognises that learning-disabled children in residential educational settings are not included within these DfE Section 20 national statistics. This speaks volumes about these children's invisibility. Recent, not entirely reliable, estimates suggest that the total number of children in residential special schools (including children with needs other than learning disabilities) is 4,878, with a further 1,268 young people in post-16 residential colleges (UK Gov., 2020). Seeking the data to understand the level of residential care for learning-disabled young people is frustrating; they are not collected or provided in ways that offer easy access for analysis.

2.8.2. Arguments against institutional care for children

From the 1940s onwards, Goldfarb and Bowlby reviewed the damages of institutional care for children compared with family-based care, highlighting the importance of a primary caregiver for child development. The damaging psychological consequences of institutional care, and residential care in particular, have been much commented upon (Moulson *et al.*, 2009; Rutter *et al.*, 2009). Goldfarb's (1945) and Bowlby's (1959, 1980) works were particularly influential and highlighted several emotional, behavioural and intellectual impairments that characterised children who had been raised in residential care. Research suggests:

- There can be significant deficits in intellectual and cognitive development. This is problematic as learning-disabled children ordinarily face many developmental challenges;
- children in institutions can struggle to concentrate and form emotional relationships (Rutter *et al.*, 2009);
- placing children in institutions interrupts their chance for a full family life, contravening Article 8 of the Human Rights Act 1998.

Children with complex learning disabilities can be placed in residential schools to access specialist education. Schools, by nature, cannot offer consistent primary carers. Secure, warm relationships are indisputably psychologically important for any person, whether they have a learning disability or not. Residential institutions can disrupt relationships, involve more impersonal care and make emotional and secure attachments more difficult to maintain. A British 2022 independent inquiry report into child sexual abuse (Jay *et al*., 2022) reported that residential special schools recorded nearly ten times the number of concerns per student as non-SEN residential schools.

These data and anecdotally provided information evince that some learning-disabled children are cared for in residential institutions from very young ages of 11 years and sometimes younger. DfE data show however, that children without disabilities who need to be 'looked after' by the state who are under 14 years of age are unlikely to be placed in residential options (Narey, 2016). Health and care professionals typically argue that younger children who cannot live with their families are better placed in kinship or foster care; as their emotional needs and well-being are better served within a 'familial' environment (Narey, 2016). Different standards are applied to learning-disabled children.

There is no national government child-care overview of the residentially based populations of learning-disabled children. This makes assessing whether QoL is being properly addressed more difficult, rendering this group invisible. A DfE-commissioned review of children's social care published in 2022 specifically excluded the social care needs of disabled children, referring to a SEND review that was underway and considering SEN.

Annual reporting from Ofsted inspections provides some information on service quality. In 2020, 21% of residential special schools were assessed as requiring improvement to be good. Regarding general local authorities' SEND arrangements, Ofsted and CQC conducted joint inspections starting in 2016; and of 141 local area inspections published by 21 March 2022, 76 received written statements of action, indicating significant weaknesses in SEND arrangements (UK Gov., 2022). Ofsted local authority social care inspections do not consider learning-disabled children specifically.

2.9. Arguments for residential special schools

Whilst ample research describes the negative impact of residential homes on attachment for general populations of children, much of it is focused on orphaned and abandoned children who are often living in other countries with different cultural contexts. More positively, Brown *et al*. (2011) found, in a UK study, that parents reported that when their learning-disabled child attended a specialist residential school, they noted improvements in their children's behaviour and well-being, leading to their children returning home for periods. Parents commented on increased family life stability, involvement of siblings in more normal community life and improved spousal relationships, raising overall QoL for the entire family (Brown *et al.*, 2011).

Although criticisms can be levelled at institutional care, one of the defences of residential special schools is what is called the 'waking day' curriculum, in which learning is encouraged across the whole day, not only during classroom hours. This enables additional life skills to be taught, such as travel training, cooking, home-building skills and personal care. Children also have opportunities to develop more friendships. The residential system at its best is designed to offer support for those with complex conditions; and a holistic package of psychological, social and health care and education services for individualised support around a child. For some families, the pressure of coping with a child's profound learning disability makes good-quality residential options the only realistic option to achieve good integrated care solutions supported by specialist expertise (Abbott, Morris and Ward, 2001).

Debates continue about the efficacy of placing disabled children in residential special schools; with concerns expressed about their well-being and how their overall needs are being met (Lenehan, 2017; NICE, 2018). How parents feel about such decisions and why they come about is worth further exploration. Where a child lives and goes to school and who they have relationships with significantly affect their quality of life. In reality, few studies regarding learning-disabled children's residential experiences in the UK context exist. Gore *et al*. (2015) highlighted thirteen peer-reviewed research studies on residential placements and their outcomes for learning-disabled children. They found methodological quality limitations. Only two achieved maximum quality ratings, and three scored less than 50% on quality scales (NIHR 2015), highlighting that much remains unknown about this group of children.

2.10 Institutional health provision

In addition to considering the use of residential special schools, the use of health institutions is important. Mencap (2019b) reported that the number of learning-disabled children in hospital inpatient units, known as Assessment and Treatment Units (ATUs) had more than doubled from 110 to 240 between March 2015-2019. Whilst these numbers are small, they should not be ignored. The average length of stay in these units, intended to be only 6 months, is around 5 years (Mencap 2019b). They impose significant restrictions on liberty, with many recorded instances of restrictive interventions used against children, young people and adults (5,520 in May 2020). QoL can be poor. A disturbing example is that of Bethany, an autistic young person in an ATU, whose living conditions were reported to a Parliamentary Committee in 2019:

> *'She had only a foam mattress. She had nothing to do all day. She was watched and monitored by guards. She was fed through a hatch like a wild animal, like a dangerous creature. What was the crime that this girl had committed? The only thing was that she had autism, and she lived in a society that did not provide adequate community care.'* (Parliamentary Report, 2021, para. 5)

Other concerns have been highlighted by incidents where institutional care in medical establishments failed catastrophically, including Winterbourne View (2011), Whorlton Hall (2019), and the tragic cases of Connor Sparrowhawk (2013) and Oliver McGowan (2016), both 18 at the time of their deaths in NHS-based institutional services.

2.11. The case for more community support

The primary reason for using residential provisions for learning-disabled children is to enable access to special education provision, rather than for child-care or safeguarding reasons. Although legislation establishes principles of normalisation, insufficient investment in community provision has been made to achieve it. Nussbaum (2002) argues that a just society should not shrink from the cost of supporting those with learning disabilities; access is their right. Despite social policy rhetoric that speaks of deinstitutionalising services for learning-disabled people, the lack of funding and strategies for community-based support in the UK tell a different story.

Families and informal carers report dissatisfaction with community provisions (McGill *et al.*, 2006). Within community-based plans, parents are predominantly the main carers. The reportedly minimal support services they can draw upon can put unbearable strain on families, including siblings. The available research indicates that the choice to access a special education residential school is exacerbated when family circumstances deteriorate or parents believe their children's needs cannot be met locally (Hassiotis *et al.*, 2008; Barron *et al.*, 2013). In an NIHR peer-reviewed study, Gore *et al.* (2015) found that challenging behaviours are often cited as a major reason for choosing residential placement for a young person. Placements are also often out of the area (Emerson & Robertson.,1996; Pilling *et al.*, 2007).

Barron *et al*. (2013) found that 'informal care systems' for complex disabilities account for an average of around 86 hours per week of care for families and, if costed properly, would equate to circa £1,554/week. This was the most expensive element of community-based care packages, comprising 60% of the total average package cost of £2,543/week. Despite professionals' perception that residential education provision is more expensive than community-based services, the available evidence suggests that good-quality community provision for complex needs is not actually less expensive (Mansell *et al.*, 2008). This may be why community care receives limited investment. Current community care relies heavily on one parent being a full-time carer, affecting family income. They may have to abandon work or reduce their paid employment hours. Residential placements are state-funded, and whilst this is unlikely to be the primary reason for choosing the residential option, it can enable the parent to return to work, improving the family's overall QoL.

Constraints on the availability of additional community care disincentivise parents from remaining carers, given the extreme stress some families experience. The lack of funding for community-based provision indicates service commissioners' lack of foresight. This restricts families' choices and, therefore, their quality of life. Like other types of learning disability research, very little analysis of the economic costs that influence and contribute to families' decision-making is available, although it is recognised as an important part of the overall context (Lemmi *et al.*, 2016). In 2022 the Department for Education announced what they described as safety valve capital injections; providing financial bailouts for local authorities with large educational budget deficits. However local authorities will have strings attached and must make savings on SEND spending. There is a Government and local authority narrative that SEND services are too expensive; but there is little evidence of an analysis of how community based provision might better support families.

2.12. Education and Employment

Historically, learning-disabled children have been actively excluded from education at times. The 1944 Education Act judged them ineducable, which was not addressed until the Education (Handicapped Children) Act 1970 made education universal. The principle of ineducability and societal attitudes were challenged by the *Warnock Report* (1978), which asked:

> *'In the case of the most profoundly disabled, one is bound to face the questions: Why educate such children at all? Are they not ineducable? ….. Our answer is that education is…a specifically human good, to which all human beings are entitled……, no civilised society can be content just to look after these children…., it must all the time seek ways of helping them.'* (*Warnock Report*, 1978, p. 7).

The *Warnock Report* became the foundation of the Education Act 1981, promoting inclusivity. The Act states that children should be educated in mainstream schools or classes whenever possible and should receive support towards this goal. This is the basis of the modern SEN system. The *Warnock Report* recognises that the successful education of children with SEN depends on parents' full involvement (DES, 1978). Warnock argues for active parent partnerships but describes professionals as experts.

Nowadays, 21st-century discussions about educating learning-disabled children have become mired in ideologies about what inclusivity means; mainstream versus specialist provisions; and community-based versus residential provisions. Some parents feel strongly that their children should be supported within mainstream provisions, as the 1981 Education Act specifies. They contend that this is part of normalisation and inclusivity and is their child's right, arguing that it provides:

- more real-world experiences;
- opportunities to learn within a diverse group of students of all abilities;

- positive individual challenges as seeing other children achieve encourages the disabled child to also excel; and
- a traditional classroom that creates more opportunities for a wider curriculum.

Conversely, other parents of learning-disabled children argue that their children are not properly included in mainstream classrooms and that special schools are better able to meet complex needs. Policy arguments are still made for enabling learning-disabled children to access specialist education and support even when the costs are not exactly ideal (DfE, 2018; *Equals*, 2017; Imray and Hinchcliffe, 2014; Nussbaum, 2007; Pinney, 2017; Webster, 2019).

The *Warnock Report* establishes that some children may need to attend special day or residential schools to better meet their needs. The late Baroness Warnock, interviewed in March 2018, 40 years after her seminal report, argued in favour of the need for separate specialist provisions for some children. She remarked on despairing of the rigidity of arguments about inclusivity that only referred to mainstream provisions (Webster and Warnock, 2018; Webster, 2019).

Nevertheless, a fundamental principle underpinning the law is that if a parent of a child with SEN wants to place them in a mainstream setting, they cannot be denied this because the child's needs or disabilities are too great or complex (IPSEA, 2022, citing the SEN Code of Practice). Wedell (2019) argues that a flexible approach to the pedagogy of special educational needs is needed and points to Bernardes *et al*.'s (2015) contention that the fragmented system must be addressed because some families feel unsupported and that their children are not being afforded the opportunity to achieve their potential.

In England, a child with an EHCP will have a named education placement in their plan (Section 43, CFA, 2014). This could be mainstream school, day special school or college, or residential special school or college. The proportion of learning-disabled children with an EHCP who are educated in mainstream schools has decreased from 36% to 26% since 2010 (Public Health England, 2019; UK Gov., 2020). The remainder are either attending special day schools or colleges, residential special schools or colleges (circa 1.5%), or are educated at home (percentage unknown; UK Gov., 2020). Data are partial and fragmented; the DfE (2018) data do not differentiate the percentage of learning-disabled children at special day schools.

2.12.1 Employment

How employment is viewed in a capitalist economy is significant for learning-disabled people. Historically, the 18th-century Enlightenment period moved intellectual thought from a religious context to notions of rational and scientific thinking. Education became important (Campbell, 2011; Ryan, 2021). The Enlightenment coincided with the economic changes of the Industrial Revolution. People began to be measured by their ability to cope with new technological and commercial processes. Some children and most adults were expected to undertake paid employment, participate in trades and contribute to economic productivity. People with learning disabilities were considered unprofitable members of society in this context because of their lack of skills and ‘intelligence’. Consequently, they were perceived as a financial burden and largely excluded for their inability to participate in industry.

During the 20th century, attitudes shifted and legislation became more focused on engaging disabled people in the workplace with some support for training and ‘rehabilitation’. The Disabled Persons’ Employment Act 1944 sought to better provide for disabled people’s ability to secure employment. This created a disabled persons register and led to training schemes and rehabilitation programmes to enable access to work. Employers were required to recruit disabled people for at least 3% of their workforce. The reforms saw limited success; disabled people were still largely excluded from the workplace during the 20th century.

The Disability Discrimination Act 1995 made it unlawful to discriminate against disabled persons in employment contexts. The Equalities Act 2010 reinforced this. However, the success of employment reforms for those who are learning-disabled has been limited. Only a little over a quarter of adults with severe or specific learning difficulties held paid employment in 2020 (Census, 2021). Employment remains an exclusionary factor in people’s ability to participate in society; and those with the most complex disabilities are the most disadvantaged (Mencap, 2018).

Many attempts have been made to better draw disabled people into the workplace. UK Labour Governments between 1997 and 2010 focused on eliminating social exclusion through education and employment. The government aimed to enable people to live the most full, independent lives possible as members of their local communities, ensuring access to education and employment. Specifically, the 2001

White Paper *Valuing People* described a new 'Strategy for Learning Disability for the 21st Century'. The then-Prime Minister, Tony Blair, stated:

> *'What's… a real cause for concern and anxiety is that many parents of learning-disabled children face difficulties in finding the right care, health services, education and leisure opportunities for their sons and daughters. At best, they can feel obstacles are constantly put in their way by society. At worst, they feel abandoned by the rest of us.'*

These ambitions were admirable and the commentary reflects a growing acceptance of what has become known as the social model of disability, which argues that people are disabled by barriers in society, not by innate impairment.

The White Paper identified several challenges to be addressed, including:

- poorly co-ordinated services for families, especially those with severely disabled children;
- insufficient support for carers, particularly those caring for people with complex needs;
- the limited choice and control that learning-disabled people often have over many aspects of their lives;.
- their limited opportunities for employment.

Valuing People focused on work and employment skills as the route to independence and social inclusion; concentrating less on reforming social care aspects. With hindsight, the policy has been recognised for its importance; but inclusion framed through employment fails to recognise the wider context of individuals who cannot work due to their learning disabilities; but who seek alternative routes to a good quality of life. Not everyone can achieve inclusion in the economy, but a mature society seeks to support everyone on the basis of their needs, not their work (Shakespeare and Watson, 2015).

Subsequent governments have built upon the theme of linking education to employability as a policy driver. This strategy has not been successful for learning-disabled people. Overall, only 6% of learning-disabled adults who receive long-term social care support in England hold paid work (NHS Digital, 2018). A neo-liberal focus on economic productivity for those who cannot participate in paid work forces a reliance on often-inadequate benefits and family care. At least half of all learning-disabled adults live in the family home and 29,000 of these adults live with parents aged 70 or over; many of whom are too old or frail to continue as carers (Foundation for People with Learning Disabilities, 2022).

Dimensions, a UK charity supporting learning-disabled people, identified several barriers to employment.

- Employers' and fellow employees' perceptions, stigma and lack of belief in learning-disabled individuals' capabilities.
- Inaccessible recruitment processes for people with learning disabilities or autism.
- A lack of specific support and communication aids or more structured working environments.
- Limited access to transport.
- Digital exclusion.

The Equalities Act 2010 was intended to protect disabled people from discrimination. Negative societal attitudes persist however (Farrugia, 2009; Green *et al*., 2005; McLaughlin, 2019). Research suggests that learning-disabled people's reality is largely of exclusion from the workplace. Emerson and Hatton (2008) estimated, at its most extreme, that 0% of people with profound learning disabilities hold paid work. With no further evidence from more recent statistics to suggest that this has changed, it is clear that few alternatives are available to enable meaningful participation in life outside of family care. In this respect, choice and control in being able to participate in an economically productive and fulfilling life are severely curtailed.

Oliver (1990) argues that capitalism has led to the pathologisation of disability, with disabled people being controlled through exclusion and medicalisation. The rise of capitalism, with its need for a workforce defined by people's capacity to be usefully trained and productively employed, has created the constructs of 'able-bodied' and 'able-minded' individuals. Those individuals who cannot be included productively become identified as dis-abled people. The focus on employment as a route to useful citizenship remains a key neo-liberal policy driver within the UK in the 21st century. It fails to recognise that, for some individuals with complex learning disabilities, participating in paid work remains unlikely. The UK Government's 2022 green paper *SEND: Right Support, Right Place, Right Time,* comments that disabled children seek the same goals as other children, including employment in adulthood.

There has been a failure of public policy to date in meeting these children's aspirations and preparing them for normal work lives. Alternative strategies in addition to employment initiatives are required; purposeful activity is essential to well-being and a good quality of life.(Frankl 1959)

2.13. Parental employment

When considering employment in the context of learning disabilities, it is also important to recognise that the carer role required of parents affects their own opportunities for employment, thereby creating economic insecurity for the family. A parent's ability to work is restricted, but the benefits system compensates insufficiently.

Heslop (2013) argues that employment can be a difficult and unreliable route out of poverty for families with disabled children; barriers include inflexible employers, expensive childcare, and worries about losing benefits. Contact a Family (2018) highlights the financial impact of raising a disabled child, with 33% of families facing extra costs of over £300/month. Additionally, 56% of families say those costs are only partly met by disability benefits. The Joseph Rowntree Foundation (JRF, 2020) also reports that disabled people face higher costs of living. Kuklys (2006) highlights the disproportionate level of household income that is spent in families with a disabled member compared to families without.

Social policy has instilled a reliance on families as informal carers; reforms to benefits and the tax credit system have been made partially to support this. Universal credit reforms create contradictory message however, focusing on getting people back to work and setting carer allowances at paltry levels. The welfare benefits system utterly fails to cover the costs that Barron *et al*. (2013) indicated are needed for informal community care. At least one parent, usually the mother, of a child with complex needs will likely be unable to work because of the high levels of care that they provide. Parents use family financial, practical and emotional resources to supplement the lack of available services and support family QoL. Parents who cannot afford to do this may find that their children become disadvantaged. The JRF (2020) found that poverty is especially high among families of disabled children – 40%, which is more than twice the rate for families with no disabled children.

2.14. Eugenics

No historical analysis of learning disability can or should ignore the terrible consequences and impact of eugenics. Defined by Francis Galton (1883) as the 'science of improving inborn human qualities through selective breeding', the disturbing development of the eugenics movement in the first half of the 20th century still influences attitudes today (Reaume, 2014; Cameron, 2016; Goodley, Runswick-Cole and Liddiard 2016; Koch, 2000; Ryan, 2021).

The eugenic philosophy of social Darwinism applies concepts of natural selection within the context of sociological, economic and political thinking. Ideas of positive eugenics encouraging so-called 'good heredity' traits are promulgated whilst negative eugenic programmes consider how to control 'poor heredity' traits. This involves a general view that some people are so disabled that their deaths are preferable to continued life, judging people as 'better not to have been born' (Pernick, 1996, p. 15). A sense of aesthetics and disgust for those who deviate from the norm is linked to this.

In the early 20th century, this belief system proved catastrophic for learning-disabled people. US psychologist Henry Goddard (1866–1957) claimed that 'feeble-minded people' were multiplying at twice the rate of the general population; which were leading to more feeble-minded children; and these would clog the wheels of human progress. Negative eugenics led to beliefs about sterilisation, segregation and institutionalisation (Koch, 2000).

During the 1930s and 1940s, national campaigns for voluntary sterilisation (*Brock Report*, 1934) became linked to economic productivity models that presented people with cognitive challenges as drags on the national economy. Learning-disabled people were feared for carrying genetic factors that were deemed socially undesirable. Sterilisation became a 'reasonable' social intervention. Notable socialist intellectuals, including the Webbs, the Fabian Society, Beveridge, Marie Stopes and John Maynard

Keynes, supported eugenics as scientific progress. Open discussion declined significantly after 1945 due to the links between eugenics and Nazism.

Times have changed, but although it is uncomfortable, forms of eugenics still affect 21st-century practice and societal attitudes. In recognising its impact on the fundamental rights of disabled people in the 20th century, it is important to consider whether similar attitudes prevail in contemporary, 21st-century society. Negative attitudes about individuals' worth affect not only their quality of life but can arise problematically in relation to questions about choice and control of fertility; and who is prioritised for medical care.

i. Contemporary attitudes and 'new eugenics'

Human rights legislation, inclusion policies and societal education reflect improvements in societal attitudes towards learning disabilities. Whether this has fully challenged real-life everyday institutional discriminatory behaviour is under researched (Scior and Werner, 2015). Sadly, learning-disabled people continue to evoke negative reactions, including feelings of revulsion, pity and charity, sometimes being perceived as 'non-human'. Goodley (2011, p.722) comments, 'the disabled subject becomes framed as the antithetical other to the desired ableist norm so cherished by contemporary society'.

Goffman's theory of social stigma describes attributes that are perceived as socially discrediting in a particular way, leading to others classifying an individual as undesirable; a rejected stereotype rather than an accepted, normal one (Goffman 2009). Goodley, Runswick-Cole and Liddiard (2016), citing Kittay (2011), point to how society still describes and responds negatively to those with 'severe cognitive impairments', arguing that learning-disabled people still experience the stigma of being perceived as less sentient and lacking autonomy.

Whilst the eugenics of the early 20th century is now rejected as a philosophical position, disability activists argue that institutional ableism still enables 'new eugenics'. Campbell (2015, p. 56) comments that *'matters of eugenics are inherently ontological and positioned within the realm of human subjectivity. There may no longer be overt discussions about compulsory sterilisation, but discrimination occurs in other ways, including human fertility policies that can end or limit life and some health-care practices, which have huge negative impacts on learning-disabled people.'*

ii. Antenatal screening

Disability activists argue that modern eugenic practices are more covert, with the government and professionals apparently playing a less direct role. However, social pressures and the eugenic attitudes of clinical geneticists in most countries result in eugenic outcomes despite the lack of state coercion (Campbell, 2015). King (1999) argues that prenatal testing, as supported by health policies, aims to reduce the number of people with genetic disorders. Individuals are encouraged to engage in antenatal screening with notions of normalisation and making ‘the right decisions’. Because of advances in genetic medicine, disabled people can be seen as abnormalities and invalids rather than as citizens, perpetuating a medical model of disability rather than a social one (Shakespeare, 2011).

UK law allows babies screened during pregnancy and found to have genetic conditions such as Down syndrome to be aborted up to full term. This has been described as a form of new eugenics that reflects ongoing discriminatory attitudes about disabled people having lives that are less worth living (Brown and Schippers, 2019). Shakespeare (2011, p. 39) argues that the permissibility of late terminations even when the diagnosis is compatible with life, sends the message that ‘it is better to be dead than disabled’.

Additionally, new technologies that are available through fertility treatment, including pre-implantation diagnosis and embryo selection, embryo engineering and gene therapy convey messages about what is desirable in humans and what is not. The onus is placed on individuals to use an overarching framework of ‘risk-assessment’ and ‘positive eugenics’ in their decision-making. The provision of genetic diagnostic testing of embryos is subject to controversial individual, religious, medical, economic, cultural and ideological interests (Bouffard, Viville and Knoppers, 2009).

iii. Covid-19

Disability rights activists have also argued that new eugenics are evident in the societal response to the Covid-19 pandemic. Ktenidis (2021), citing Liddiard (2020), describes the ontologically violent messages during Covid-19, where daily announcements of Covid-19-related deaths triggered different reactions depending on the group the person belonged to; if disabled, then their death made sense and was expected. However, if the person did not present any features of vulnerability, e.g., a young, healthy, able-bodied person, their death came as a surprise and so was somehow much more newsworthy and tragic.

Wolfensberger (2005) controversially describes the notion of ‘death making’ to reflect the many ways, from direct to indirect, in which people’s lives can be abbreviated and where notions of utilitarianism (what yields the most benefit for the least cost) become more important than higher values of altruism, concern for others and the common good.

The confidential inquiry into the premature deaths of learning-disabled people (CIPOLD, 2013) for reasons other than Covid-19, identified significant differences in the mortality rates of learning-disabled people compared to the general population (Ryan, 2021). Learning-disabled people often suffer premature deaths due to not receiving the services they require; in this respect, their lives are abbreviated. The sanctity of life becomes important in these situations. During the Covid-19 pandemic, there were significant opportunities to measure how learning-disabled people fared; how their lives were valued and how their quality of life was supported compared to the more general population. Covid-19 drove every citizen to face the possibility of their own early mortality. The virus affected the able-bodied norm, and for many, it was the first time they had faced a real and imminent threat to their well-being and longevity.

Responses during the pandemic brought into sharp relief the value placed on learning-disabled people within the UK. Public Health England (2020) reported that people with registered learning disabilities died with Covid-19 at a rate that was 4.1 times higher than the general population after adjusting for other factors, such as age and sex. However, as not all deaths of learning-disabled people were registered in databases, the real rate may have been as much as 6.3 times higher. Deaths were also spread much more widely across the age spectrum. The death rate for learning-disabled people aged 18 to 34 was 30 times higher than that of those in the same age group without disabilities.

After the first lockdown in March 2020, the UK government focused on medical priorities as they contemplated the NHS being overwhelmed with patients who had contracted the virus. Inevitably, this led to discussions about the prioritisation of medical treatment. In this context, the National Institute for Clinical and Care

Excellence (NICE) issued guidelines based on the idea of frailty scores. If the system became overwhelmed, those with the highest scores would not be prioritised and would receive palliative care at home. In the drafting of the frailty scores, learning-disabled people were automatically given higher scores; meaning they would not receive specialist life-saving treatment regardless of their health or age profile.

The NICE guidelines raised serious questions about discrimination and can be viewed as an example of Wolfensberger's 'death making' in the life-abbreviating impact they could have had on some individuals. Braidotti (2013) describes how the concept of humanity has been monopolised by a political ideology that recognises some more than others. She comments that whilst all citizens are human, some are more mortal than others and some are more disposable.

The NICE framework was successfully challenged in court, resulting in guidance that learning disability in itself was not a reason to withhold treatment and that the scoring system should not be applied to children.

The long-term impact of Covid-19 on whole populations remains unclear at the time of writing this literature review; however, evidence is already beginning to emerge that those who are learning-disabled have not fared well. This is when measured by several other factors, including their mortality, education and how they were supported through periods of lockdown and self-isolation.

2.15. Conclusion

In this chapter, it's argued that it is important to consider how learning disability is perceived within society; and what the literature tells us already about how learning-disabled children and young people and their families experience a system that is technically designed to support them. The latter part of the 20th century saw shifts in belief systems to focus on respect, a right to dignity and increasing choice and control for the individual, but the literature suggests that much more progress remains to be made for learning-disabled children.

The contemporary context has been explored and evinces that the historical context still echoes across practice, despite fundamental changes for the better. This literature review chapter helps to contextualise the complex environment that families must navigate to achieve the desired outcomes for their children.

Chapter 3: Constructs and their Intersections

3.0. Introduction

This chapter forms the second part of the literature review. Within this research, several social constructs are considered that inform our understanding of how learning disability is perceived societally and professionally; as well as how these intersect and affect families seeking the best quality of life (QoL) for their children. Understanding the theoretical basis of social constructs and how they underpin ideas that are widely accepted within society, thus becoming societal rhetoric, makes examining the development of meaning within societal discourse possible. It supports exploring the basis of shared assumptions about the experiences of disabled children.

This chapter explores the factors that can influence and shape families with disabled children's experiences. It focusses on key constructs that are considered influential from the literature review and discussions with families. These constructs are explored and discussed, and include:

- Childhood
- Parenthood
- Quality of life (QoL)
- Power (choice and control)

First however a commentary is provided on how disability is understood in contemporary times by professionals and why a Critical Realist perspective of disability has been applied to this study.

3.1. Understanding Disability theories

A non-disabled researcher's place in critiquing disability models and theories built from the lived experiences of disabled activists and academics must be clarified from the outset. Ryan (2021) cites Goffman (1963) in his categorisations of the 'sympathetic other'; the person who is ready to adopt the standpoint of an individual and their position without having direct experience themselves; and 'the wise'; the individual who undergoes experiences that inform their understanding and give them rich insights. This researcher's positionality inhabits a space between these two categorisations and seeks to both 'sympathetic' and 'wise'.

As discussed in the previous chapter, societal understandings of disability have shifted hugely. Disability activism has challenged and reconstructed understandings of disability; engendering change and reflecting universal human rights and impacting on social policy and legislation. This has been informed and shaped by the development of different theoretical concepts of disability (ontology) that have evolved into a theoretical body of knowledge and meaning (epistemology). These continue to generate political, academic and professional debates about the nature of disability. The canon generated from differing academic perspectives of disability continue to make for impassioned discussions. Watson (2012) argues that models can be problematic because researchers get bound up in a particular ideology. Haegele and Hodge (2016) comment that conceptualisations of disability are important though because they influence and are influenced by professional organisations and individuals who have the power or authority to establish definitions in society.

In this thesis critical realist perspectives underpin later discussions about disability when drawing on families perspectives. Critical realism offers a qualitative theory of causality (Roberts 2014), which is relevant to this study. Recognised here though are differing academic understandings of disability including more constructionist positions; significantly the social model (Oliver, 1983), which is discussed in more detail in paragraph 3.2, and contrasted with the medical model because of their combined influences on contemporary health and social care practice.

Other constructionist perspectives should also be acknowledged for their significance. Critical disability studies (CDS), as an example, has sought to analyse the inter relationship between disability and impairment in terms of knowledge and power (Meekosha and Shuttleworth, 2009). CDS deconstructs ideas about disability and investigates how the ideologies that surround disability have been constructed (Vehmas and Watson, 2014). Equally, Ho (2008), and Campbell (2012), explore ableism and adopt constructionist positions arguing societal attitudes devalue or differentiate disabled people in valuing able-bodiedness and equating it to normalcy. These bodies of work challenge the social norms that define particular attributes as impairments that leads to stigma being attributed to different populations (Schalk, 2017). However, the exploration of disability needs to understand individual experiences as well as social and economic circumstances and these constructionist models do not fully engage with this (Shakespeare and Watson, 2010; Vehmas and Watson, 2014). Critical realism offers an alternative analysis in recognising societal impacts but also focuses on how the physical embodiment of disability is understood and what bodily pain and discomfort means for many disabled people. This discussed in more detail in section 3.3.

The next section however focuses on the social and medical models of disability, because of their continued influence on current health and social care practice. It is argued later in this thesis that they maintain cognitive authority for professionals. Command over the knowledge within a particular field over time becomes the cognitive authority (Brittain, 2004). This can maintain structures of control and exclusion (Meekosha and Shuttleworth, 2009). When positively applied, knowledge can influence government, policymakers, and society to develop better responses to meet the support needs of disabled children and adults. Similarly, though negatively applied it can contribute to maintaining existing inequalities.

3.2. Medical and social models of disability

In any discussions then about the ontology and epistemology of disability the significance of the medical and social models of disability should be recognised. These two models are possibly still the most strongly established discourse in contemporary professional disabilities practices. The language of the social and medical models is woven through governmental policies, professional guidelines and agency accountability systems.

Medical discourses of disability developed as doctors and scientists replaced religious leaders in establishing their authority and power to define disability through their knowledge of biology, treatments and cures (Brittain, 2004). Early 20th century thinking reflected in the medical or biomedical model, presents disability as a personal problem that is directly caused by disease, trauma or other health conditions (Hunt, 1981; Oliver, 1983; Macdonald and Deacon, 2019). The medical model became a measure of human pathologies, developing notions of function and dysfunction where impairments caused by disease, injury, or health condition have come to frame what we understand as normal; thus, disability becomes linked to dysfunction (Fitzgerald, 2006; MacDonald and Deakin, 2019). Medicalisation supports interventions in the form of individual professional treatment with an overall aim to ‘cure’ the individual. Alternatively, it seeks an adjustment to the individual’s condition to become ‘more normal/typical’ and to ‘overcome’ the disability.

The social model of disability offers an alternative construction of disability challenging the limitations of the medical model. Mike Oliver (1983), building on the disability activism of the UPIAS in the 1970s, identified disability as a social construct, arguing that assessing and labelling individuals separates and ‘others’ them for deviating from the norm (Oliver, 1983; Hunt, 1991; Finkelstein, 1996). In this sense, difference is not valued (Goodley, 2015). The social model has reinforced the view that disability results from the organisation of society rather than from individual premises (Bengtsson, 2017). It further argues that solutions should not be directed at individuals but rather at society (Haegele and Hodge, 2016).

In the social model ‘disability’ and ‘impairment’ are separated. Disability, defined as a social construct, highlights the disadvantages or restrictions caused by social organisations that do not account for people’s impairments (abnormalities of the body or conditions) and thus exclude them from community life (Goodley, 2001). The problems disabled people experience are within the environment; an environment that fails to accommodate people with impairments. Thereby society fails this population (Haegele and Hodge, 2016).

Oliver (1996) refers to the writings of Marx in discussing the barriers for disabled people attributing them in part to the economic structures of society. Capitalism produces certain social categories and standards of performance, making people with disabilities requiring of institutional support which becomes a deficit model. It is argued that if barriers to inclusion are created by society, rights to participation and equality must be promoted and responsibility placed on society to remove those social barriers (Oliver, 1983, 1990, 1996; Finkelstein, 1996; Bengtsson, 2017).

That people with impairments become disabled by society has become significant in professional discourse. Addressing societal barriers has become firmly embedded over time in professional practice understandings of disability. Mitra (2006 p.237) discusses the dichotomy of the two models and points to the key principles which in relation to the social model recognises the oppression of disabled people who *“face* *discrimination and segregation through sensory, attitudinal cognitive, physical, and economic barriers. Their experiences are therefore perceived as similar to those of an oppressed minority group'* whilst *"The major concern of the medical model at the political level is to provide health-care and rehabilitation services"* to improve life quality. Mitra (2006) recognises the medical model is criticised because of its commentary on what is normative thereby placing deficit in the individual. An example is the medical model's influence on the classification of special educational needs, including the 'mild, moderate, severe and profound' labels. Such classifications exemplify disabled children as deficits from the norm and are seen as problems. Palmer and Harley (2012) comment that, in an educational context, the medical notion of fixing some conditions incentivises segregated special education classrooms.

For medical professionals though the application of the social model can be difficult to understand; particularly for those in the fields of treatment and rehabilitative services, where medical interventions relieve suffering and pain. They are asked to move from prioritising care, to helping disabled people take control of their own lives. Feely (2016) cites Vehmas and Watson (2014, p.649) who argue that certain impairments for example, motor neuron disease and depression are undesirable 'not merely because of the cultural representations attached to them but because these conditions cause suffering irrespective of one's cultural environment'. Understanding the nature of the interrelationship of easing pain and prolonging life whilst also removing barriers to participation, continues to be professionally challenging but very relevant.

There is no question that the medical/social dichotomy is still a significant contributor to professional and policy disability discourses. The social model in particular has been hugely influential in professional practice in health, care and education, and also powerful in challenging societal understanding of disability. As a political model, it focuses on needed societal changes, separating societal and individual responsibility. Oliver's works (1990, 1996, 2016) make a foundational contribution and have hugely influenced working practices, Critiques of the model have argued however that it insufficiently recognises individual experiences or embodiments of disability; and how these physically and emotionally affect the disabled person. Its proponents counter-argue that it does recognise the need to reduce pain, suffering and to maintain life but that the political is important and must be addressed. Understandings of disability continue to evolve and also to explore the interactions amongst the individual's personal characteristics, available resources, and the physical, social, economic, and political environments (Mitra 2006).

It is not difficult to evidence in applying a simple internet search and using the terms social and medical models of disability, that the medical/social dichotomy has become something of a conventional theoretical canon within organisational and policy systems. They are deeply embedded in professional understanding. Shakespeare (2010) comments that since the Disability Discrimination Act 1995, most statutory and voluntary organisations have adopted the social model approach. In its success, it has become something of a sacred cow, an ideology that has not been easily challenged (Shakespeare and Watson, 2015). The model has consistently been applied to train many social workers and professionals (Barnes and Mercer, 2004; SCIE, 2022) and has been included in the delivery of disability equality training in the UK (Gillespie-Sells and Campbell, 1990; Rieser and Mason, 1990).

There is actually something of a false dichotomy between medical and social models, the former often represented as bad and the latter as good; but both have relevance. Ton *et al*. (2021) argue in order to synthesise the relevant elements of these two models, some interactional models have emerged over time. They comment that one of the most well-known and influential interactive models for professionals is the International Classification of Functioning, Disability and Health (ICF) developed by World Health Organisation (WHO 2001). This encompasses human functioning across three levels: the body level, the personal level, and the social level.

3.3. An alternative perspective: Critical Realism

Whilst acknowledging then the historical importance of the social model, and its value in challenging structural inequalities; its critics argue that the experience of disability is much more complex. Professionals and policy makers in simply applying the social model will adopt an incomplete and unsatisfactory account of disability which can be criticised for its narrowness (Crow, 1996; Shakespeare and Watson, 2001; Thomas, 2004; Shakespeare, 2014; Feely 2016). Shakespeare (2008) argues that developing more adequate understandings of disability phenomena and improving the quality of life for disabled people are linked and urgent concerns. He discusses how disability research in the UK, can be blocked by an unhealthy reliance on the social model of disability and an unquestioning faith in the benefits of identity politics, Shakespeare and Watson (2002, p.19) comment:

> *‘(disability) is so complex, so variable, so contingent, so situated, it sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality.’*

Owen (2015), points to the development of critical realism in offering a way of bridging the gap between chronic illness and disability, and of avoiding disagreements over the social and medical models. With its concern regarding the nature of causation, agency, structure, and relations, and the implicit or explicit ontologies that we operate within (Archer *et al*., 2016), critical realism provides an approach where the ‘mediatedness of knowledge…is stressed’ (Sellars, 1927: P. 238). It offers a focus on plurality and different relational forms. Arendt (2003) highlights these experiences of plurality; that humans are all separate individuals. This plurality requires an elaboration on the complexities of disabled people’s experiences. To incorporate them into one collective social understanding becomes exclusionary by obscuring the granularity of each individual’s experience.

Critical realism recognises then different levels of reality: an empirical level, consisting of our experiences; an actual level, consisting of events and phenomena; and a real (or deep) level, consisting of a multitude of mechanisms and structures that sustain and generate actual events and phenomena (Bhaskar, 1975). Bhaskar’s original works offer up a multifaceted account of disability, enabling a multiplicity of levels including biological, socio economic and cultural considerations (Danermark 2002; Feely 2016). This multiplicity works well within qualitative study which is mapping out a theory of causality (Roberts 2014). Bhaskar recognises that the world is a complex system determined by a multitude of factors (Ton *et al*., 2021). These realities can be stratified into the physical, the biological, psycho-social, socio-economic, cultural and normative (Danermark 2002; Bhaskar and Danermark 2006). In this respect disability is therefore more than a social construct.

Critical realists argue that disability in its embodiment involves the integration of emotional, physical and societal experiences. These are determined by both internal and external circumstances (Bhaskar and Danermark, 2006; Shakespeare and Watson, 2001). Shakespeare (2014) also highlights a number of intrinsic factors in relation to disability including the nature of impairment, the individual’s attitudes towards it, personality factors and structural or extrinsic factors including others’ attitudes, the environment, support systems and social or economic issues. He comments:

‘*It is the interplay between these factors that make up the disabled experience, or in short “people are disabled by the society ‘and’ their bodies”’* (Shakespeare, 2014, p.74).

Ton *et al*. (2021) argue that Bhaskar’s ontological and epistemological approach informs understanding of how the structures and mechanisms that disabled people have to navigate also interact with people’s individual agency. Human agents and social structures are ontologically distinct entities. However why and how a person takes a particular approach is determined in part by their social context and relationships (Sen, 2009). Whilst social and cultural structures will certainly impact for individuals, the way they exercise personal agency can challenge and ultimately transform those structures. Critical realist approaches seek to get beneath the surface of a set of circumstances and explore the inter relationships between human agency and structure making them relevant to this study.

Danermark (2001) recognises that disability research where underpinned by principles of critical realism will require elements of differing interdisciplinary understanding; including social, psychological, biological and molecular sciences. Different academic and professional disciplines apply different ontologies linked to their own understandings of the world. This involves for the researcher reflexively understanding and analysing problems at different levels and through the lens of different ontological perspectives.

In recognising this latter point my approach, informed by my own inter-disciplinary professional background, seeks to be holistic. It is informed by critical realism; considering the multi-faceted experiences of different family members caring for a learning disabled child; and inquiring into the nature of things including individual agency, structures and relations.(Archer *et al*., 2016). Qualitative methods are applied to understand families’ breadth of experiences and in seeking to understand the layers to explain the phenomena of inter relationships between human behaviour, values and feelings and how these interact with professional and societal systems, structures and processes.

Reflexivity is applied to the study which leads to questions about the causal relationships linked to different aspects of social relations. Whilst an interdisciplinary research project will consider the same phenomena, understanding of those phenomena can be manifest in different ways dependent on different understandings of reality. The differing understandings and theoretical perspectives about disability from different agency disciplines can impact on the children's and families' experiences. This is an important point to consider for this study where the interdisciplinary nature of learning-disabled children's experiences across education, health and social care are explored. It can impact through different understanding about 'what is right' for disabled children according to different professional disciplinary viewpoints.

3.4. Intersectionality: disability, childhood and parenthood

It is evident from reviewing the literature that disability research has engendered different and evolving conceptualisations of disability. Theoretical perspectives have increasingly drawn on achieving social justice and civil rights, whilst understanding the impact of physical and embodied experiences of impairment and of ableist societal responses.

The literature on disability tends to predominantly reflect principles of adult agency. That disabled people should not be disenfranchised or prevented from articulating what is important and meaningful for them. Key aspects of theoretical perspectives already discussed will equally apply to disabled children. Watson (2012) comments on the considerable body of research that suggest that disabled children and their families are subjected to persistent discrimination and disadvantage, citing Emerson and Hatton (2007). Currently though, no disability models focus on a full framework for understanding the experiences of disability from the perspectives of children and their families and this requires further exploration. Many disability models have been developed in work with disabled adults; attempts have been made to apply them to disabled children but their experiences may be different (Watson, 2012).

There are also differences in how disabled children's rights are understood. Even within the general juvenile population these are not always well served and the concept of the agentic child is still not fully accepted societally (James Jenks and Prout 1998; Sorin and Galloway 2006; Watson, 2012; Clark and Richards 2017). Whilst social science researchers have increasingly recognised the agency of children, giving them relational agency with a right to participate in decisions about their lives (Watson 2012; Connors and Stalker, 2007); within health and social care practice the widely applied developmental models of childhood do not comprehensively support ideas of agentic children. All children can be disenfranchised by this but there are particular inequalities for learning-disabled children where their sentience, as well as their apparently delayed development, is sometimes questioned (Sapiets, 2021).

The experiences of a child's disabilities affects not only the child but also their parents. Children are very reliant on parents and carers throughout childhood, theirs is usually a deeply symbiotic relationship. New family models that explore what it means to be a disabled child are needed. These explorations should intersect with societal constructs about what constitutes a good childhood, and also models of parenting, as these are complementarily integrated. Children generally depend on their parents. They navigate their juvenile worlds with the support of parents or carers who advocate for them and make key decisions on their behalf, until they attain the capacity to make their own decisions. Intersecting the experiences of learning disability, childhood and parenting therefore becomes very complex.

Equally it should be recognised that societal and professional attitudes exert different effects. For instance, a disabled child naturally relies on the parent in a child-caring relationship. The social, cultural and political contexts surrounding care are important to understanding its significance (McLaughlin, 2006, p.1). 'Caring' in the context of adult disability has become a potentially pejorative term that patronises and pathologises disabled adults who do not seek 'care' but independence (McLaughlin, 2006). For all children though, disabled or non-disabled the care of a parent figure is crucial. Yet the parents of disabled children can find themselves criticised for both caring too much and creating dependency; and caring too little by seeking services. There is an argument for a wider family systems approach to understanding nature of care in relation to childhood disabilities.

A further aspect of learning-disabled children's experiences are expectations about reaching typical developmental milestones. Developmental expectations can become problematic and sometimes negatively impact on both children and their parents. Societal expectations for parents of disabled children, particularly mothers, often translate into expectations that they become experts in caring for different conditions; and to abandon their aspirations and life plans to become carers (Runswick-Cole and Ryan 2029; Ryan 2021).

Macdonald and Deacon (2019) argue that new theoretical waves will arise within disability studies, and qualitative investigations will develop understandings from disabled people's experiences to inform professional practice. Even a basic exploration of childhood and parenthood soon raises questions about what society believes constitutes a good childhood; and then what is expected of a good parent. In this context understanding disability through the perspectives of childhood and parenting experiences within families is important. This is a gap this study seeks in part to close. The next two sections develop the discussion further in relation to intersectional issues of disability, childhood and parenthood. It considers the literature on conceptualisations of childhood and parenthood in the UK context.

3.5. Constructs of childhood

Children have a special place in UK policy considerations. Watson (2012) comments in the context of disability studies and childhood, that social studies within both disciplines share some common themes including a desire to present children as active agents with rights; who able to participate in choices about their own lives. A good childhood in the UK is now likely to be assessed by policymakers in terms of what equates to a societal understanding of a good QoL. To achieve this, the Children Act 1989 states: '*that the best interests of the child must be paramount in all decisions and actions that affect them'.*

Aynsley Green (2019) and Layard and Dunn (2009) argue that British children in many respects have never lived so well; with better homes and access to education, more possessions and greater possibilities for access to knowledge, travel and technology than their grandparents' generations. However, in terms of outcomes, the UK has some of the poorest in the developed world regarding mental health, general health, social care, youth justice and poverty. Children's voices are rarely heard, particularly learning-disabled children's (Aynsley Green, 2019).

Wyness (2019) argues that childhood being a social construct means that its study can illuminate wider issues in society. How we treat our children, and more, how we treat disabled children, speaks volumes about our priorities. Discourses of childhood should be understood as cultural narratives that are steeped in political and social meanings. Notions of what constitutes a child and defines childhood have changed with time. Society no longer sees children as economic assets, an insurance policy for their parents against old age, as in Victorian times. Instead, in the Global North, they are perceived as individuals to be nurtured, invested in and given optimum chances to enjoy good lives and, ultimately, to develop into well-balanced, healthy and economically productive adults. This notion of 'economic productivity', as discussed in Chapter 2, is problematic in the context of learning disabled children.

In most cultures, childhood is seen as a form of apprenticeship, a transitional stage for adulthood. The child, in their immaturity, is viewed as incompetent, so adults must assume responsibility on behalf of the child. Within the United Kingdom, this patriarchal model still heavily influences the sociological context of childhood (Cooke, 2018). In addition, universal developmental models of childhood continue to be influential particularly within health and social care, where individual children needing to achieve certain milestones is still used to assess their progress. How and when they achieve these, along with notions of risk impact for parents in how good their parenting is perceived to be by professionals. Developmental models are being increasingly contested though as social science informs understanding. Professionals are beginning to apply relational agency for children in decisions about their lives (Sorin and Galloway 2006, Bolin 2019). Regulatory bodies build into their inspection processes the child's rights to influence decisions about their lives. This remains a work in progress however, and childhood agency is still not meaningfully integrated into some professional practice. There is evidence that disabled children are particularly disenfranchised. Societal attitudes towards learning disability and doubts about sentience mean notions of agency are often hugely aspirational at best, or unrecognised at worst. Gangneux *et al*. (2019) argue that for disabled children and young people, the professional focus tends to be on them being at risk; their agency is ignored and this can be in contrast to their non disabled peers.

Sorin and Galloway (2006) in developing more contemporary ideas of childhood point to constructed notions of childhood developed, perpetuated and contested by powerful adults who act and speak on behalf of politically and economically disenfranchised children. They describe co-existing societal childhood constructs which include, the child as innocent, the out-of-control child, the child as adult-in-training, the child as commodity and the agentic child

They argue the ideal is an agentic child, a ‘social agent’ in relationship with adults, where power is shared. This rejects notions of children’s passivity and innocence (Woodrow, 1999; Fasoli, 2001). Ebbeck & Waniganayake (2016) equally contend that children can learn to express their views, make decisions, and participate as citizens and change agents. All children develop understandings of the social world as they grow, but these take time to fully form. Children will experience many social actors in the process of making decisions about their lives, including parents and professionals; research highlights that disabled voices have traditionally been associated with social exclusion and marginalisation (Finnvold, 2018; Koller, Le Pouesard and Rummens, 2018; Griffin, 2020). This marginalisation continues to impact for learning-disabled children and their perceived agency.

Cockburn (1999), cited by Wyness (2019), argues that it can be difficult for children to be seen as fully constituted members of the social world as their lack of ontology makes meaningful participation and status in involved decision-making difficult. Whilst children may generally lack a meaningful stake in society because of perceptions of their inherent immaturity (Cockburn, 1999; Wyness, 2019), patriarchy and stigma perpetuate negative beliefs about learning disabilities and children’s capabilities in some professionals (Walkerdine, 1993).

James, Jenks and Prout (1998) contend that ‘disability’ is frequently omitted from discussions about the voice of the child, and different characteristics are often ignored. Disabled children are treated as a homogeneous group, and there are risks to applying common meanings for all children. The differences within groups of children and the ‘variety of childhoods’ they experience must be explored (Levin, 1994, cited in Davis, 1998). Society must continue to seek to understand and respect that disabled children have valid views, ideas and rights to participate as citizens without discrimination or stereotyping by those who do not understand them.

Griffin (2020) recognises that professionals are increasingly encouraged to listen more to the voices of children. By trying to understand a child's rich world and culture, we understand better their choices and decisions. She argues that there should be a process of encouraging children's participation by treating it as a significant learning opportunity for a disabled child; this can engender greater levels of personal control and move them towards higher levels of empowerment. She points to the development of models of empowerment of disabled children and encourages their greater use, despite the evident barriers to this practice.

3.5.1. Developmentalism and special needs

The need to listen to children's and young people's views is increasingly incorporated into legislation and policy documents (CFA, 2014; Ofsted Framework, 2019). This change reflects valuing children's contributions within society, recognising their role as citizens whilst assessing how to meet their needs. Professionals are involved in systems of assessing needs and should incorporate the views of both children and their parents to understand them.

Marchant (2019, p. 525) indicates the complexity of legislation that creates a *'baffling array of …guidance'* in relation to assessment. She argues that families will often have experiences of assessments that pathologise their child in a model of deficit when they are tested against professional or societal conceptions of 'normality'. This system does not give children agency. Assessments can become oppressive for families and low expectations related to disability contribute to poor outcomes for children. The Disabled People's Movement, in politicising disability, has sought to shift attention away from 'deficit' models of bodies and minds; to focus instead on how pathologising and exclusionary environments disenfranchise and silence disabled people (Campbell and Oliver, 1996).

A problematic element of assessment for disabled children involves their progress against different developmental milestones. Professional assessments are designed to determine a child's progress in relation to these developmental stages. This has acquired something of a hegemonic status within childhood studies (Walkerdine, 1994). Disabled children who fail to meet the generalised developmental expectations of the policy discourse are pathologised.

Foucault (1977) refers to regimes of truth; the things society holds as true. During the 20th century, childhood studies was heavily influenced amongst others by Piaget's (1936); Bowlby's (1959, 1965, 1980); and Vygotsky's (1978) psychological and psychosocial models of child development. Their models became professional 'regimes of truth'. Whilst more contemporary understandings of childhood have evolved, (Sorin and Galloway 2006; Gangneaux *et al*., 2019) Developmental models continue to be applied in the 21st century by medical and social care practitioners; where children start as biologically immature individuals expected to reach various developmental milestones until they achieve maturity in their early 20s. If they do not meet the expected milestones, they are problematised as non-normates.

Whilst the social meaning of mental or physical impairment varies over time, disabled people commonly become targets for intervention. Disabled children are expected to actively work to fit in and become more 'normal' regardless of the barriers they face. Where they fail to achieve this, the system intervenes. Children who miss the expected milestones of more typical children of a similar age are infantilised; low expectations of their capabilities may be applied in assessments, to their detriment. They can become segregated, institutionalised and discriminated against (Adams and Leshone, 2016). Goodley *et al*. (2015, p. 770) comment on '*the historical markings of disability as object of curiosity and register of fear (which) serve to render disabled children as non-human'.*

Burman (2008, p. 22) comments that *'The normal child, the ideal type distilled from the comparative scores of age-graded populations, is a fiction or a myth'.* Billington (2008) also insists that developmental psychology cannot represent the real diversity of children's functioning, but that developmentalism continues to underpin understandings of 'normal' childhoods. There is little acceptance of children taking their time to meet milestones. Someone with a developmental delay may be patronised, othered, treated as an individual to be 'cured' or rehabilitated. There can be a failure to recognise both the granularity and the continuum of development or its stop-start nature. Normalcy has become entangled with developmentalism; children who do not meet 'normal milestones' are assessed as having 'special needs' and not additional support requirements.

Children’s needs are those things that adults and society perceive as ‘needed’ to ensure all children’s well-being – their health, care, education, safety and socialisation – as they progress through childhood. For disabled children who require additional childhood support, ‘special’ needs are part of the professional and societal lexicon. In the early 20th century, levels of cognitive capacity were categorised. This practice has not changed; health, education and social care agencies refer to mild, moderate, severe and profound learning disabilities. The main system supporting the UK’s children with disabilities’ access to services is titled the Special Educational Needs and Disabilities (SEND) system. For learning-disabled children, the language of need remains focused on difference; what the child cannot do that others can. The help required to reach perceived societal norms is termed ‘special needs’.

This terminology highlights societal discourses about the perception of disabled children. Learning-disabled children don’t have ‘special needs’; they have the same needs as the generalised population of children. They may require additional support to meet those needs because of their disabilities. This research explores a strengths-based approach to supporting children, seeking to change what has become a language of deficit. The limited research on strengths-based approaches to learning disability, mostly exists within the positive psychology movement and has tended to focus more on neurodiversity. The societal language of strengths and deficits regarding the childhoods of disabled children requires further discussion.

3.6. Parenting constructs

When considering childhood, it is important to consider the complementary construct of parenthood. The experience of childhood is heavily influenced by the experiences of the parenting received. The Human Rights Act recognises and supports parents’ primary role in raising children; a principle also reflected throughout the Convention on the Rights of the Child (UNCRC). Article 5 states that governments must respect the rights and responsibilities of parents and carers to provide their children with guidance and direction as they grow up. Parenthood and how it fits within societal norms is widely discussed in the fields of sociology, political science, cultural studies and feminist theory (Polivanova, 2018). Parenting across history has been constructed according to the dominant ideologies of the time; this then dictates what is ‘good’ for children. Caring in this context can be both valued and marginalised.

The family's role is linked to parenting and models of parenting. The term 'family' is recognised across many cultures as the setting within which most people, at some point, live and conduct the private, personal aspects of their lives. (McKie *et al*., 2004). It is also the setting in which domestic relationships and activities ensure the everyday maintenance of health and well-being. Also, when required, it supports recovery and rehabilitation from chronic illness or disability.

Societally, we expect parents to meet their children's needs and prepare them for adulthood. Constructs of parenting discuss elements in this context and often focus on the mother's role, which can be complicated. Women can experience caring both as a form of imprisonment (McLaughlin, 2006) and fulfilment. Societal notions and expectations promote 'scientific motherhood' (Ladd-Taylor and Umansky, 1998, p. 9). Medical models of disability in the context of learning disabilities can lead to professionals emphasising scientific motherhood in a search for 'scientific' methods to achieve normalcy. This involves diagnosis, finding a cure and alleviating suffering. Parents are expected to understand and keep updated on current treatment ideas as well as nurture their developing children. Goodley, Runswick-Cole and Liddiard (2016) point to the mother–child dyad that is often seen as the key site of inquiry when researching disabled children. Mothers, more than fathers or other family members, have been scrutinised and held accountable for producing typically developing children (e.g., Ainsworth and Bowlby, 1965).

Societally, in the UK, parental roles have become more fluid as men adopt more child-rearing responsibility (Opondo *et al.*, 2016). Within the family, there tend to be two key parental roles: the main economic provider and the main family carer (Becker, 1981). These notions can be problematic in the context of disability, where caring can make accessing work difficult for some parents. More women now have careers, although mothers still tend to curtail their careers to be carers (Parker, 2015). Becker (1993) concludes that women's childbearing gives them a comparative advantage in family work, whereas the gender wage gap grants men a comparative employment advantage. More recent analysis shows however, the curtailment of mothers' careers even when they held the higher wage in the household pre-childbirth (IfFS, 2021). In this respect the pay gap does not seem to make a difference in terms of who becomes the main care giver.

Traustadottir (1988) found that caregiving retains an inextricably linked societal identity as mothers' work. Working Families (20I8) surveyed the parents of disabled children and found that 76% of parents – mostly mothers – of disabled children accepted a career demotion to meet their caring responsibilities; and that 45% worked at lower skill levels than they had before their disabled children were born. Regardless of women's personal career aspirations, vestiges remain of the Victorian ideal of motherhood and 'the "good" mother (who) "remains self-abnegating, domestic, and preternaturally attuned to her children's needs"' (Ladd-Taylor and Umansky, 1998, p. 6). McKeever and Miller (2004) contend that this applies strong pressure on mothers of learning-disabled children to conform to traditional ideologies of care and devote themselves selflessly to their children's welfare. For women who have profoundly disabled, dependent children, this tends to mean that mothers are expected by society to forfeit or modify their lives to provide the 24/7 complex care regimes that their children require. This can mean forgoing personal aspirations and ambitions to keep their children at home and out of institutions (McKeever and Miller, 2004).

Although the mothers of disabled children report high levels of satisfaction in being carers (Wickham-Searl, 1992), Ruddick (2007) argues that mothers are devalued in society. Whilst meeting societal expectations in their roles as carers their devaluing comes in three forms: the low status of caregivers, being female and their association with disability. This low status means that few men give up careers to care for their disabled children (Wickham-Searl, 1992). Linking the low status of women's work with the stigma of disability transfers the stigma to the caregiver as well.

Care and health work in the home and family is both constituted by and constitutes gendered social identities such as father, mother, wife and husband. These activities are implicit (but largely unacknowledged) in social understandings of femininity and masculinity. They result in expectations that women will care for babies and young children. Thus, domestic work and informal health work continue to be unequally divided between women and men, with implications for health and income throughout life (Bowlby *et al.*, 2010). The stress placed on mothers in their endeavours to support their children is evident. For instance, mothers of learning-disabled children experience more mental ill health than mothers of non-disabled children (Breslau, Staruch and Mortimer, 1982; Bright, Hayward and Clements, 1997; Blum, 2007).

3.6.1. ‘Good’ and ‘bad’ parents

In the context of parenthood, Burman (2008) points to the rise in popularity of parenting manuals and magazines that discuss what parenting should be; and develop notions of the ‘good parent’. Scientific discoveries have brought social change, and developmental models dominate in popular understandings of parenting. Mothers are acutely aware of the developmental milestones for their children. When children exhibit an ability or inability to reach those milestones, it constructs both the mother’s image of her child and her success as a mother (Burman, 2008).

Being a good mother is a social construct. Sousa (2011) argues that the mother is expected to be selfless and devote all her resources to caring. The parents of disabled children, particularly mothers, can be pathologised for their endeavours to do their best. Mothers of learning-disabled children often encounter the ‘warrior parent trope’ in which the mother battles the system to access the right services and interventions for their children; whatever the cost as the parent (BASW, 2021). Parents become important political actors who challenge, through their care activities, the marginalisation of care for disabled children (McLaughlin, 2006). Through intensive caring relationships with their children, parents gain an appreciation of the injustices embedded in societal judgements about disability. The risk for ‘warrior’ parents is being perceived by professionals as difficult and demanding; sometimes leading to attempts to side-line and contain them. Conversely, a different trope; The ‘superhero parent’ is praised for just getting on with life, managing things and being undemanding of services; thereby celebrated by professionals who can pass on their responsibilities. McKeever and Miller (2004) argue that what are perceived as pathologised maternal behaviours are a predictable response to the parent and child’s situation in a society that devalues disability and treats family support as a burden on the state.

Both ‘superhero’ and ‘warrior’ parents will struggle to access adequate support for themselves or their children. The demanding parent is dismissed, and the superhero is left to ‘cope’. These tropes create scenarios where parents are disempowered and choice and control are undermined. Ryan and Runswick-Cole (2008, p. 200) comment that:

> ‘*whilst experiences of mothers with a disabled child can differ markedly from the experiences of mothers of non-disabled children the consequences and*

> *outcomes of these experiences, such as developing a 'special competence' is largely overlooked. Mothers can work to effect change on behalf of their children and, in some cases, for disabled people more generally, however, this role of activist mother is largely undervalued.'*

3.7. Parent/child relationships

Parent/child relationships are critical for a good childhood and quality of life. Parents are their disabled children's allies: their enduring and loving relationships with their children are in stark contrast to those with paid professionals who maintain limited hours of contact and emotional attachment (Dale, 1995). What then happens if the interests of the child and the parent diverge?

Ryan and Runswick-Cole (2007) point to commentary on social media of disabled people expressing their unhappiness with their parents' influence on their lives. Some argue that they are silenced because parents can't speak for them. The construction of the 'parent as oppressor' has led professionals and some activists to argue that parents should have less influence over their children's lives, particularly as they get older. The British Council of Disabled People (BCODP), for example, does not think that parents should select the type of education their children receive. The BCODP argues that all disabled children must be supported in attending mainstream schools. They believe that many parents choose otherwise based on a lack of experience and a fear of professionals (BCODP, 2005).

Thomas (1999) further argues that the 'agents' or 'carriers' of disablism are sometimes those closest to the disabled person, including parents. As allies, parents can experience by proxy the same discrimination their children face (Read, 2000; Ryan, 2005). Parents begin to 'know their place', moderate their behaviour and learn to internalize the oppression (Thomas, 1999, p. 48). Professionals working with families must navigate these complicated dynamics given the symbiosis of childhood and parenthood. In this context, parents are often categorised by professionals as having adjustment problems.

Governments seek to address the complications of meeting both children's and parents' needs through their approach to developing family policies. Children and parents are technically supported through various welfare, employment, education and taxation policies. Human rights legislation supports the right to family life, but in UK law, the rights of the child are paramount. In decisions about children, their best interests must take priority (Goodley, 2015). This balancing of children's and parents' needs is something the system constantly navigates to achieve a good quality of life for citizens.

These two sections on childhood and parenthood in the context of disability serve to highlight some of the issues families must navigate due to societal constructs and belief systems. These, linked with an understanding of disability, all affect families' quality of life, which is discussed in the next section.

3.8. Quality of life

This thesis focuses on quality of life (QoL). This is a subjectively based construct that lacks a universally accepted definition. Schalock (2000) points to over 100 different frameworks; however, Fallowfield (1990) contends that we can all express ideas about what QoL means for ourselves or for others. Like 'common sense', everyone has an understanding of how it frames their world. This section considers several QoL constructs that are important in the context of analysis within this thesis and how the commentary of the families involved is understood.

The literature on QoL tends to encompass several key factors, including physical, mental and emotional, social, economic and spiritual well-being. Rojas (2016) argues that the difficulties in definition mean more effort is concentrated on measuring QoL than conceptualising it. An interesting idea as knowing what is being measured is required to measure it meaningfully.

The potential for all individuals to live what they would ideally define as a good life will far exceed what can typically be managed in actuality; all individuals can have aspirations but face limits of possibility. In reality, a life is not entirely within a person's individual control and is heavily influenced by society, policy and economics. Expectations of what 'good' looks like are driven by policy narratives as well as direct experience. As QoL is partly socially constructed, all citizens rely on how society and the environment operate.

Northway and Jenkins (2003), citing Koch (2000), point to how concepts of QoL originated from both the clinical and social. Social perspectives emerged in the 1920s to challenge social conditions as part of a social justice movement. Clinical perspectives emerged from negative perceptions of the quality of the experience people with physical or cognitive impairments suffered due to their conditions. This influenced the eugenics movement before and after the Second World War. As already explored in chapter 2, this has had huge impacts for learning-disabled people.

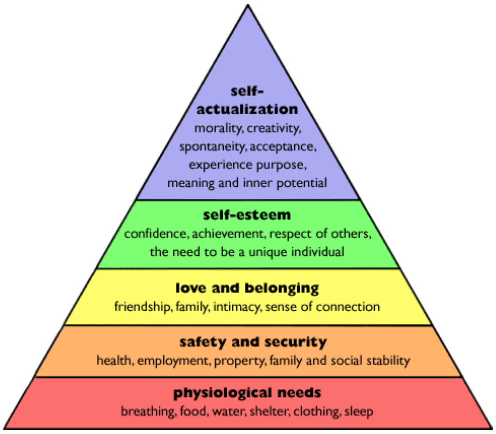
Research on QoL for learning-disabled children is limited (Ncube, Perry and Weiss, 2018). It has been fragmented across different disciplines and mainly consists of small-scale qualitative studies (Stalker, 2012). Learning-disabled children with complex support needs are rarely asked directly about their experiences or well-being. They tend to be left out of decision-making that affects their lives; reducing their ability to make their own life choices for QoL, because, often, decision-making organisations fail to consult them (Mencap, 2017). The challenges in involving learning-disabled children in research are discussed later in this thesis.

QoL models vary in their complexity and how they link components. Different models can consider insiders' views (people measuring their own QoL) and/or external policy (Brown and Gordon, 1999). Four models are discussed below.

i. Maslow

Probably the most well-known framework that informs conceptualisations of QoL is Maslow's hierarchy of needs; providing the desired conditions to live well (Maslow, 1943). His instantly recognisable hierarchical diagram (Figure 4) arranges these conditions into hierarchies of pre-potency, i.e., that the desire to fulfil a need usually rests on the satisfaction of another, more pre-potent need. In this respect, no need or drive can be treated as isolated or discrete; each is related to the satisfaction or dissatisfaction of other drives. This hierarchy has become commonly recognised even among laypeople. Other theories regarding QoL have evolved from it and include hierarchies of basic and higher-order needs in their foundations. Many of the families in this research reference Maslow's framework.

Figure 4: Maslow's Hierarchy of Needs



ii. Schalock

Schalock, a well-cited psychologist in this field, comments (2004, p. 203) that:

> *'an enhanced quality of life is a realistic and obtainable goal for all persons, including those with intellectual disabilities. Understanding this has resulted in a number of productive changes in service delivery principles and practices.'*

He defines QoL as something that reflects a person's desired living conditions, as well as any societal perceptions, presenting eight core dimensions (Schalock, 2000, 2004):

- Emotional well-being
- Interpersonal relationships
- Material well-being
- Personal development
- Physical well-being
- Self-determination
- Social inclusion
- Rights

Like Maslow, he identifies a hierarchical nature to these dimensions but challenges early societal ideas about different measures of QoL that differentiated between higher-functioning and non-verbal or lower-functioning people. He highlights the need for rights and not comparisons of what could be expected for different people; stating that QoL can be pursued from three perspectives:

- Individuals pursuing a life of quality for themselves
- Service providers producing quality products
- Evaluators (policymakers or funders) analysing quality outcomes.

Schalock recognises the challenges involved in different constituents emphasising their preferred analyses. He argues that funders are most likely to focus on cost and efficiency outputs, whereas service users will emphasise the value of quality-of-experience outcomes (Schalock, 2004). These tensions will create dilemmas about priorities when families are seeking support, and service commissioners are struggling to manage budgets. Managing expectations becomes important alongside the recognition of people's rights to decent lives in the interests of social justice.

Adopting a social justice perspective emphasises inclusion, empowerment, respect and community living and work options. Social policy stresses the desirability of person-centred outcomes that support independence, inclusion in economic life through employment and participating in community as a basis for satisfaction with life. For learning-disabled people, there has been a shift in focus away from the belief that scientific, medical and technological advances alone would result in improved lives towards an understanding that personal, family, community and societal well-being emerge from complex combinations of these advances (Schalock *et al.*, 2002).

iii. UK Government well-being approach

QoL as a concept has been embraced by the UK government and defined in terms of overall well-being. The Office for National Statistics (ONS) uses four measures as quality of life proxies, which are often referred to as the ONS4:

- Satisfaction
- Worthwhile
- Happiness
- Anxiety.

The approach captures three types of well-being:

- Evaluative
- Eudemonic (similar to Maslow's hierarchy)
- Affective experience

Adults are asked to assess each of these aspects of their lives in an Annual Population Survey (APS) published by the ONS. Methodologies for understanding children's QoL however are poorly developed and the National Institute of Care and Clinical Excellence (NICE) indicates the need for standardised and validated preferencebased measures of health-related QoL that are designed specifically for use with children (NICE, 2013; Lamb, Murray and Lovett, 2021).

A suite of outcomes for children was previously helpfully defined by the government within Every Child Matters (ECM, 2003) (See 1.7 above). This agenda was dropped after a new Government was elected in 2010, although some public-sector agencies still informally apply the principles, some even referencing them on their websites. Nothing comprehensive has replaced the ECM outcomes to inform children's QoL outcomes. Ofsted, the main regulatory body that inspects children's services delivered by local authorities, indicated in 2018 that it would no longer frame inspections via QoL outcomes. It would focus on inspecting 'the things that matter most to children's lives' considering 'the experiences and progress of children' (Ofsted, 2021). Data gathered for inspections do not consider life outcomes so much as legal and process status. This appears quite transactional, and children's QoL in the round is, arguably, not being fully considered.

Within this research, data from family interviews are referenced against the government's main QoL data framework to see how family notions of what matters correspond to government measures.

iv. Nussbaum's central capabilities approach

Nussbaum's work is valuable in providing not only a framework for QoL but also the basis of an assessment of social justice, supporting policy design and proposals for social change. She specifically addresses QoL in relation to learning disabilities. She argues that each person should have opportunities focused on choice and freedom. Good societies should promote opportunities or substantial freedoms for all people, which they may or may not exercise at will (Nussbaum, 2011; Sen, 1979). She has developed a capabilities framework focusing on ten central capabilities:

1. Life
2. Bodily health
3. Bodily integrity
4. Senses, imagination and thought
5. Emotions
6. Practical reason
7. Affiliation
8. Other species
9. Play
10. Control over one's environment.

The capability approach addresses three core concepts:

- Functioning
- Capability
- Agency

Nussbaum has been criticised because her framework reflects the values of a contemporary American liberal and is not a global model (Stewart, 2001; Okin, 2003). She has also been described as elitist and over-optimistic about what constitutions and governments can achieve and afford (Menon, 2002). Nussbaum counters this by arguing that she offers her framework for consideration and not imposition (Nussbaum, 2004, 2011). She describes how, philosophically, social policy has tended to focus on rational inquiry, critical thinking and scientific achievement. However, she argues that the theoretical and philosophical positions adopted tend not to be inclusive of those who are perceived as lacking sentience; for instance, learning-disabled people (Nussbaum, 2002).

Nussbaum's work specifically addresses learning-disabled people's rights, arguing for their views to be heard and actively influence decisions in their lives. She argues that this has been undermined by perceptions of a lack of intellectual capacity and treating individuals as less human, which significantly affects QoL and their rights to retain agency. She forcefully challenges inequality, discrimination, marginalisation and the notion that people's political and social entitlements are proportionate to their innate intelligence or skill.

Nussbaum argues that capabilities should not be viewed meritocratically but based on human rights; where thresholds to services support those who need more help. Resources should be applied to enable disabled people to participate freely in society as non-disabled people's equals. She argues that a child with Down syndrome may prove more expensive to educate but a just society that educates all, should not shrink from the cost (Nussbaum, 2002).

In this thesis, like the application of the UK government QoL framework, data from family interviews are referenced against Nussbaum's capability framework to see how family notions of QoL correspond to that measured by Nussbaum's central capabilities. (See Chapter 6).

3.8.1. Economic QoL considerations

Cost is a significant, undeniable factor in the delivery and scope of services. Both Nussbaum and Schalock contend that a just society will fund such services as are needed to ensure a good QoL for learning-disabled people. QoL has at times been used however, as a basis to evaluate and justify the allocation of scant resources under economic constraint (McVilly and Rawlinson, 1998). Social attitudes about groups can influence how these decisions are made (Koch, 2000). Societal judgements can be applied to clinical interventions about which individuals will get the most value from support. This has included the denial of services for some groups, as the earlier discussion in Chapter 2 regarding Covid-19 demonstrated.

Financial challenges exist. Expenditure in England for children with complex needs was forecasted at £9.1 billion in 2022 and 2023 (LGA, 2021); although it is difficult to assess how much of this total supports learning-disabled children. As in other types of research regarding learning-disabled children, there is very little analysis of the economic costs that influence and contribute to decision-making; despite the recognition of economic factors as important parts of the overall context (Doran *et al.*, 2012, cited in Knapp *et al*., 2016). The existing research recognises that supporting learning-disabled children with complex needs, does cost more; and may be even more costly than is currently understood (Mansell *et al*., 2007).

Debates about costs alongside continued stigma and ableism associated with learning disabilities puts a good QoL at risk; attitudes of otherness can be used and abused. Notions of intrinsic and extrinsic worth can also be applied in dangerous ways. Presumptions of inferiority may lead to the denial of provision, rather than the individual being afforded services and opportunities (Northway and Jenkins, 2003). Brown (1999, p. 301) argues that the risk of a focus on intrinsic value is that it:

> ‘*will identify that people with an intellectual disability do indeed have a poorer QoL and this knowledge will infer that people …comprise a group who are inferior because their lives are inferior’.*

Historically speaking, QoL has tended to be promoted in UK public policy via economic rather than psycho-social models of well-being (Bruni and Porta, 2016). However, in the context of learning disability, a QoL focus that recognises both the intrinsic value of human beings and the extrinsic value of every individual in society is vital (Rojas, 2016). Learning-disabled children contribute significantly to others' QoL, and a values-based philosophy requires embedded models of involved citizenship.

When considering value and worth measured in terms of societal contribution, it is also useful to consider the linked concept of purpose. Frankl (1959) proposes that all people are motivated to discover a purpose for their lives and doing so is a natural human inclination. Without purpose, he argues, feelings of meaninglessness and emptiness ensue. Emerson, the 19th-century poet and philosopher, comments that the purpose of life is not to be happy; it is to be useful, to have it make some difference that you have lived and lived well.

Purpose is a generalised construct that has come to represent a stable intention to accomplish something personally meaningful, leading to productive engagement with some aspect of the world beyond the self (Damon, Menon and Bronk, 2003). Feelings associated with a lack of purpose include depression, risk-taking and boredom (John Templeton Foundation, 2018). Purpose can be achieved through work, family life, leisure interests or by contributing in ways that make a difference to others. Thinking through ideas about purpose informs thinking about how cost, value and worth are considered. A just society will consider the needs of all, including learning-disabled children, and promote policies that enable the development of purpose over and above notions of employability.

How learning-disabled children are enabled to achieve meaning and purpose is an important consideration. It is sometimes ignored or neglected when attitudes are founded on notions of sentience as a measure of worth. Achieving purpose is an interesting question to explore further when considering behaviour challenges that are sometimes flagged in relation to children with complex needs. If behaviour is accepted as a means of communication, can a life that fails to support purpose lead to boredom, frustration and then challenging behaviours? Is a lack of focus on emotional well-being through a purposeful life contributing to the need for expensive services to 'manage behaviour'? If SEND services are dominated by education support models that promote economic productivity, but where wider purpose is not considered or understood, might this lead to other needs not being met? The emotional consequences for the child could have financial impacts due to the need for more specialist services.

In recent decades, an increasing emphasis on person-centred care for individuals receiving public services has arisen, including for learning-disabled people. This focus stems in part from the QoL movement. Wolfensberger (1980, 2005) highlights the experience of systemic devaluation for learning-disabled people and advocates for social valorisation to enable lives that are as culturally normative as possible. All individuals should be able to have purpose, exercise choice, have a richness of experience and make decisions about how to spend their time, who they are friends with and where they live.

Accepting this precept can transform service delivery, with agencies' commissioning services aimed at creating an environment that enables choice and control. Whilst the rhetoric of the 'choice' agenda is now at the heart of public service policies, individuals often experience a different reality (Boyle and Harris, 2009). The rationing of services, possibly at every stage of decision-making and during times of austerity has insufficiently supported the needs of learning-disabled children to achieve a good QoL. Exercising choice and control is bound up in the nature of the power within relationships, which is discussed in the next section.

3.9. Constructs of power

Families of learning-disabled children seek to exercise choice and control in their everyday lives to achieve the best possible QoL outcomes. Their right to exercise choice is embedded in the CFA 2014, but meaningful family involvement in decision-making is not being achieved (SEND Select Committee, 2019).

All families caring for a learning-disabled child will work with a range of public service agencies. This can involve a complex network of organisations and relationships. The modern social policy discourse conceptualises the service user as an autonomous 'social agent'. Practitioners should work with service users as social agents in a relationship of empowerment. Despite this discourse, evidence suggests that rather than social agents, service users are still treated as passive recipients. How professionals perceive and value certain groups of service users can affect power relations (Dominelli, 2002). All parties within service-based relationships have knowledge, insights and the ability to control by both giving and taking power. Giddens (1987) argues that power is a negotiated reality between parties; where neither party is completely powerful or powerless. Understanding power relations for families and professionals in this context is essential. In a society that insufficiently values disabled people, this has the potential to affect professional practice as well. Power is conceived of as existing in the social and political environments that give rise to the politics of disablement (Owens, 2015).

Avelino (2021), recognising the complexity and importance of power has developed a meta-analysis identifying different manifestations of power dynamics, which she presents as a framework. She argues that as a contested concept (Lukes, 1974), power becomes difficult to define. Instead, she differentiates what she describes as seven prevailing points of contestation. These are in summary:

1. **Power ‘over’ versus power ‘to’,** who is exercising power and how is power exercised for and against change?

2. **Centred versus diffused:** How and to what extent is power diffused? Decentralising is often implicitly assumed to be good and more equal. Where are the centres of power? What issues are kept off the agenda?

3. **Consent versus conflict:** How are consensus and conflict manifested and then used to create change? Are they experienced as oppressive or emancipatory?

4. **Constraint versus enablement**: Who or what is creating constraint? Who or what is creating enablement? How is structural power manifested and changed? Is this for the good?

5. **Quantity versus quality:** What types of power are being applied and what resources are being utilised? How does this reinforce, innovate and transform change?

6. **Empowerment versus Disempowerment:** Who is disempowered by whom or by what? What are the unintended/intended consequences? Is it intentional?

7. **Power equalling knowledge versus power not equalling knowledge:** What kind of knowledge or ideologies are being applied? To what extent is knowledge used to achieve change or to constrain it.

This framework is helpful as it provides useful insights into how power might manifest when families and professionals interact, and the challenges parties may face in navigating their relationships. Avelino (2021) argues that there is increasing focus on creating more just societies and in this respect understanding how power is applied to create change and innovation is important to understand. Power is relationally constituted and is part of social context (Barnes 1988), with changes in social context comes renegotiation of power. Where social policies give parents and children more choice and control, power dynamics will be contested so understanding how this might manifest is crucial.

3.9.1. Neoliberalism and the power of the professional

Professional practitioners sit within system structures. How they exercise their professional roles and power is influenced by these structures and social policy imperatives. In the public sector, the ideology of neoliberal managerial systems of service delivery has dominated for the past three decades. Neoliberalism explicitly addresses the non-economic preconditions of functioning markets and the interactive effects between markets and their surroundings (Biebricher, 2018).

Neoliberalism argues for:

- marketisation within public services as it is more likely to be efficient and effective;
- consumerism, the idea that individuals should be responsible for themselves and run their own lives;
- managerialism, the idea that the public sector can benefit from the knowledge and expertise of the private sector;

In neoliberal managerialist systems, professional agencies hold systemic power in how the market is managed. Effectiveness and efficiency measured in cost outcomes and managing budgets in a market-led system inevitably affect consumer choice; and whilst technically having a voice, families must navigate these powerful professional systems. Government policy has focused on more engaged models that offer choice and control to service users in how services are developed and delivered, such as direct payments and personal budgets. This consumerist approach technically enables disabled people to purchase services as they wish; rather than be assigned to them by the state. If budgets are too small however, this becomes meaningless.

Neoliberal policies are structurally evident across children's services.

- Schools have become more autonomous in how they shape and deliver their provisions, being held to account through codes of practice and inspections. Parents are given choices about the schools their children attend.
- Children's social care has moved away from more welfarist principles toward managerialism and managing risk (Briskman, 2009). There is an increased focus on accountability and meeting outcomes (Banks, 2009).
- Whilst universal health care for all is available, the development of the private health market is accepted as part of the system of choice for consumers purchasing services.

Mladenov (2015, p. 446) highlights that:

> *'an important element of neoliberalism is the retrenchment of the welfare dimension of the state, which is seen as an impediment to the optimal functioning of the markets'.*

Neoliberal new managerialism has created competing discourses. There is a culture of agencies' contracts and efficiency and effectiveness targets alongside discourses of consumerism, user involvement, political participation and creating a 'social actor' role for the service user; who is meant to become a consumer with economic behaviours (Beresford and Wallcraft, 1997). Shifts in terminology and conceptualisation have transformed service users into rational shoppers in health and social care markets that afford choice and control (Rose, 1999; Le Grand, 2003).

The narrative is that the development of quasi-markets for service delivery leads to greater public participation in the design of services, with shared decision-making between professionals and the users of welfare services. Briskman (2018) argues that it has instead created a closed environment that is antithetical to welfarist social work principles of social justice and the importance of human relationships. This leads to service containment. The market is not an appropriate mechanism for access to high-quality care and adequate welfare support when in need, and such access is the hallmark of a compassionate society and should be seen as a right.

Avelino (2021, p. 425) notes:

> *'that where there is governmental and societal enthusiasm for change, 'the "dark" and "unintended" effects of social change…often tend to be underemphasised, as well as the fierce power struggles and inequalities that come with it'.*

This criticism can be applied to neoliberalism. Mansell (2006) predicted that in the face of growing welfare costs, a managerialist government would make greater use of markets and positively encourage a mixed economy of provision. The use of criteria to ration service availability would emerge, replacing rights-based eligibility with discretionary managed budgets. The taxpayer, not the individual service user, would become the customer, leading to public servants making proxy decisions about services underpinned by financial judgements and 'good enough' standards being applied, suggesting a minimalist approach to service quality.

Mansell (2006, 2007, 2008) is critical of the potential impact of these features, arguing that they will ultimately limit individual service users and choice. Service rationing replaces entitlement to services as a right with assessment and access only in extreme crisis. This scenario is not conducive to service user choice and control. In the context of UK Government austerity and public service cuts from 2010 onwards these tensions have played out.

3.10. Co-production

This research explores the impact of neoliberal approaches for families of learning-disabled children. Neoliberal ideas discuss the devolved power of service users and their involvement in service design and co-production.

Part III of the Children and Families Act (2014) promotes partnership through an underlying principle of the SEND Code of Practice known as co-production; defined as the delivery of public services in an equal and reciprocal relationship between professionals, service users and their families (Boyle and Harris, 2009). At the very least, Education, Health and Care Plans (EHCPs) are intended to be co-produced, with professionals and families working together to identify the required services. The term co-production was first coined during the 1970s by Elinor Ostrom and recognises that members of communities are not passive consumers; their knowledge and insights can be involved in the design and delivery of services. This, theoretically, allows different types of collaborative relationships to be developed with families, achieving better outcomes. SCIE (2013, p.1) describes: '*In its simplest essence, to co-produce is to make something together. Co-production is not just a concept, it is a meeting of minds coming together to find shared solution.*'

Wright (2014) argues that in children's services, almost no service can be delivered without service users' contributions in relationships of co-production. Khine, Mi and Shahid (2021) argue that as co-production is relevant to every public service, it is important to explore how it can be supportive across different stages of service production. Shared decision-making in models of co-production sounds progressive, but the literature suggests that it is currently used in rather restricted and technical ways. There is little peer-reviewed research on the efficacy of service user/professional co-production; however, Bovaird and Loeffler (2013); Wright (2014), and Oliver (2014) all found that co-produced services are much more effective.

Co-production, theoretically, should offer something of a win/win to both families and professionals in pooling and recognising expertise to generate benefits. At face value, greater user involvement is generally explained as ethically right and good. It transforms the user from a passive, dependent role that relies on the paternalism of professionals to a more active, involved role, enabling empowerment and respect as an autonomous individual.

Cribb and Gewirtz (2011) argue that the reality is more complicated, they question how disabled children and their parents can be truly empowered. Neoliberal economic considerations on behalf of the taxpayer may minimise co-production when costs are considered. Choice then becomes meaningless as the service user is not an autonomous agent but only receives the available services. Genuine co-production is prevented because scant resources make relationships of reciprocity too difficult. McLaughlin (2006) argues that parents in this scenario will tend to encounter a minimalist approach from statutory agencies about QoL support, driven by the need to control budgets. Many professional narratives argue that the costs of SEND services are unsustainable (*Municipal Journal*, 2019; Bryant, Parish and Kulawik

2022). Who makes decisions involving resource allocation tests the actual levels of co-production.

i. Challenges of co-production for professionals

Economic considerations are not the only challenge in co-production partnerships. These require practitioners to give up elements of their professional power, creating a more dispersed, less centralised model involving reciprocity and enabling ‘power to’ not ‘power over’ (Avelino, 2021). This dynamic is different from how many professional systems work, requiring cultural change in relationships. Bovaird (2007, p. 858) comments:

> ‘*Co-production among public service professionals and service users… suggests the need to reconceptualize service provision as a process of social construction in which actors in self-organizing systems negotiate rules, norms, and institutional frameworks rather than taking the rules of the game as given’*.

In a climate of managing risk, safeguarding, regulation and resource restrictions, with agencies held to account by the government through inspections, it is important to consider how likely or easy this culture change is to achieve. Purcell (2020, p. 171) comments:

> ‘*Public and political debate about the English child welfare system has tended to take place in the shadow of high-profile child abuse inquiries’*.

This has resulted in a system that focuses on managing risk and addressing public confidence regarding child safeguarding, rather than a family welfare system (Parton, 2014). Local authorities can fail inspections on the basis of poor safeguarding practice, with significant consequences for senior leadership; but they are unlikely to be judged as failing if they do not embed co-production in their practice. Professionals may feel that they have too much to lose, constraining their power to permit systemic collaboration. Strong institutional power cannot be ignored, and culture can prevent progress. The findings of the 2019 SEND Select Committee on CFA 2014 affirm this view.

ii. Challenges of co-production for families

Families can have concerns about co-productive relationships as well. Depleted of emotional capital, they may not welcome the extra pressures of co-production as greater expectations are placed on them potentially for little return. Emerson and Hatton (2007) describe the high levels of stress that families experience; and particularly identify the high level of intangible costs carried in terms of emotional well-being, in addition to economic pressures. Involvement can become a form of enforced empowerment where parents are given responsibilities they may not want; or feel out of their depth accepting. Sharing the professional burden of management complexity, which requires judgment and specialist knowledge for which professionals receive training but the family probably does not, may be more input than some families want.

Gilbert (2004, p. 456), citing Barnes and Prior (1995), challenges the idea that parental choice in co-productive decision-making is always valuable, stating:

> *'choice can be anxiety provoking because having no choice but to choose contributes to the growing complexity of daily life; this might be unwelcomed and disempowering, thus provoking distrust'.*

Anxiety about choice can lead to an over-reliance on professionals' views and advice, thus creating a very specific form of dependency on them (Giddens, 1990). This can lead to service users making uninformed choices based on faith in the professional, or a context of 'the professional knows best'. Barnes and Prior (1995) and Gilbert (2004) argue however, that when there is no coercion, services are predictable and significant, and users can participate meaningfully, choice can be empowering.

iii. Decision-making in co-production

Struggle is not limited to families; professionals can oscillate as well if during the co-production of decisions, individuals and families make choices that are recognised professionally as potentially harmful. This causes ethical dilemmas. Co-production in the professional discourse is invariably described as a positive feature until the service user challenges the services provided or makes a poor decision. Thus, service users may discover that their decision-making rights and freedoms to choose exist only up to a point; and only while professionals feel the service user's involvement is helpful or valid.

When views are seen as disruptive or unrealistic, decision-making rights can be removed and the system can return to paternalism. Service users can find themselves encouraged to participate in decisions about medical treatment or encouraged to co-produce a service in a community support package; but adopting activist forms of citizenship, such as campaigning for better services, complaining about standards or taking a local authority to a tribunal for funding, may abruptly halt co-production.

Co-production does present opportunities for shared power, but professionals in collaborative relationships will be influenced by their own expectations about parents and how they should behave; as well as attitudes towards the sentience of learning-disabled individuals. Issues that are seen as difficult or problematic can minimise co-productive working. Understanding societal constructs about parents' roles and notions of good parenting, alongside what a good childhood looks like; and the agency of children in the context of service delivery are, therefore important.

3.11. Conclusion

This chapter discusses theoretical perspectives of disability and has considered key constructs in the context of childhood, parenthood, QoL and power. These constructs can be understood separately as well as in their intersectionality, forming part of the complex backdrop of learning-disabled children's lives. Discussed is how disability activism, and theoretical perspectives about embodied disability, have challenged societal barriers in progressing the rights of disabled people. The point is made however that understanding disability in the context of children and their parents or carers is less well addressed.

The critique of literature in this chapter in combination with discussions in Chapter 2 about the legislative, policy and historical context of learning disabilities, highlights that understanding and supporting the needs of learning-disabled children in the UK is a rich area for research.

Six years after the implementation of the Children and Families Act 2014 these chapters provide context for this study, which focuses on families' views about their present and future needs in caring for a disabled child and how much choice and control they can exert to achieve a good quality of life for their disabled child and the nuclear family.

Chapter 4: Methodology.

4.0 Introduction

In this chapter, the methodological approach to the research is discussed. The aims of this research were to explore perceptions about quality of life for families with a learning-disabled child. How family values, experiences, history and context shape those family lives and how family members exert choice and control in navigating the circumstances of caring for that child.

Adopted for this study are principles of interpretive phenomenological enquiry, applying a critical realist perspective in focusing on family members' subjective experiences. A range of methods were employed to address the research questions. The study is primarily qualitative, developed through in-depth open-ended oral history interviews with parents, semi-structured interviews with older siblings and play sessions with disabled children and younger siblings. In addition to family narratives an in-depth analysis of EHCPs was also undertaken, this combined with families' accounts provide insights about quality of life.

These methods are described in greater in this chapter and the rationale for the varied approaches in working with different family members is explained. Broadly speaking though, conversational narrative methods were adopted because these can encourage more lively exchanges between participants and the researcher. Hinchman and Hinchman (1997 p. xvi) describe how narratives are important as '*discourses [which] connect events in a meaningful way for a definite audience and thus offer insights about the world and/or people's experiences of it'* They consequently build insights into the deeper layers of human experience beneath surface awareness and how the individuals telling them make sense of their worlds.

This narrative approach is differentiated from more formalised methods, such as written accounts and reports which can be hampered by literary conventions and are, consequently, less personalised than conversations (Bornat *et al.*, 2000). In this context lifeworld (Habermas, 1987) is also explored; where life experiences and how individuals reflect upon them becomes an integrated whole for understandings of family life. The narratives people share are therefore not only about piecing together a series of events but also about creating a coherent picture that makes sense and meaning in the context of individual family member’s lives.

In describing the methodology, the approach to data coding and thematic analysis is also explained, and why coding was subsequently cross-referenced with QoL frameworks; including the UK government well-being framework and Nussbaum’s central capabilities framework. The patterns and relationships in how decisions are made within families and how this influences outcomes for children and young people are identified and explored.

Epistemological and ontological considerations are discussed as well ethical considerations. The results of the study are presented in the subsequent chapters.

4.1. Epistemology

Epistemologically, this research, with its focus on narrative, is phenomenological and adopts a critical realist perspective in seeking to understand human agency, and social structures and the relationships between them. Edmund Husserl, credited with defining phenomenology, grounded his theory in the concept of understanding human experience. He argues that understanding the essences of experiences creates an understanding of the true nature of a phenomenon (Patton, 2002). Rustin (2000) comments that investigating society, which is built from individual experiences, should be of interest to those who are concerned with understanding the spaces in which meaningful lives are created. This is a valid theoretical basis from which to learn about family experiences of learning disabilities.

Understanding a phenomenon involves more than individual experiences; it is also about how they interact with wider society, systems and agencies. Individuals and groups cannot be wholly separated from the worlds in which they live or the culture within which they were raised and to which they belong. Husserl (1962) developed the idea of the individual lifeworld. He framed it as how an individual finds meaning in the world and how their experiences of their environment are interpreted; in essence, the sum total of the physical surroundings and everyday experiences that comprise an individual’s world.

Habermas (1987) further specifies that lifeworld exists within the domain of social life, family and culture, but argues that it can be subsumed into ‘the system’ where money and power can colonise family and individual experiences and understandings (Garrett, 2013). Finlayson (2005, p. 56) further argues '…*networks of instrumental action increase in their density and complexity, so they gradually intrude into the lifeworld and absorb its functions'.* The philosopher Heidegger also recognises the influence of the wider environment and asserting that a person's individual history and experience create their conscious knowledge of a phenomenon, but they cannot be separated from the influences of the wider environment. Heidegger's approach is interpretive, with Husserl's approach being more descriptive (Reiners, 2012).

Archer (2000), adopting a critical realist position, contends that all people are social actors who also belong to collectives (or agencies) and that these are varied and diverse. These arguments affirm that while individual experience is important, it is also critical to understand not just the nature of knowledge but also the nature of being. As individuals, we are affected by culture, policy, laws and societal systems and constructs; how we interact with these is significant. Moustakas (1994) argues that we each live in an individualised world where we seek to make sense of our lives, but where social identities can be contested or uncertain. Phenomenological research methods provide a useful framework that enables enquiry into the true meaning of phenomena and how these can naturally emerge with, and from within, their own meaning, thereby helping to develop an understanding of the essence and nature of being. These reasons support the selection of these methods for this study. Whilst experiences are individual, there can be some commonality to the lived experiences we have, and how we perceive them. This commonality of understanding can lead us to understand the essence of a phenomenon, where perceptions can become universal. The exploration of these experiences allows phenomena to be understood, enabling the development of a generalisable description of meaning and context (Neubauer, Witkop and Varpio, 2019).

This research focuses on the meaningful lives of learning-disabled children and those who care for them. The approach I adopted seeks to find meaning and structure and explore what Patton (2002) describes as phenomenological questions: understanding the essence of families' lived experience and how it is influenced by their environments and societal systems. Adopting a critical realist perspective enables what Fleetwood (2014) refer to as epistemic relativism; allowing researchers to work with different social actors (*in this study family members*) to interpret phenomena in different ways.

Van Mansen (1990) recognises that phenomenological approaches, by nature, are recollective, or based on past experiences. This study encouraged parents through the telling of oral histories to reflect on their experiences past and present since the diagnosis of their child's disabilities; and for siblings, on their experiences of making sense of the past, and future hopes and expectations.

4.2. Ontology

> *"There is more to the world…than patterns of events. It has ontological depth…'*
> (Sayer, 2000, p. 15)

Ontologically, I examined the development of jointly constructed understandings of the world from individual family members. Through these, I sought to build an understanding of the basis of individual and then shared assumptions about reality both within and across these families with learning-disabled children adopting a critical realist position.

Bryman (2012, p. 491) describes how life histories create the opportunity for narrative analysis to generate knowledge about sequences of events and how these permeate people's lives, thus contributing to our understanding of the world. Ontologically, meanings are developed by individual family members and synthesised within the family unit. These then interact with other meanings, including those of professionals. Social and legal systems also intersect to construct a mutual understanding of family experience. Points of agreement and contention inevitably arise during this process.

Constructionism builds on the idea of 'social actors' who, in their belonging to social agencies, make sense of phenomena. Agencies can vary but are collectives of interest that can include families, communities, professionals and governments. These agencies are not static; they are built upon constant revisions of understanding and knowledge based on new experiences (Bryman, 2012). Social constructionism by nature focuses on meaning that is influenced by the prevailing cultural framework of social, linguistic, discursive and symbolic practices (Cojocaru and Bragaru, 2012). For families, society will be viewed as existing both within subjective and objective realities.

Exploring social and interpersonal influences were built into this study. This recognises the significance of current societal constructs about how learning-disabled children are perceived; as well as how the system expects parents to behave. This research has sought richness of understanding both through separate individual perspectives and integrated understandings of family mini cultures; showing how family values have developed over time and providing insights into patterns of commonality within and across different family units.

A large quantity of the data collected for this study comes from applying narrative methods. Collecting family narratives and understanding them as subjective experiences enables exploration that develops appreciations that can inform and re-orient societal responses (Laverty, 2003). To quote Grele (1991, pp. 271-2):

> *'People can and do use history, and they can use it to actively involve themselves in the cultural dialogue…. People are not simply objects of study but part of a community of discourse.'*

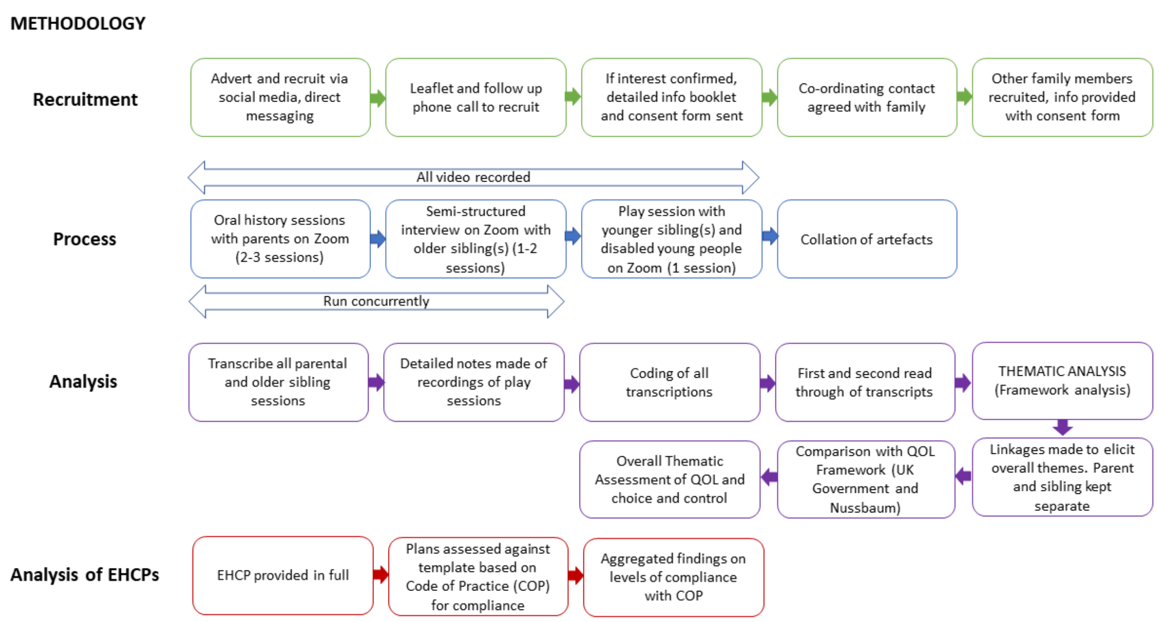
A holistic approach was taken with the research. All family members within nuclear families were invited to participate. Not all family members chose to participate (which is commented on elsewhere) but the study design facilitated the exploration of differing perspectives amongst various family members.

Drawing on families' past experiences helps to make sense of their present situations and future aspirations, which exist in many respects on the same continuum in relation to the whole family's QoL. Alongside lifeworld this study also focused on 'the system' (Habermas, 1981) and how it interacts with family lifeworlds, such as how much choice and control families can exercise in the context of obtaining services and support for their children, as well as other important aspects of their lives; and how these intersect with wider societal systems.

4.3 Research Design: Context

This research was methodologically designed before the onset of the Covid-19 pandemic in 2020. Figure 5 summarises the methodological process and includes the design modifications that were required due to the impact of the pandemic.

Figure 5: Methodology flow chart



As previously stated this study is one of narrative enquiry. References are made in this thesis to narrative methods; the narrations of the families provide the majority of the data. Riessman (2008, p3) describes how the term narrative methods can be used generically and in a variety of ways but is often synonymous with ”story”. When the term narrative is used it reflects information that the speaker has selected as important and has evaluated as meaningful for their discussions with the researcher. Narrative study has increasingly become recognised as a valid method of qualitative enquiry for understanding socio-cultural phenomena. The stories people tell can be gathered in different ways but they represent their realities. This permits the exploration of how ideologies and vested interests become integrated into their narratives (Riessman, 2008).

In choosing the selected methods, I recognised that individual’s stories would go beyond the basic descriptions of everyday life experiences, although these are relevant; details shared would likely include emotional context, the complexity of relationships, and interactions with others, including other family members, friends, professionals and the wider community. This narrative process enables a deeper understanding of the meanings that families attach both to their individual experiences and as family units and how this affects their overall choices and actions in life. As Riessman (2008, p. 3) highlights:

> ‘*in everyday oral storytelling, a speaker connects events into sequences that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story.*

The use of narrative methods makes this research predominantly phenomenological by exploring what constitutes families’ lifeworlds and how they interact with societal systems; exercising choice and navigating power relationships with professionals, agencies and commissioners to achieve the outcomes that matter to them.

4.4. Differentiating the narrative methods used.

It is important to differentiate from the outset the methodological narrative approaches used in this study. To reiterate, Riessman (2008) refers to the variety of narrative methods but maintains that they are all forms of storytelling. Within this thesis different methods were applied according to the different positioning of individuals within each family; whether it be parent, sibling or disabled child. These are explained below.

i. Oral History

This method was adopted with participating parents. Chamberlayne, Bornat and Wengraf (2000) describe oral histories as a form of biographical method providing accounts of historical events drawing on individual experiences. These can function as ‘small mirrors of cultural and social about how individuals make sense of their social worlds patterns’ (Bertaux and Delcroix, 2000 pp.74-75). ‘Historical information’ in the form of free flow accounts was gathered from parents focusing on the family story of their child’s disability as they perceived it from as early as pre-diagnosis. By telling their stories parents were able to give an overview, providing insights not only of family life but also about context, the environment, and how they make sense of it. Individuals in giving their accounts are influenced and shape their narratives within the constructs of their times (Rapley, 2004). Understandings of family situations are likely to be influenced by current social policy, legislative frameworks and societal attitudes. Some questions were prepared as prompts should they be needed (see Appendix 3) but parents could choose whatever direction they wanted to take the conversation. The intention of the design was not to restrict parents by seeking a rigid chronological timeline. The chronological ordering of events in a person's life is much less important than the events that they select, the biographical significance they attribute to them, and how they give them meaning (Wengraf, 2000). Oral histories allowed exploration of episodic elements of children's and parent's lives; how decisions are made and developed.

Laub and Sampson (2003) discuss supporting participants in trying to pinpoint major turning points in their lives. An aim of this study was to enable parents to reflect on their turning points; what Rescher (1995) calls the brilliant randomness of everyday life, including notions of luck and chance. Conversations about who holds the locus of control are relevant; these influence people's understanding of events and their effect on lives (Pritchard and Smith, 2019).

ii. Semi structured interviews-

This method was applied with older and adult siblings (those participating aged 15 years and above). This enabled the collection of open-ended data but with the opportunity for follow-up questions, providing a relational focus (DeJonckheere and Vaughn, 2019). It created a structure for me as the researcher to engage in conversations with participants to understand their thoughts, beliefs and experiences. This felt a more relevant method for older siblings who may not have sufficient understanding of the family's overall contextual history. Seeking open-ended dialogue with young people who may be less confident in their understanding of context made free-flow oral histories less appropriate. The use of a semi-structured format gave them a foundation to work from whilst providing them with the opportunity to talk about what they wanted to regarding what mattered to them about family life. It also enabled me as the interviewer to explore particular themes or responses further. Appendix 5 outlines the schedule of questions prepared for these interviews

iii. Play sessions

I believed from the outset that it was important to include learning-disabled children and younger siblings in this research. However, methods applied had to consider capacity and capability and how to build relationships and trust between the researcher and children involved in the study. Using play can help to build positive adult/child relationships. This can take time but can be rewarding for the child whilst being helpful to the researcher (Hart and Colwell 2014). The plan was to include play sessions, originally using Talking Mats, a picture based communication tool, with those children and young people for whom semi-structured interviews would have been inappropriate due to issues of capacity. Modification to design had to be made due to Covid-19. Talking Mats could not be used so bespoke approaches were developed with parental input.

The final element to data collection was the analysis of Education Health and Care Plans (EHCPs) to link narrative experiences back to how policy and law influence outcomes. The EHCP is a statutory plan that sets out the assessed needs and intended outcomes for young people. It should be co-produced with a child, their parents and professionals. How they are framed provides valuable insights into professional approaches to disability and also how the plan corresponds with family aspirations for the child.

4.5 Recruitment

Families were recruited through parent networks on Twitter. The internet has gradually become much more integrated into daily life with online interaction becoming a regular part of daily life (Golder and Macy, 2014). Garcia *et al.* (2009), cited by Caliandro (2018), argue that the online and offline worlds are increasingly merging into one within society, being populated by numerous communities that are not simply virtual but are also concrete entities. Social media platforms are used to post thoughts, feelings and opinions on almost every aspect of life. I chose Twitter to recruit participants knowing from previous professional experience that many families with learning-disabled children share information through Twitter communities, using the platform to voice both positive and negative views about the system. Twitter is used to engage with a wider group of people than would be possible through local face-to-face networks alone (Chew and Eysenbach, 2010).

i. Criteria for participation

The main criteria applied for participation were:

- that individuals were members of a nuclear family who have a learning-disabled child with complex support needs;

- that child was being assessed for, or already had an EHCP (Age range for an EHCP is 0-25 years).

Not every member of the nuclear family was required to be involved in the research for the family to take part; but as many family members as possible were preferred, to broaden the understanding of whole family experiences. Importantly, the study sought to include disabled children themselves wherever possible, but participation was affected by their capacity and their parents' consent. Participation in the study included families who were receiving community-based services, or residential services, or shared care.

ii. Recruiting the cohort

The initial plan was to recruit circa 20 families but feedback at the first PhD annual review advised this as unrealistic for a single researcher and to scale back; but to recruit sufficient cases to fully explore complexity and the nuanced narratives of social phenomena. The plan was to apply purposive sampling; this typically allows for deeper levels of analysis than is usually possible with representative sampling, allowing the inclusion of contexts and phenomena that can support the answers to the research questions (Mason 2002). It is difficult to identify consensus in the research literature about the minimum number of cases required for meaningful qualitative research; although it is recognised that qualitative studies' sample sizes tend to be small. Chase (2005) suggests that sample sizes will be lower in narrative studies to enable deeper analysis; generally, 6 to 15 is acceptable. The research design was therefore, modified to recruit up to 10 families, enabling a single PhD researcher to undertake a more realistic study; whilst ensuring sufficient data to support depth of study.

Efforts were made to identify more isolated families (a common issue for families of learning-disabled children), to ensure their inclusion within the group. One of the benefits of social media is that some more socially isolated families access online information networks. Two families within the cohort were evidently more isolated but accessed social media for information.

After attaining ethical approval, I contacted direct several Twitter accounts that represent learning-disability parent-network communities, asking them if they would be prepared to share my request for volunteers and information about the study. These agreed to put out an advert through their social media channels. The dialogue moved to email discussion where I explained my background, sent draft flyers for comment, which they helped me to shape for greater appeal. These were subsequently ethically approved. Adverts were posted on Twitter; prospective participants were asked to follow and direct message me for more information. There was no further involvement from the broadcasting bodies from this point and families who contacted me remained anonymous.

Ultimately, two family cohorts were recruited; one in late 2019, before the Covid-19 pandemic, and the second cohort in autumn 2020, after the first pandemic lockdown ended. Had too many families come forward, I intended to ensure a broad range of different family circumstances wherever possible. Some families self-selected out or did not meet the criteria. All families who wished to participate were included. Nine families of varying sizes were ultimately recruited, with 28 individuals participating from a possible total of 40 family members.

Summary of the recruitment process for Cohort 1:

- Advert shared on social media and contact made with the researcher through direct messaging.
- Preliminary information provided to prospective participants and if interest continued, a telephone call was arranged to discuss in more detail.
- Those who wished to proceed received more detailed written information in the form of a booklet with a consent form.
- A lead parent emerged for each family during recruitment, they co-ordinated contact with other family members including partners.
    i. Older and adult siblings who wished to participate were linked directly by the parent with the researcher. Parents were no longer involved with their older children’s participation from this point with the exception of the 15 year old participant. Information was sent to older/adult siblings who either then confirmed their participation or not.
    ii. Parents asked younger children and their disabled child if they wanted to be involved. If they did then child/young person friendly accessible information was sent to the parent to share with their child/ren. Assent

forms were included with the information for completion with the child. (see later section on ethics re consent and assent.)

The information given to families before their involvement included:

- Details of the study and an explanation of methods to be used and the time commitment;
- my status as a PhD student; the university to which I was attached, and the academics supervising the study;
- what would happen to their information and data and how they would be used;
- details about procedures for ensuring their confidentiality, anonymity, safe data storage, and how long information would be retained;
- information about safeguarding;
- A statement to inform participants that they could withdraw from the study at any time.
- permission to use anonymised information in the thesis related to the study.

See appendices 1, 2, 4, 6 and 7.

Once participants had full information and agreed to participate, consent forms were completed by parents and also older siblings (this proved to be siblings aged 17 and above). Where possible younger and disabled children completed assent forms alongside parental consent forms.

The original plan was to undertake interviews in the family home. With the outbreak of the pandemic, home visits were modified into online Zoom meetings instead. The same recruitment process was largely followed for Cohort 2, but it was clarified from the outset that participants' sessions would all be online.

4.6 Data Management Plan

The data management plan stated how data would be collected:

- Two to three meetings with parents in family homes to gather oral histories of their life experiences since the birth of their learning-disabled child; These subsequently moved to online due to covid restrictions. Individual meetings with each parent to take place between two and three weeks apart.

- Semi-structured interviews with older or adult siblings focused on their experiences growing up in a family with a learning-disabled sibling and their perceptions of the whole family's QoL. Up to two meetings were factored into the design with adult siblings.
- Play sessions with younger siblings originally planned to use Talking Mats^{TM} methodology to understand children's experiences growing up with a learning-disabled sibling. Talking Mats however could not be used due Covid restrictions requiring online sessions. Free play sessions with art materials were used instead.
- Where possible, sessions involving learning-disabled children were planned and these were originally designed to use using Talking Mats^{TM}, a picture tile based communication tool, to hear about their lives. The Talking Mats version purchased pre Covid-19 could not be used on Zoom. Bespoke approaches were agreed with parents in advance instead. It was agreed that in play sessions we would focus on proxy measures for children's perceptions of QoL, letting children decide how far into the future they wanted to consider. The areas explored are included in Figure 6 below :

Figure 6 Guide for exploring proxy measures re children's quality of life with children (co-produced with parents)

- What you like doing…
- What you do not like doing….
- The people who are important to you …
- How people describe you….
- What you are good at…
- What you would like to get better at…
- What you hope for when you are older…

- Analysis would be undertaken of EHCPs for individual children to consider how needs had been assessed and outcomes achieved by agencies in partnership with families.

As already stated modifications to the design of this study were required due to the Covid-19 pandemic. This also affected the timetable and scheduling. Families understandably did not feel they could make the space to be involved in research whilst home-schooling during national lockdowns and deferred participation. The UK government had mandated stay-at-home orders from March 2020, and schools closed except to key workers' children and those with SEND. Whilst children with EHCPs were eligible to be in school during lockdowns, many schools felt unable to provide them with safe spaces and so many children with SEND were home-schooled.

This scenario caused extra pressure for families, making research involvement at that stage unappealing. Many families also lost other professional support during lockdown, respite care and home care. The research was interesting to families, but, unsurprisingly, unrealistic for many families during lockdowns.

Recruitment proved slower with the second cohort due to the pandemic; however, it did benefit from some snowballing recruitment as parents from Cohort 1 recommended the study within their networks.

4.7. Introducing the Families

Having outlined the design, this section introduces the study participants, provides family pen pictures, describing the cohort and levels of participation. No real names are used in the study, but pseudonyms are given. Whilst sufficient information is provided to give family context, so as to maintain anonymity, this is sometimes vague where it could identify family groups or individuals. The families can be divided into two broad groupings: those with an autistic child and those with a child with Down syndrome. Two families included young people who are both autistic and have Down syndrome, although both families identified Down syndrome as the 'lead condition'.

The profile of each family serve to illustrate the range of individual circumstances and include:

- The size of the family

- Where each disabled child is positioned within the family (e.g., youngest)
- Economic or employment circumstances
- Family motivations for engaging with the research

1. Andrews family

The Andrews family are a family of five, the middle child of three is learning-disabled; he is now a young adult. He is autistic with particularly complex support needs. His primary condition was diagnosed late, which caused him difficulties. He has several complex physical health conditions, and language delay.

Both parents had professional careers when their son was born. Mrs A left hers to be a full-time carer; her husband is the main earner. The family have made significant adjustments over the years to accommodate their son’s needs and expect to continue to do so in adulthood. They have had long-term involvement with many mainstream and specialist services

Their interest in participating in the research was to ensure that the voices of families with lived experiences are recorded and understood in hope that the system may change.

2. Bali Family

The Bali family are a family of four. Their oldest son is autistic and has cerebral palsy due to birth complications. His autism diagnosis was made around age three and the family received early years autism services to support their son. They are a close family with a small, tight group of friends but little extended family nearby.

Both parents are from India and moved to the UK after the birth of their first child. They are both professionals. Mrs Bali has not been able to pursue the career path she originally planned, instead focusing on supporting her son’s development. They are less familiar than some of the other participating families with professional systems in the UK.

Their interest in the research is their hope that their experiences can further inform professional and societal knowledge about disability to improve services. They believe in and greatly emphasise the value of education. They see a PhD research study as a significant way to build knowledge.

3. Carter Family

The Carter family are a family of four; the younger child of two, a daughter, has Down syndrome. This was not diagnosed until after her birth as it was not identified during pregnancy.

Both parents are professionals and have used their knowledge to seek the best plans and services for their daughter and strongly challenge the system. They also set up a charity to support other parents of children with Down syndrome. They believe strongly in mainstream education for disabled children and as a family have very clear views about what inclusive services should look like.

Their interest in participating is to share ideas around inclusivity and tackling stigma around Down syndrome. Through sharing their experiences, they add to the body of knowledge about living positively with a disability rather than accepting deficit models.

4. Davies Family

The Davies family are a family of six. Their second-oldest child of four, a son, has Down syndrome. Antenatal screening was declined and the parents were unaware of their son's disability until he was born. Mrs Davies has a difficult history of miscarriages and this, along with her strong religious beliefs, meant that her son being diagnosed with a genetic condition would not have made her consider a termination. Mrs Davies is a practising Roman Catholic, which is very important to her sense of identity and inclusivity within her community. Mr Davies is not a Roman Catholic.

Mr Davies works in local government and Mrs Davies is a full-time carer. They have a wide extended family that offers substantial support. All four children are close to each other in age; they are a tight family unit. Their son with Down syndrome, now of secondary school age, goes to a special school.

They identified as a working-class family who are not well off but manage. Extended family resources are shared amongst all family members who need help, including other brothers, nieces and nephews of Mrs Davies's wider family.

Their interest in participating was to be helpful and to raise more awareness and understanding about all disabilities, not only Down syndrome.

5. Evans Family

The Evans family are a family of four. The younger of two children, a son who is now a young adult, is autistic and has complex epilepsy that was diagnosed when he was seven. His older sister lives and works away from home.

Mrs Evans described the difficulties in obtaining a diagnosis for her son, whom she recognised quickly was developing differently from how her daughter had developed.

Both parents are professionals. Mrs Evans is a highly qualified palliative care nurse specialist who gave up her career to become a carer. Once her children were older, she set up a business in which her husband joined her.

They identify as working class who through education, hard work and training have become professionally successful. The family use their financial resources to support their son’s additional needs.

The parents’ motivation for participating was to be helpful, raise awareness about the difference good quality professional services can make; and to share their experiences of what good support looks like for families.

6. Francis Family

The Francis family are a family of three. Their only daughter has Down syndrome. This was diagnosed in utero seven months into the pregnancy, and the couple passionately declined a late termination.

At the time of the research fieldwork, Mr Francis and Ms Streeter were in a long-term stable relationship. They have since married. Mrs Francis is a qualified teacher with expertise in Down syndrome, although became a full-time carer for her daughter. Mr Francis works but his employment is unstable. The family identify as working class; they have a strong sense of regional identity.

Mrs Francis has become an activist for improvements in the way Down syndrome is understood, and for changes in antenatal care and services for children with this genetic condition. She is a campaigner for disability rights, also identifying as disabled herself. This partially motivated her to participate in the research.

7. Gregg Family

The Gregg family are a family of five. The youngest of three children, a daughter, has Down syndrome. This was not identified until after her birth and was a shock to her parents.

The family are academically gifted, and the importance of education and having a career and purpose is a key family narrative. Mr Gregg has a very successful and demanding career in finance. Mrs Gregg who is university-educated was a full-time carer for her children when they were younger, and now works professionally.

Mrs Gregg, in particular, has become an educator who raises awareness about Down syndrome. She has built a large network to talk about it to professionals and challenge stigma. The family's participation in the research was motivated by their wish for wider societal knowledge and more acceptance of disability generally and Down syndrome specifically.

8. Haines Family

The Haines family are a family of five. The youngest child of three has Down syndrome. This was diagnosed antenatally, but the parents did not want to terminate the pregnancy, although the option was offered. Mrs Haines is an advocate for raising knowledge and awareness of disability and Down syndrome.

Due to the ages of the children in this family and the fact that Mr Haines did not wish to participate, only one family member is involved in this research. Both parents are employed, Mrs Haines flexibly, as she is an author.

Mrs Haines has a very strong belief in a positive approach to disability and challenging deficit models. At the time of this study Mrs Haines was in the early stages of navigating the professional systems and had invaluable insights about early help. Sharing these insights motivated her to participate in the research.

9. Jackson Family

The Jackson family are a family of four. The younger of two sons has Down syndrome, which was identified during pregnancy. Mrs Jackson has a difficult antenatal history and had previously experienced a traumatic stillbirth. This young man has some of the most complex needs within the research cohort; he will need intensive support throughout his life. The family have very involved relationships with the NHS, education and social care. They spoke positively of the services and supports they have received from all agencies, although they feel that the system does not always work well.

The Jacksons are graduates and run a joint business. Mrs Jackson has been a full-time carer for both of her children and wanted to spend time with both her sons as they grew up. The couple then set up a business enabling flexible working patterns to support their younger, disabled son.

Mrs Jackson volunteered for the research because her experiences of service partnerships and co-production have been so positive. She wanted to share how much of a difference this makes to the quality of life for a whole family. She recognised that this experience is not true for all families and believes it is important to speak up about the aspects that work well. Their motivation for participating in the research was to acknowledge the support the family have received over many years; what makes a difference and to build service knowledge.

4.8. Research Cohort Profile

Information was provided by parents regarding family composition and information about their learning-disabled children's health conditions (see Figure 7). The complexity of their health care needs is apparent.

Figure 7: Research cohort (Learning-disabled child within each family highlighted in bold type)

Family	**Family Composition: age profiles**	**Number of interviews or play sessions**	**Health Conditions of learning-disabled son or daughter**
Andrews	Mother 50s	2	Autism plus learning disability Duodenal atresia Benign Joint Hypermobility Syndrome; affects walking and balance Nonverbal (receptive and expressive language disorder) Eating disorder Potential mental health difficulties or PTSD Asthma, reflux, difficulties sleeping Sensory processing disorder eczema
	Father 50s	1	
	Son 22	1	
	Son 19	Artefacts shared	
	Daughter 17	Declined	

Carter	Mother 40s	3+1	Down syndrome Learning disability Significant/complex speech, language, and communication difficulties Moderate sight loss and fluctuating hearing loss (glue ear) Physical developmental delay – gross and fine motor skills Problems with auditory processing of information Auditory memory difficulties
	Father 40s	Artefacts shared	
	Son 18	1	
	Daughter 15	1	
Bali	Mother 40s	2	Autism Cerebral palsy Cognitive learning disability Expressive language difficulties
	Father 40s	3+1	
	Son 19	Unable to participate	
	Son 15	1	
Davies	Mother 40s	2	Down syndrome with learning disability Heart condition Being assessed for autism
	Father	Declined	
	Daughter 14	1	
	Son 12	1	
	Daughter 11	1	
	Son 9	1	
Evans	Mother 40s	2	Autism Learning disabilities Epilepsy (Lennox Gastalt syndrome) Limited language comprehension Sight impairment Tendency to glue ear Chiari malformation (cerebellar tissue protrudes into the spinal canal)
	Father 40s	1	
	Daughter 22	Declined	
	Son 19	Declined	
Francis	Mother 30s	1	Down syndrome Duodenal atresia Heart valve issues Sleep apnoea Ankle condition requiring orthotics (hypertonia) Hyperthyroidism
	Father 40s	1	
	Daughter 4	Too young to participate	
Gregg	Mother 40s	2	Down syndrome with learning disability Speech and language support needs
	Father 50s		

	Daughter 19 Son 17 **Daughter12** interview	1 1 1 1	Glue ear/grommets Sight impairment
Haines	Mother 30s Father 30s Daughter 11 Son 9 **Daughter 3**	2 Rest of family did not participate.	Down syndrome Heart valve condition Speech and language support needs
Jackson	Mother 40s Father 40s Son 21 **Son 15**	2+1 Declined 1 Unable to participate	Down syndrome with Duodenal atresia Stoma bag Epilepsy Autism Hearing impairment Sight impairment Nonverbal but with receptive understanding (possibly selectively mute)
Total	28 family members of a possible 40 participated in some form.	40 interviews undertaken. Some participants gave multiple interviews	6 with Down syndrome 4 (1) autistic young people (2 with both Down syndrome and possibly autism) 2 with epilepsy 6 non-verbal or limited language 6 duodenal atresia All but one child or young person with Down syndrome have degrees of hearing and sight impairment requiring hearing aids and glasses.

- In all nine families, both biological parents were living together. The research did not require parents to be in a cohabiting relationship, but the cohort evolved in this way.
- There were no step-parents or blended families.
- Seven of the families were white British; one parent was from Northern Ireland. In one family, one of the parents was from an EU country and married to a British citizen. They have lived in the UK for many years, attending a British university although they attended school in Europe.

- For one family, the parents were born in India; the couple have lived in the UK for more than two decades. Their extended family live in India.
- Three of the families are Roman Catholic, though not all actively practice, their faith is important to their identity.
- In each family at least one parent had achieved higher levels of education, though not all had attended University.
- Three families identified strongly as working class.
- No family members discussed their sexuality.
- At the time of the fieldwork, the disabled children were 3 to 19 years of age.
- Siblings were 9 to 22 years old.

i. Gender balance

Overall, there was a reasonable gender balance across the cohort:

- 5 male and 4 female learning-disabled children.
- 9 mothers directly participated in the study and 5 fathers.
- I father contributed artefacts
- 6 male siblings participated in the study and 3 female siblings.
- There were slightly more male children within the families overall.
- Notably, two female adult siblings chose not to participate and communicated this as a statement about their anger with the disability system.

ii. Demographics

A requirement that families live in England was the only geographical consideration for eligibility; EHCPs are not in place in the other three nations of the United Kingdom.

Within the cohort four families lived in northern England and five families lived in southern England, including London.

iii. Forms of participation

Every family member was given the choice to participate and how they wished to do so. The type of involvement of each family member who participated is set out in Figure 8.

With regard to the nine learning-disabled children and young people in this study, for those who could participate it was agreed in advance with their parents that we would undertake play sessions. These children (3) also gave their assent.

For other learning disabled children information about them came from a mixture of artefacts and parental reports (see Figure 9).

Figure 8: All participants' methods of involvement. N.B Some participants did direct sessions and also provided artefacts. *parent participated indirectly **young person participated and provided artefacts too

Participant identity	**No.**	**Oral history provided (Parents only)**	**Semi-structured Interviews (Adult and older siblings only)**	**Play session Younger children**	**Individual session with learning disabled child**	**Written info**	**Artefacts shared**
Mothers	9	9	-	-	-	1	1
Fathers	5+1*	5	-	-	-	1*	
Children with LD	4	-		1	2		1 (photos, films) 1 ** (photos films)
Adult/older sisters	1	-	1	-	-		1**(video)
Adult /older brothers	5	-	5	-	-	1** (essay)	
Child sisters	2	-	-	2	-		
Child brothers	1	-		1	-		
Total	28	14	6	4	2	3	4

Figure 9: Summary of disabled young people's types of involvement.

Young person	Direct participation	Indirect participation (met online but no focused session)	Artefacts shared by parents or children themselves	Parental descriptions of their child
John 19	No	Yes	Yes	Yes
Fraser 19	No	No	No	Yes
Manav 18	No	Yes	No	Yes
Elsa* 15	Yes	No	Yes	Yes
Rainbow 12	Yes	No	Yes	Yes
Phillip 15	No	No	No	Yes
Karate Dude 12	Yes	No	No	Yes
Kate 2	No	Yes	No	Yes
Martha 3	No	No	Yes	Yes

4.9. Overview of conducting participative methods

In accordance with the study design, once a parent made contact with the researcher and having been sent preliminary background information this was followed up with a telephone call. All parents making initial contact elected to be the lead coordinating parent. Of the nine families participating, eight mothers and one father became the coordinating parent. During telephone calls, I learned a little about the family and I explored who might also wish to participate within the family; including whether the other parent would be likely to participate, clarifying that this was not a prerequisite for involvement but would be welcome. A more detailed 'booklet' and consent form was sent if there was continued interest. Where partners wished to participate, the coordinating parent put me in touch via email. One father who did not want to participate directly provided an artefact for inclusion.

For adult siblings, parents agreed to seek their son's and daughter's views about participation. If siblings were interested in being involved, I contacted them directly once permission had been given to convey their details to me. Specifically designed adult sibling information sheets and consent forms were then provided see Appendix 4. After direct contact was made with adult siblings parents were no longer involved. I did not share anything about siblings interviews with parents other than pleasantries about their offspring if the parents mentioned them.

Participation with child siblings was arranged via parents, gaining parental consent to meet with the children online. Children's information leaflets, designed in easy-to-read format were provided for children (See Appendices 6 & 7) parents were requested to go through these with them. Assent forms for the child as well as consent forms for the parents were provided.

In all but one session where young people were under 18 years of age, the parent was present, either in the background or jointly participating in the session. One sibling who was technically still a minor at 17 years of age met with me online alone and gave consent in their own right.

i. Parental Sessions

Each family selected a lead contact. This happened naturally as the families organised their participation. First interviews were always with the lead parent. They tended to tell the full story as they saw it, over two or three sessions each 90-120 minutes long. Their partners added additional perspectives through a further one or two sessions usually each 60-90 minutes long. It was apparent that these couples talked to each other between sessions and discussed what was shared.

In session 1 the 'lead' parent focussed on scene setting; covering diagnosis and family, professional and community responses to this; and then the story of the child's life to date. This tended to follow a chronological time line as parents structured it this way. Second and third sessions with the lead focused more on impact and emotional context as well as experiences of different relationships. In sessions with the other parent, they referenced what they believed I had already learned re their child's story from their partner, and then they built on this in providing their own insights and perspectives. The focus in these sessions was much more on impact than events. The oral history approach provided very rounded insights of family life from a parental perspective. Parents told me as the researcher when they felt they had completed the stories they wanted to tell. This dictated the number of sessions organised.

ii. Learning disabled children's participation

Three children, all of whom have Down syndrome directly participated in the study. Each of these children chose pseudonyms for themselves and are referred to by those names in this thesis. Elsa was 15 years old at the time of the study. Karate Dude, a boy and Rainbow, a girl, were both 12 years old. In each Zoom session mothers were present in the background. This creates some data limitations as there could be things children will not discuss with their parents present. In the sessions, all three young people used role play and acting to convey information, finding this easier at times than explaining orally. Parents clarified language when necessary as all three children's speech was sometimes hard to understand. Each child receives support from speech and language therapists as part of their EHCPs.

Each child prepared differently for our sessions pre-agreed with parents involvement.

- Elsa worked ahead, producing a PowerPoint presentation that she titled 'My Future Dreams' (See figure 11, for examples).
- Rainbow worked through a simple advance-prepared questionnaire that described things that are important to her talking through and acting her answers in our Zoom meeting.
- Karate Dude came to the session in a relatively unstructured way. He understood why we were meeting and used play materials and props to talk about his life, and his likes and dislikes. He frequently used roleplay during our session.

In addition to these three sessions the parents of a fourth young person, Johnathan, who is autistic, provided several artefacts comprising film clips, photos and short vignettes about him. I met Jonathan briefly online during two sessions with his mother; there were no structured sessions with him. He requires substantial understanding from skilled professionals for support.

Whilst Johnathan struggles to be heard, his parents know that there have been times when he has felt safe and secure, and during these times, he has had a better life. They argued that if people take the time to listen and understand, it benefits their son and can inform his support needs. To show this happier, more content side of their son, his parents shared video clips of him walking with them by the river, sitting on a swing whilst on holiday, hosing the garden patio with his dad, mixing cakes and using echolalia (repeating patterns and phrases) from Disney films. His mother, Angela, emphasised that whilst her son may not be able to articulate his views and wishes orally, he can communicate them. She explained:

> ***‘…*** *he has receptive and expressive language disorder, so that’s obviously something that is really important to understanding my son. So, he doesn’t really have a voice apart from screaming or refusing to do something. I don’t think anybody apart from us really understands my son, nobody hears his voice or what matters to him.’*

Jonathan’s parents indicated that if their son is not understood and kept ‘in mind’, his needs will never be met, which will be catastrophic to his well-being. A lack of understanding of any individual can escalate to very poor outcomes and a very poor quality of life. It is important to recognise Jonathan as an individual; although he could not directly participate in this study, a sense of him as an individual must be understood and included. In this way, he is seen.

iii. Adult and older siblings

Meetings with adult and older siblings followed a slightly more structured format with questions to guide discussion but plenty of free flow conversation. All of the siblings talked fluently about their experiences, observations and reflections about being part of a family with a learning-disabled sibling. One young person chose not to have their camera on. All sessions lasted 60-90 minutes. Each sibling felt they had covered what they wanted to say in one session. Two siblings also shared artefacts with me that they felt provided insights into life for their disabled sibling.

iv. Younger siblings

Four younger siblings, aged 9 to 15 years, were also included in the study. An online play session occurred with one family with three siblings. A Parent was present in the background during this session. This can impact on dynamics, however halfway through the session the children’s mother suggested I met the older two girls alone and she kept the much younger brother busy elsewhere. They talked freely about their experiences of family life and how others outside the family responded to their disabled brother.

A sibling from a different family aged 15 also met with me with a parent present. This was not a play session but a conversation. This family felt more comfortable with their son being involved in part of the parent’s first session but the conversation was very open and the parent fed back to me afterwards that they had learned a lot from listening to their son and valued his insights.

4.10. Design of Data analysis

'We understand the world before we begin to think about it'.

Weinsheimer (1985, p. 11), cited by McManus Holroyd (2007)

A researcher during analysis needs to reflect on their pre-understandings and the meanings within them to determine their legitimacy containing their influence on new understandings. Undertaking this research involved a heuristic journey in which my understanding of the families' stories was influenced by my own experiences and perceptions as a researcher (Moustakas, 1990; Sultan, 2015). As a social work professional, I am situated within a certain dominant perspective of social care. What I know about is predominantly based on training, learned practice theories and orthodoxies and work-based experiences. These provide useful knowledge that both constructs and frames my understanding of social work discourse. I recognised from the outset I would interpret with a heuristic insider's perspective of professional practice. I acknowledged this as both a strength and a weakness and comment on it later in this thesis.

It has been explained that a large proportion of the data reported in this thesis were generated through family narratives; oral histories for parents; semi structured interviews with older siblings; and play sessions with children within the families. The fieldwork was designed to maximise families' views and enable the researcher to reflect upon professional knowledge and experience as part of the research process.

These qualitative methods provided information rich cases which help to build knowledge (Patton, 2002; Palinkas *et al*., 2015). The basis of sampling was theoretical, identifying manifestations of disability, and constructs of childhood, parenthood and quality of life. Families' understandings of power in the context of them exercising choice and control is woven through the analysis. In addition to the family narratives, a detailed analysis of children's Education Health and Care Plans (EHCPs) was completed. In analysing the data themes, the methodology sought to draw out information to develop knowledge about the central issues for families in achieving good outcomes for all family members; exploring depths of understanding about the reasons for the success or failure of strategies that families have adopted to achieve their desired QoL.

i. Process of analysis

In the interpretive process of analysing the data I recognised therefore from the outset that I would be influenced by my prior professional experience of working with other families. I sought to remain objective and to suspend my preconceptions as much as possible, learning directly from the families whilst understanding that I would not always view data clearly, given my past experiences. Therefore, I reflected carefully when seeking meaning from the patterns that families identified.

I applied framework analysis, using a cross-sectional analysis on a combination of data description and abstraction. Sets of codes were identified from the narratives and then organised into categories to manage and organise the data. The framework created a new structure for the data (rather than adopting participants' full original accounts), reducing the data in a way that supported me in answering the research questions (Gale *et al.*, 2013). Through this process, codes were grouped into clusters around similar and interrelated ideas or concepts. The framework method provided a systematic and flexible analytical approach. Whilst analysing the themes, I constantly reflected on my professional knowledge seeking to suspend preconceived ideas about 'how things are', keeping an open mind and being curious and prepared to be surprised. I also kept a reflective log.

The analysis of the data was an iterative, non-linear process. Braim and Clarke (2006) recommend that analytical phases not be followed linearly because more information can be drawn from the analysis by keeping the approach iterative. Ricoeur contends that: "the activity of narrating does not consist simply in adding episodes to one another; it also constructs meaningful totalities out of scattered events." (1981, pp. 278-9). The analysis is designed to be methodical but recognised the need to move back and forth through the data, referencing, cross-referencing and linking back to the research questions. The approach initially involved single-case analysis coding, progressing to multiple-case analyses and comparing and contrasting what emerged. This enabled the development of generalisations to apply broad concepts to the material, something Wengraf (2000) argues is a natural process even for a novice researcher. His helpful four-stage process includes considering; history of lived life, context, subjectivity and the told story. Riessman and Quinney (2005) also identify some key features of good narrative inquiry. This includes developing detailed transcripts; focussing on structure and discourse; paying attention to the micro and macro context of stories told; adopting comparative approaches to identify similarities and differences between accounts

The process involved all sessions with family members being video recorded on Zoom. (one was audio recorded only) from these recordings verbatim transcriptions were made; unless sound recording was poor in which case contemporaneous notes were made. A first and second read through of all transcripts allowed for preliminary analysis. Each transcript then had a single code analysis applied which was reviewed twice to define and refine themes. Codes were initially sorted to provide a thematic analysis. This too was reviewed and refined.

Codes were then cross-referenced with the UK government well-being framework criteria to investigate how family priorities correspond to government indices. This process was repeated using Nussbaum's capabilities framework. These were relevant reference materials for analysis. The former, a UK based well-being framework is logical for families living in England; the latter because it addresses capabilities in the context of learning disabilities; an approach that concentrates on the actual capability of persons to achieve lives they value rather than solely their rights or freedom to do so. Ton *et al*. (2021) argue that inquiries seeking to understand the inequalities within the context of human capabilities will find qualitative methods well suited to understanding the realities of social actors and provide a foundational method for critical realist research.

The analysis and revision of combined themes involved using spider diagrams and thematic maps to evidence elements of connectivity amongst them. I applied what Wengraf (2000) sees as a continual cycle of analysis, using reading, writing and reflection as I achieved increasing familiarity with the data. Through this process, I investigated constructs including disability, childhood, parenthood and QoL. The analytic aim was to develop themes from the data and analyse that data; rather than simply reporting on it. Whilst I read widely during the initial literature review phase, further reading became necessary during the analysis phase, both to follow up on ideas and to make sense of what emerged from the analysis.

Finally, a template was used to analyse EHCPs, breaking the plans down into their component parts and analysing each section assessing SMART objectives and level of family and agency involvement to investigate how the formal plans match families' perceptions of assessed need; and their satisfaction with their EHCP's stated outcomes. Research by the DfE (2018) found that family satisfaction with the EHCP process when considered alongside an expert panel's assessment of the quality of the resultant plan do not always correlate (Adams *et al*., 2018).

For the purposes of analysis in this research, a grid was developed presenting each prescribed section of the EHCP (A–K). This helped to assess whether each section of each child's plan covered the SEND Code of Practice requirements. It also permitted cross-referencing with the families' views on needs.

The combination of data from interactions with families and the analysis of EHCPs formed the basis of this research in understanding the how families exert choice and control to achieve a good quality of life.

4.11. Reflections on the research design and the impact of Covid-19

In the years ahead, academics will recognise that the body of academic research undertaken from 2020-2022 was significantly affected by the Covid-19 pandemic. National lockdowns led to academics and universities reworking research methodologies, as in this study. I attended several online free access webinars that had been quickly instated by several academic institutions about adapting research methods. I used opportunities to draw on very experienced research academics for advice on study design and ethical considerations.

These insights led to modifications in the research methods. The main changes being the move to online meetings and adapting how I involved children in the research. There were some advantages to online sessions which enabled good quality recordings which are easy to review and therefore aided analysis. Families did not have to concern themselves about health risks arising from home visits during a pandemic, or considerations of when the researcher leaves their home. It is easy to reference domestic responsibilities that need their attention, enabling the swift conclusion of Zoom sessions if required.

There were challenges though. Online meetings generally prevent the fuller opportunities to build rapport that face-to-face meetings offer. It is harder to sense mood. Some participants felt self-conscious about seeing themselves on camera and one agreed only to meet with the camera off. If cameras are off, it is harder to identify stress or anxiety other than through tone of voice, making support in these sessions more difficult.

It was not possible to use the purchased version of Talking Mats^{TM} on Zoom making children's participation harder to achieve. Discussions with parents enabled bespoke approaches to sessions with learning-disabled children. Bespoke approaches however create limitations of replicability. Careful reflection was applied to decide whether the methods made sense and provided meaningful insights that were not tokenistic. The methods largely worked but fewer children were involved that might otherwise have been the case if there had been face to face sessions where rapport could be built with time.

4.12. Ethical Considerations

The ethical considerations of this study were assessed through Durham University's internal system of approval. The study did not involve patients or staff members of NHS facilities, no external approval procedure was required.

The fieldwork involved a vulnerable group of learning-disabled children and their parents and siblings who live with the embodiment of disability. The sharing of family experiences is always likely to involve sometimes painful and traumatic memories, as well as positive experiences and celebrations of successes. Families through the use of narrative can disclose sensitive personal information that must be treated with respect and confidentiality. This needed to be well understood and planned for. The principle of do no harm was applied (Brown 2014).

Ethical considerations included issues of informed consent, use of assent, confidentiality and anonymity. A data management plan was submitted with the ethics application which considered secure storage of data and the need to produce some benefit as a result of the research. Once published, the research should not allow families to be identified and the information shared should not harm any individuals or the well-being of the family unit. Copies of information provided, consent and assent forms can be found at Appendices 2, 4, 6 & 7.

Given participants were invited to talk about personal issues relating to their family life, I believed it important to ensure that they had some information about where to seek further advice, support or counselling if the issued raised in interviews merited this. I had prepared contacts should these be required. The study design paid particular attention to any additional vulnerabilities for disabled children, recognising the importance of safeguarding practice and thinking through the possible repercussions carefully. If a child disclosed information that led me to believe they were not safe, I would need to address that information with appropriate responses and follow-up actions that could include contacting other agencies and accessing supervisory oversight. In working with the participants, clarity was required from the outset regarding these safeguarding considerations to ensure that participants understood this when giving consent.

The University's ethics procedures required that children and young people under the age of 18 participating in the study needed parental consent. Whilst observing this requirement I also built in that assent would be sought from any minors involved and forms were designed for this purpose. This requirement for parental consent for the older but non adult siblings raised questions about young people's rights to give their own informed consent. Gillick competency assumes children over 16 have capacity to make their own decisions in key areas. There were two siblings aged 15 and 17 participating in this study for whom semi structured interviews were appropriate. The 15 year old assented but his parent wanted to also sign a consent form for his participation. The 17 year old who was months from his eighteenth birthday signed his own consent form without written parental consent but their verbal agreement.

Giving assent or consent in working with children including learning-disabled children, implies that the participants are competent, pro-rational beings (Wyness, 2019). Age and capacity can mean excluding very young children or those who have learning disabilities. This created a risk for the study of some children's views only being mediated through others. the British Sociological Association guidelines state: '*in some research contexts, especially...field research it may be necessary for the* *obtaining of consent to be regarded…as a process, subject to renegotiation over time.' (BSA, 2017, A.19)*

A child may struggle with written information and being asked to volunteer. Cock (2006) argues that in working with learning-disabled children, making observations over time about whether respondents are happy to contribute to research is important and she emphasises using assent; she argues for being guided by parents about what their children can manage.

My approach ultimately involved working closely with parents, agreeing with them on the information their child needed and in what format, and then constantly assessing and observing how children interacted with the study, reading their cues and being guided by parents on preferred styles of communication. I also learned from parents and siblings what to look out for as indicators of a child's discomfort/distress; families were very attuned to this. For all individuals participating it was emphasised that participation was entirely voluntary and that they could withdraw even after giving consent.

Full ethical approval of the design, data plan and accompanying materials was obtained through the University's ethical process.

4.13. Conclusion

This chapter has described the overall methodology applied to this research and has provided a rationale for the particular approach to narrative research that was adopted. It has addressed a number of ethical issues and described the influence of my biography on the research process. The next chapter considers the quality of design of this study before moving on to findings from the data analysis.

Chapter 5: Results of Data analysis and findings

5.0. Introduction

This chapter presents the analysis of the data collected from families participating in this study; exploring data findings in relation to families' perceptions of life experiences; the services they receive; and the relationships they find significant. It begins to consider key aspects of the overall research question regarding the choice and control that families believe they exert in achieving a good quality of life for themselves and their learning-disabled children which are developed further in subsequent chapters.

Before exploring the findings however consideration is firstly given below to how the research design addressed issues of quality related to assessing validity, reliability and generalisability of the study; addressing head on potential limitations with the data obtained through qualitative research.

5.1. Exploring validity, reliability and generalisability

One of the most frequently highlighted problems with qualitative methods is that studies are insufficiently empirical, based on a series of anecdotes and impressions mostly based on samples that are too small for generalisability (Pope and Mays 1995). Also argued is that data is analysed by subjective, biased researchers influenced by their own perspectives; thereby making reproducibility problematic; other researchers could reach completely different conclusions.

The rebuttal to these arguments is that they presuppose that there is one external reality for all, that can be accurately measured, understood and applied. Pope and Mays (1995) recognise this and point to the subjectivity that is also present within quantitative studies, whose reliability still depends on the researcher's judgment and skill, the appropriateness of the question being answered and the data collected. Design quality regardless of research style, therefore, is paramount.

i. Validity

Before going on to explain the findings of this study, given these criticisms of qualitative methods, it is important to consider whether this research has measured what is intended. Could the same results be obtained by using the same methods, and how far can the findings be applied to a wider context?

In order to ensure rigour in qualitative research, systematic design is vital, from the data collection to the interpretive methods applied and then how the findings are communicated. In describing the different stages of the study in some detail in Chapter 4 above, it provides the opportunity to produce for others a plausible and coherent explanation of the phenomena under scrutiny (Pope and Mays 1995).

There is some reality that qualitative methods can appear less concrete than quantitative fact-based research but phenomenological approaches recognise that each human being lives in a world that has particular meaning to them (Patton, 2000). Everybody's experiences in relation to a phenomenon are valid and build knowledge. This gives qualitative research validity. Schwandt (2000) points to the importance of understanding the insider positions of social actors and how they define their worlds. He argues that this is a powerful and central concept for understanding the purpose and value of qualitative studies, which derive validity from careful design and analysis.

As the researcher applying a case study methodology, I need to evidence that I understand what these cases represent. Yin (2009) differentiates between different types of cases that seek different things. In this research, the cases are not intended to be generalisable across a whole population of learning-disabled people; they are not a homogeneous group; but they are a revelatory group offering opportunities to understand the phenomena of lived experience for a group of families whose lifeworlds include learning disability; and whose views are underrepresented in research.

ii. Reliability

Britten and Fisher (1993) comment that there is some truth in the quip that quantitative methods are reliable but not valid, and that qualitative methods are valid but not reliable. To support reliability, from the outset, I applied analytical rigour to how the data would be interpreted maintaining meticulous records of interviews and observations, documenting the analysis process in detail. Mason (2006) argues that defending the ability of one's chosen data sources and methods when seeking to explain concepts is necessary. For this research, a coding frame was developed to apply to the verbatim transcripts produced. Interviews conducted on Zoom provided the advantage of not only relistening to audio recordings but also watching the recordings to note expressions and body language. This helped with understanding interviewees' moods and comfort.

In collecting data, I understood that a researcher must seek to triangulate information wherever possible and reflect on their biases. Detail can be lost over time for participants, skewing their narratives. Seeking to verify facts is important, particularly when it is straightforward to do so or in the public domain (e.g., news events or historical context). This does not imply disbelief in participants' accounts but recognises that people shape their narratives in sometimes strongly emotional ways. Research methods that require interpersonal interaction are inevitably emotionally rich and can be coloured by emotion that changes the perspective (Bondi, 2005).

Other researchers could not be involved in analysis due to the singular nature of this PhD study; however, during the research, coding systems were shared and tested out under supervision, and my rationale and approach were discussed. A challenge to the credibility of any qualitative research is the researcher's adoption of a neutral stance in relation to the phenomenon being investigated. It is unrealistic to think that any individual making sense of others' narratives would not apply any of their own understandings of the world. This can colour interpretation; however academic supervisors challenged my thinking and perceptions, sometimes resulting in my returning to the data and re-evaluating. Maintaining a reflective log also challenged my thought processes.

iii. Generalisability

Patton (2000) acknowledges that social phenomena are contextual and bound by different variables, making producing empirical generalisations in social research very difficult. He argues however, that context is important and the locality of data provides the knowledge and insight to build context. Stake (2000) argues that the priority within qualitative research is to do justice to the specific studied cases. Taking insights from the particular, helps to build patterns of understanding and meaning. Pope and Mays (1995) also suggest that generalisability is not just about what can be learnt from a single case, but also carefully describing the context and particulars of the case study. This includes flagging the similarities and differences between the case study and other settings of the same type. This can contribute to a body of social theory and empirical work to develop a deeper understanding.

The purpose then, of qualitative study is not to produce rigid rules founded only on quantitative empirical data; but rather to develop theoretical insights, challenge constructs and fixed ideas, and develop hypotheses that can be tested to develop meaning and greater understanding. This study does not seek to argue that everything discovered within it becomes generalisable across the whole population of learning-disabled children. The very heterogeneous nature of disability, even within the small cohort involved in this study, would make overall generalisations unwise. However, the experiences of those involved in the study and their realities have provided knowledge and understanding that build patterns of meaning which offer more generalisable results for some populations of learning-disabled children.

5.2. Reflexivity

Mauthner and Doucet (2003), drawing out the personal, interpersonal, social and institutional contexts that can influence the researcher and participants, examine the considerations involved in data analysis and reflexivity and their impact on qualitative research. Empathy is important to building trust and rapport with participants, as is being non-judgemental, although the emotive nature of some disclosure can also lead to overidentification, rather than compassion.

A key reflexive principle for the researcher is to approach the data openly and with curiosity, rather than setting out to prove their particular perspective. Patton (2000) describes this as a commitment to understand the world as it unfolds and be true to the data. Given my professional background in social work with its culture of regular supervision to challenge one’s practice, assumptions and unconscious biases, I used a reflexive heuristic process to remain true to the data. Reflecting during academic supervision proved important as supervisors challenged me if they saw problems with my reflexivity or overidentification.

From the outset of the study, I felt the importance as a researcher of accepting an individual’s truths whatever the context; understanding that the neutral researcher should not make judgements about individuals nor overidentify with their narratives. I was very aware of my context as a professional, a parent and, specifically, the parent of a child with a hidden disability and how this makes me particularly protective of her. In this, I could relate to the stories that parents told, although they have experiences of different disabilities. I was aware that I needed to be careful about overidentifying with participants and avoid the temptation to be unquestioning, accepting things at face value and failing to check facts.

The important principle was to judge what the data offered for understanding and meaning making. Good research relies on integrity, independence and neutrality. The interview process is not a one-way interaction however, and participants' sharing of personal insights and the researcher's reaction to these are part of the process. Compassion is often a natural and appropriate emotion despite the risks of overidentifying and losing objectivity as relationships grow. I recognised that it was necessary to make careful judgements about the data and the stories that participants told. The engaging ways they shared their stories and occasionally very personal information raised the possibility of being unquestioning in my feelings of empathy and compassion for their situations. Academic supervisors commented on occasions that I might be taking what was said at face value, which could be misleading. I subsequently followed through with my thinking by exploring factual information.

The researcher's constant challenge in this type of qualitative research lies in the need to suspend their attitudes, beliefs and suppositions to focus on the participants' experiences of the phenomenon under investigation, to gain a better understanding of the social world. I came to this research with my own lifeworld comprising my conscious experiences as well as my more obscured consciousness.

In this context, the 20th century philosopher Buber distinguishes between concepts of I–Thou, focusing on the experience of being present with others, and I–It, focusing on the experience of self (cited in Moss, 2015). Buber highlights the importance of having a true sense of oneself as well as developing authentic relationships with others. This focus on being present with others, seeking to be empathetic and seeking understanding of their perspectives whilst being self-reflective is a helpful differentiation.

During the research, by using supervision and reflective practice, I could step back after interviews and further explore the information that was shared, triangulating it where I could. I took opportunities to present my work to research groups within the department where I was a researcher, enabling access to more experienced researchers who provided constructive challenges and helpful insights through feedback. My journey through the research process, however, was one of constant self-reflection to avoid my personal biases influencing my understanding of the issues being discussed. Doing so was not without its challenges but an invaluable process.

5.3. Analysing the data

To recap, the data was obtained through narrative methods with 28 participating family members and limited inclusion of some artefacts. In addition, six EHCPs were analysed against a template specifically designed for the research based on the SEND Code of Practice requirements for EHCPs.

The following is considered in this chapter:

- Data in relation to learning-disabled children and what it tells us about what matters to them.
- Data derived from oral histories with parents and semi-structured interviews with siblings; analysed to explore parental and sibling definitions of quality of life and how they exert choice and control.
- Data relating to younger siblings' views about quality of life and how and if these reflect their family 's overall values.
- What the analysis of EHCPs indicate about how these plans support desired outcomes.

i. Learning-disabled children's data

A particular aim of this study was to give individual disabled young people within the cohort opportunities to share their experiences of everyday life, their hopes for the future, what they enjoy and what creates challenges for them. Ryan (2021, p. 18) describes how little research considers the everyday experiences of family life for disabled children, commenting that disability studies research can be underpinned:

> '*by gross assumptions about life experience that further pathologises and marginalises people singling them out and badging them as other*'.

In different ways, Prout and James (1997) comment that children should be active in the construction and determination of their social lives, the lives of those around them and the societies in which they live. The exclusion of disabled children from decision-making, particularly in relation to their own lives, echoes their exclusion from participation in society. Children are not only passive subjects of social processes and structures (Berridge, 2017); they can, however, become invisible – to their detriment – in a system that is not personalised to their needs. Not all learning-disabled children within the cohort could directly participate in this study. However, three young people with Down syndrome did participate. Their views of in response to the pre-agreed discussion areas are summarised in Figure 10.

Figure 10: Summary of disabled child participants' views about their lives

Life elements	**Elsa (the snow queen), aged 15**	**The Karate Dude, (KD) aged 12**	**Rainbow, aged 12**
What I like doing	• Looking after animals, even poo picking at the stables. • Being with a friend, chatting with her online, sleepovers and clothes shopping. • Art at school. • Maths and English at school. • Being a school prefect. • Swimming, gymnastics, drama workshops, singing and horse riding or horse grooming. • Eating out at McDonalds, going to the cinema, theatre, or park together and spending time with friends on Facetime and TikTok.	• Football, army cadets, expressive dancing and tennis. • Eating breakfast, especially if it is brioche. • Love cooking at camp and eating sausages and beans. • Acting out 'strong man'. • Playing with siblings' friends. • Computer games. • Spending time with extended family. • Playing the violin.	• Ballet, horse-riding, baking. computer games, Stage Coach, singing, playing pool, swimming, netball and trampolining. • Holidays, especially abroad. • Listening to music like Dua Lipa.

What I don’t like doing	• Getting up early. • Washing up.	• School, generally doesn’t like maths or English,	• Maths and English at school. • Getting up at 6 am to be ready in time for school.
The people who are important to me, and pets	Mum, Dad, brother, best friend. Chickens.	Mum, Dad, brother and sisters, grandparents, (worried about grandad who is in hospital), aunts, uncles and cousins, and one uncle in particular.	Mum, Dad, sister and brother, grandparents, uncle and aunt, two best friends. Family dog and hamster.
How people describe me	• Funny, kind, and good fun. • A good friend. • Caring. • Can be a little bit grumpy. • Good sense of humour.	• Fun and boisterous. • Sometimes stroppy. • Like to hang around with sister’s friends but sometimes won’t leave people alone.	• Friendly, cheerful and fun. • A little extra ray of sunshine. • Dad calls her Rainbow. • Her brother says she snores, but she doesn’t believe that. • Sometimes grumpy.
What I am good at	• English and maths • Some art, especially making models. • Helping out at home, washing up. • Looking after chickens with brother.	• Army cadets. Drawing, acting and expressive dancing. • Doing karate. • Helping uncle in the garden.	• TikTok and singing. • Geography, drama, PE, science and art. • Giving cuddles to people I love.
What I would like to be better at or need help with	• Cooking, cleaning and shopping. • Looking after money.	• School work. • Noise is difficult; need help with managing noisy experiences.	• Playing piano. • Some school subjects, but particularly

	• Remembering things. • Travelling to places.		maths and English.
What I hope to do when I am older	• Work with animals, providing animal care. • Live in own home with best friend and be able to have parents over for sleepovers. • Learn to drive and have a pink car (or ice cream van).	• Be a firefighter or in the army. • Or a karate expert or boxer. • Work for uncle who landscapes gardens.	• Not sure, but probably something to do with computers.

What learning-disabled children's data tells us

i. Elsa

Elsa has always attended mainstream schools and plans were in place for her to sit some exams, though not a full curriculum of GCSEs. She has real aspirations and a clear idea of what a good life looks like to her (see Figure 11). She was confident that this is achievable but also aware that she will need support. Elsa's information reveals that her aspirations differ little from what one might expect of many other young people of her age. Specifically, she was able to articulate what a fulfilled life into adulthood looks like to her:

- To be healthy, happy, and able to enjoy good food.
- To have loving and caring relationships; to be cared for and to care about others within her family as well as in friendships.
- To go where she wants to go and have access to leisure and activities she enjoys.
- To be free to imagine, dream, express what she thinks, and be heard.

- To understand where she fits in; she is clear that she wants a job and that adults will support her in this, particularly her mum.
- To have a relationship with nature pets and animals are important to her.
- To make free choices and advocate for herself, including where she lives and when she will leave home.

Elsa was able to move between big-picture ambitions, such as having her own home and sharing it with her long-time friend, and smaller goals like being able to invite her parents over for sleepovers. She wants to learn to drive and dreams of having a pink Mini. She wants to work with animals in paid employment, the route to which is a college that offers animal care courses for students over 16 years old.

Figure 11: Examples of Elsa's Powerpoint Slides

I think I will need help with...

- Cooking
- Cleaning
- Shopping
- Looking after money
- Remembering things
- Travelling to places

When I am older...

- I want to go to animal college so that I can work with animals
- I want to leave home when I am 18. I want to live with my best friend
- I want a job helping to look after animals
- I want to have a pink car
- I want my Mummy and Daddy to come and visit for a sleepover

ii. Rainbow

Much of how Rainbow described her life was similar to the interests of many soon-to-be teenagers: music, friends, online games and social media. She has a varied social and cultural life, enjoying ballet dancing, horse riding and baking. She plays computer games socially in small, secure gaming groups. She has a large, inclusive circle of friends within and outside of school. She attends a mainstream school and is coping with the academic requirements with support. She may be typical of many other 12-year-olds, but she is also very individual.

Rainbow was clear about what she enjoys in life and was able to discuss bigger subjects alongside smaller things. Her priorities reflected her younger age and life stage. The transition to adulthood was not at the forefront of her or her family's thinking. As a 12-year-old, the security she gains from living with her parents is still important to her. She described her routines and clearly finds reassurance in them.

iii. Karate Dude (KD)

Karate Dude (KD) presents as an energetic young man with a rich and varied social life and opportunities for outside activities. He attends a special school rather than a mainstream one. His parents believe he will cope better in a more protected and supportive environment for his secondary school stage. He has a large sibling group and enjoys time with his siblings' friends, as well as having his own friendship groups. He description of his world was strongly focused on the people who matter to him and the things he enjoys doing. He was exuberant about friendships, food, computers and life in general, although he clearly worries about the health of people who are important to him.

KD struggles with some aspects of his life because he experiences sensory overload, which unsettles him. Whilst he is noisy and boisterous himself, he finds noisy environments challenging. During the Covid-19 lockdown, KD exhibited signs of mental health issues and deteriorating behaviour that eased once his parents insisted that he return to school for at least a couple of days a week. He reported that he does not like academic work, but he does like the routine of school. He aspires to become a firefighter when he grows up.

In summary these data could not be coded in the same way as parents' and older siblings' data but were considered summatively.

- All three children have developmental challenges that are linked to their diagnosed Down syndrome. These are reflected in their EHCPs. Each of them, whilst fully able to hold animated conversations, struggles with complex language and they need people to use short, simple sentences in dialogue. They are also more comfortable with visual cues. All three adopted impromptu roleplay to explain things during our sessions.
- In relation to their lifeworlds, they all shared rich narratives about their experiences of family life and their sense of security. They all conveyed a

particular enjoyment of sibling relationships and the safety this provides them, even if siblings can be annoying! The normality of the children's experiences in day-to-day life is evident; they participate in very similar ways to their non-disabled siblings.

- These particular children's lively, animated personalities could mask the challenges they face. They need those around them to understand and be responsive to their additional support needs. The different levels of challenge the children face were evident in relation to language and cognition. Also, their sometimes disinhibited conversational behaviours could make them more vulnerable. It will always be important for those who know them to realise this; professionals will need to adapt to these children's engagement styles for support systems to work.
- Each of these children clearly gain security from routines and, although they complain about these at times, they evidently feel safer with predictable and consistent schedules. They all struggle with sensory overload. All three of them can be noisy themselves when animated, but they and their families indicate that they manage better in calmer situations. This is important in the context of school, which is a busy environment. Not recognising sensory issues risks overlooking learning support needs.
- Significantly, these sessions revealed that these three children have little if any awareness of the challenges their parents have faced and continue to face in acquiring the right services for them, particularly within academic environments. They are protected from those challenges. Parental ambitions to ensure that their children's lives are as normal as possible are reflected in the children's descriptions of, and aspirations for their own lives. They were all secure in their beliefs that they can have goals and the support of their families; and recognised their need for this support.
- The parental protectiveness that mostly keeps them unaware of the challenges in accessing services will inevitably end when these young people grow older and become adults who must access services for themselves.

Whilst this is a very small group of young people, there is much to learn from what they tell us. Their experiences provide a contextual backdrop to the rest of the findings explored in this chapter and help to keep the child in mind when considering what services and support for disabled children should look like. When considered in the round, the information from these children affirms that they seek what most humans seek: safety and security, having a good home, feeling loved, having purpose in their lives, enjoying leisure and being as healthy as it is possible to be. They understand that they are good at some things and less good at others. They all have some belief that it is possible to become more skilled, especially with practice and support. They also want to be heard by their families, teachers and friends, given choices and allowed to influence what happens in their day-to-day lives. Each child presented nuanced personalities in interviews, and they strongly challenged ableist tendencies to view disabled children, and particularly children with Down syndrome, with a singular identity (Smith & Smith 2021). That said they are typical in many respects of the general population of UK children of their age and cultural background in what matters to them.

Having summarised the findings from disabled children's data, parental data is now considered.

ii. Parental data

As described in the methodology chapter, all parental data was coded and thematically shaped. After the initial thematic analysis, codes were sorted to see how they corresponded with two recognised quality of life frameworks. QoL frameworks are useful to assess the quality of people's lives, rather than try to explain them (Rojas, 2009). Having completed codings and my own thematic analysis codes were then referenced against the UK government's measures of well-being; and Nussbaum's central capabilities approach. These were adopted as proxy measures for quality of life. In deciding to explore how the codes from the narrative interviews corresponded with the two different frameworks, the aim was not to fit the data to the frameworks but to test how the frameworks resonated with parents' priorities and, therefore, hold relevance for the families' experiences. In Chapter 3 it was explained that these frameworks were chosen because they offer opportunities to analyse both how the system influences QoL as well as the personal lifeworld.

In analysing the narrative data, more than 1,600 codes were identified (1,009 for parents and 591 for siblings). Parental codes are grouped into 37 wider themes, which are listed in Figure 12, below. This exercise was completed before any referencing was made to other QoL frameworks.

Figure 12: Parental data: Main themes related to QoL (unweighted)

Access to education
Access to health provision
Activism
Care services and support
Complexity of conditions
Co-production
Costs of care and services/economics
Couple relationships
Citizenship
Culture
Developmentalism
Disability
Economic well being
Employment
Eugenics
Extended families
Family support/kinship
Fear for the future
General well-being
Grief/loss
Health
Identity, stigma, and societal attitudes
Impact of Covid-19
Impact on other siblings
Inclusion
Leisure
Luck and chance
Mental health
National and local governmental policies,
Pride, joy and happiness
Private and public provision
Professional skills knowledge and experience
Relationships with professionals
Service availability
Social media
Supportive communities
The future

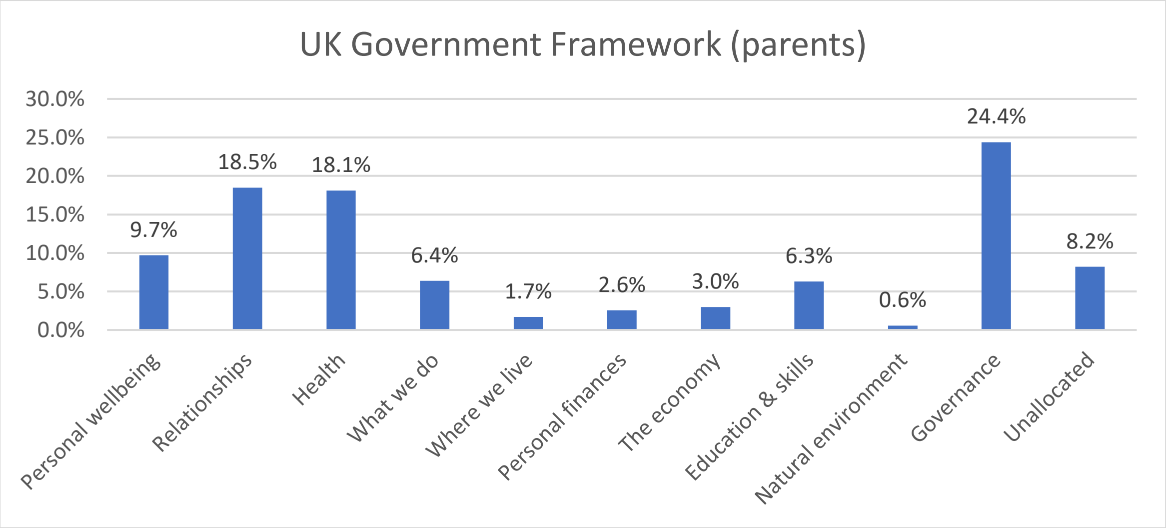
After my own thematic analysis was completed the individual coding data were firstly cross-referenced with the government's well-being measures. Families live within the context of national policies and public systems making the UK government's framework for assessing QoL highly relevant to assessing how policy supports family expectations. The framework includes 10 aspects of well-being these proxy measures are listed in Figure 13. The Office for National Statistics (ONS) gathers and publishes data nationally on these.

Figure 13. **UK Government measures of well being**

- Personal well-being
- Relationships
- Health
- What we do
- Where we live
- Personal finances
- The economy
- Education and skills
- The natural environment
- Governance

Each parental code was cross-referenced and Figure 14 below evidences how the parental codes corresponded with these governmental proxy measures. The percentage numbers in the bar chart represent how these codes matched to a governmental theme within the framework. E.g., 18.5% of parental codes correspond to considerations about relationships. In general terms, sorting the parental codes in this way revealed a degree of coherence in the application of well-being measures as defined by the UK government framework. 92% of parental codes were matched to a government indicator of well-being. However, 8% of parental codes could not be easily matched to any of the facets of the governmental framework.

Figure 14: Parental codes matched to UK government personal well-being measures

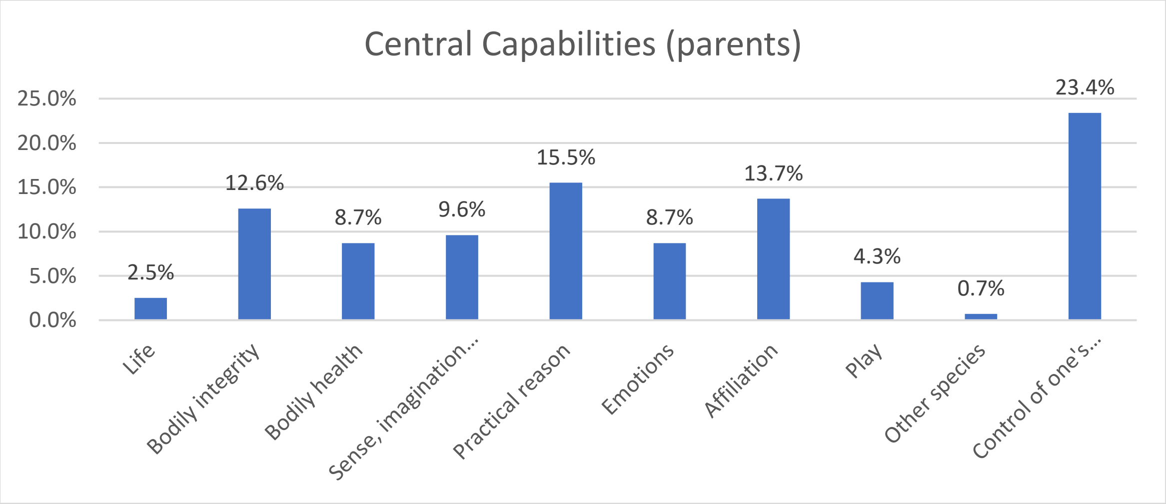


Government criteria tend to be transactional with fewer of the higher order self-actualising elements (Maslow, 1943) that families prioritised in their narratives. Most parents emphasised health, personal and professional relationships and systems of governance in relation to what contributes to a good quality of life. They discussed governance in relation to local and national policies and practices, as well as legislation, which they tended to describe globally as ‘the system’. Their focus on the system and how it operates is a key theme discussed in subsequent chapters, as are family lifeworlds and how the system affects them.

The process of referencing parental codes was repeated using Nussbaum’s central capabilities framework. The rationale for its use was discussed in detail in Chapter 3. Nussbaum contends that QoL and what it means to individuals must be considered within the context of social, political and economic conditions with principles of social justice. She describes it as a useful heuristic for diagnosing a society’s strengths and shortcomings, arguing that an individual may have the internal capability to do something, but be prevented from achieving it by the absence of opportunity or function; and by systemic barriers.

As with the governmental framework, parental data also resonated with the central capabilities framework. How it differed was that all parental codes could be matched to one of the capabilities unlike the government measures. The focus of the framework on higher order, more self-actualising capabilities worked well with the data (see Figure 15, below). Both frameworks overlap to a degree, e.g., corresponding in health and in relationships or affiliations, but there are additional facets within the central capabilities framework that more closely link to the importance that parents placed on thought, reason and identity.

Figure 15: Parental codes matched to Nussbaum's central capability measures as proxies for quality of life.



*in graph above complete wording of the two capabilities ending with … is 'Sense imagination and thought' and 'control of one's environment'

The numbers in the bar chart above represent the percentage of individual parental codes that corresponded to a theme contained within Nussbaum's framework. E.g., 23.4% of parental codes corresponded to considerations about control of one's environment.

Comparison of QoL frameworks; parents

The bar charts both show that for parents, governance (24.4%) in Figure 14, and control over one's environment (23.4%) in Figure 15, appear to feature most strongly.

Whilst they are not identical criteria, these are similar ideas, corresponding to how political and policy considerations featured for parents. This is relevant to discussions of choice and control in subsequent chapters. A strong focus on relationships (18%) and affiliations (14%) also largely correspond, featuring in the top three considerations for both frameworks.

Intuitively, one might expect health to feature highly, given the nature of some of the children's health needs. This emphasis is apparent in the government framework (18.5%) but less prominent in the capabilities framework (bodily health, 8.7%). However, health considerations appear in two other of Nussbaum's capabilities criteria: life (2.5%) and bodily integrity (12.6%). Collectively, these three capabilities equate to almost 24% of parental codes, confirming a strong emphasis on health and wellbeing considerations.

Sorting the codes against different proxy measures highlights areas of preoccupation in the participants' narratives of their lives giving them some weighting. The different distribution of codes for each category demonstrates parents' QoL priorities. During the narratives, parents reported that some QoL considerations become more dominant at different times as different aspects of life presented for them either the most challenges, or the most fulfilment. They discussed how transitions between life stages shifts their focus and priorities.

iii. Older/adult siblings' data (15–22 years)

The age range of older and adult siblings participating in interviews within this cohort was 15 to 22 years old. This represents the typical period when young people move into a new phase of their lives; they are usually completing their education, contemplating work and careers, developing partner relationships and pursuing other interests as they move into productive adult lives (Bonnie *et al*., 2015). They also accept new roles and responsibilities with changes in their social contexts. Shanahan (2000) argues that the transition to adulthood has become viewed less as a discrete set of experiences; and more as an integral part of a developing biography, that reflects the early experiences of childhood and one's upbringing, which shapes later life.

These developmental processes are reflected in these young adult siblings' narratives and are highlighted in the discussion chapters. They explored their childhoods, the kind of people they want to be, their goals in life and how they will make transitions away from their families and navigate personal and romantic relationships.

As with parental data, the transcripts from sibling interviews produced a multiplicity of codes (591); themes were drawn out and are summarised in Figure 16. The analysis of young adults data indicated a strong focus on family and what that means for the young people; with a clear articulation of family values and family identity. Siblings strongly emphasised relationships and communities. Notably, older siblings voiced their frustration that the needs of disability communities are poorly understood. Although not disabled themselves, they recognised the effect of disability on their families and thus identified with this sense of a disability community.

Figure 16: Young people's data: Themes related to QoL (unweighted)

Aspirations
Class
Community support
Careers
Caring for family members
Disability identity and community
Economics
Educating others and disability activism
Equality of opportunity
Extended family
Focus on family
Family identity
Family values
Friendships
Language
Mental health
Optimism for the future
Professional relationships
Pessimism about change
Responsibility
Sibling bonds
Social groups
Social media
Stigma and discrimination
Technology
Work

Having considered the thematic analysis, and in common with parental data, the siblings codes were also cross-referenced with UK government well-being framework and Nussbaum's central capabilities framework. The findings are presented in Figures 17 and 18. The aim in applying these frameworks is to support an understanding of older siblings' conceptualisations of QoL.

The three factors that siblings most focused on within the government framework are relationships (19.8%), governance (16.5%) and personal well-being (13%.) However, 18.7% of codes could not be matched to the framework, even more codes than those from the parental data. They again highlight the transactional nature of the government framework. Siblings unallocated codes focus on aspects that are related to attitudes, stigma and societal responses to disability, which the young people described as environmental and societal.

Figure 17: Sibling codes matched to the UK government well-being framework

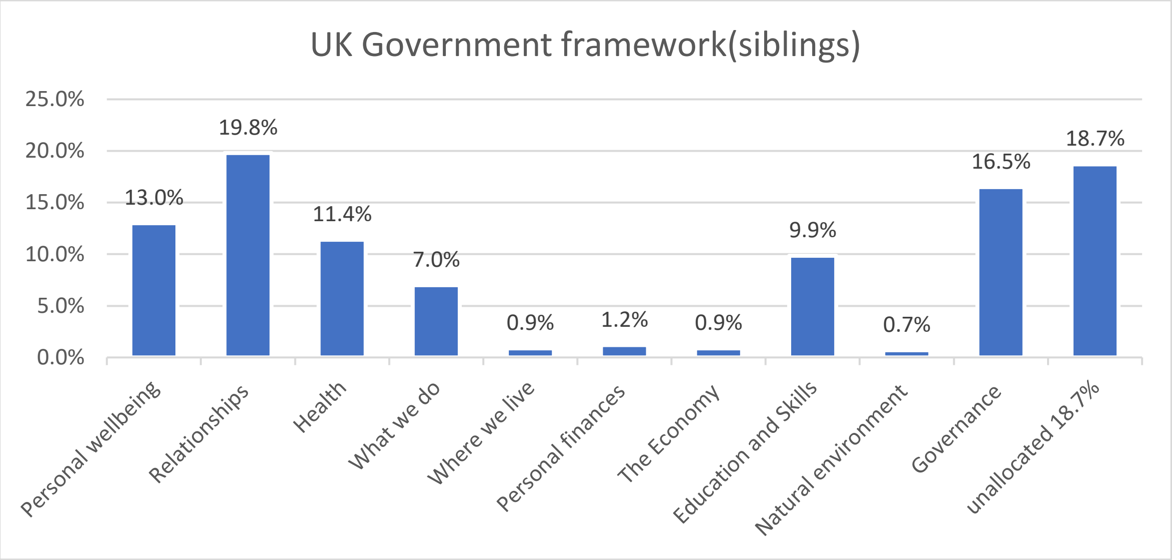
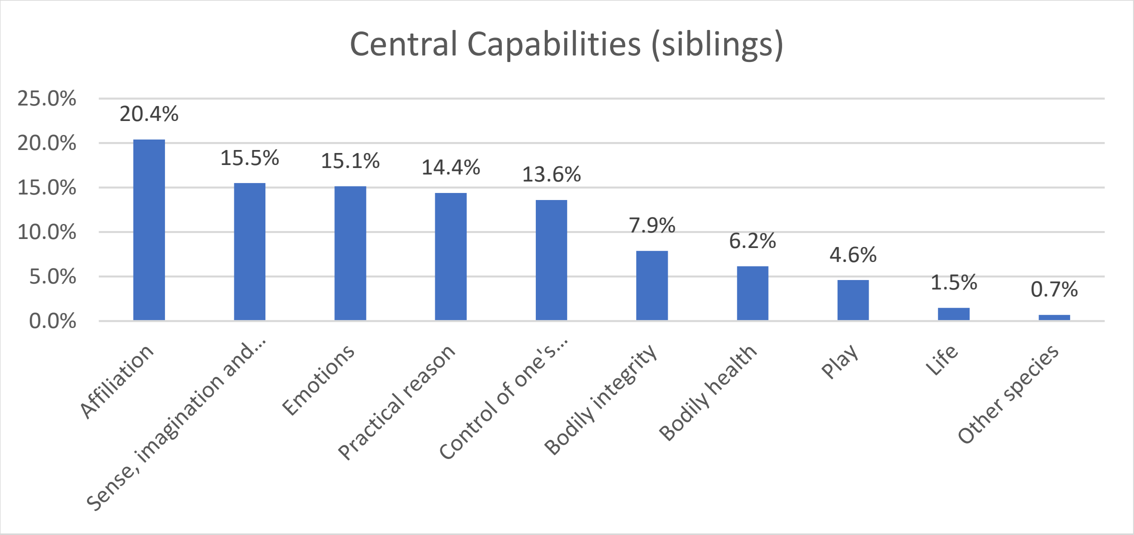


Figure 18: Sibling codes matched to Nussbaum's central capabilities framework



*in graph above complete wording of the two capabilities ending with … is 'Sense imagination and thought' and 'control of one's environment'

Within Nussbaum's framework, the predominant areas of focus for siblings are affiliation (20%); sense, imagination and thought (15.5%) and emotions(15%). There are no unallocated codes, demonstrating the capabilities framework's strengths in understanding the more philosophical nature of what matters to these young people in relation to QoL.

5.4. Comparing sibling and parental data on QoL

In considering the data in the round, it is interesting to explore whether parents and siblings emphasised different aspects in terms of QoL. Individuals are likely to weigh what matters in their lives differently at different stages. For instance, a young person may be more focused on self-determination, personal development and social inclusion; whilst an older person with caring responsibilities may be more concerned with health, physical and material well-being.

When older siblings' data are compared to parental data, different emphases do become apparent in the context of QoL, although parents and siblings also shared a significant commonality of views. Figures 19 and 20 below, show the comparisons of parental and sibling data. Siblings emphasised more relationships, emotions, and sense and imagination. Whilst parents tended to focus more on health, governance and control of one's environment. For both siblings and parents, the UK government framework does not appear to measure some of the areas in life that mattered to families, with significant numbers of unmatched codes for siblings (18.7%) and parents (8.2%).

Figure 19: UK government well-being framework: Comparison of sibling and parent data

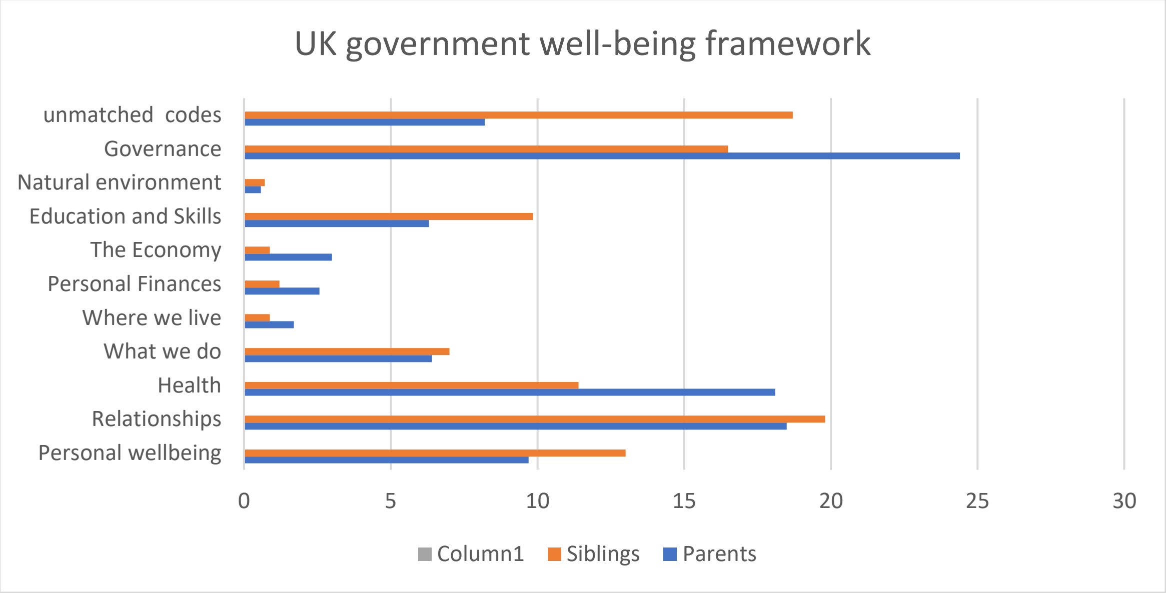
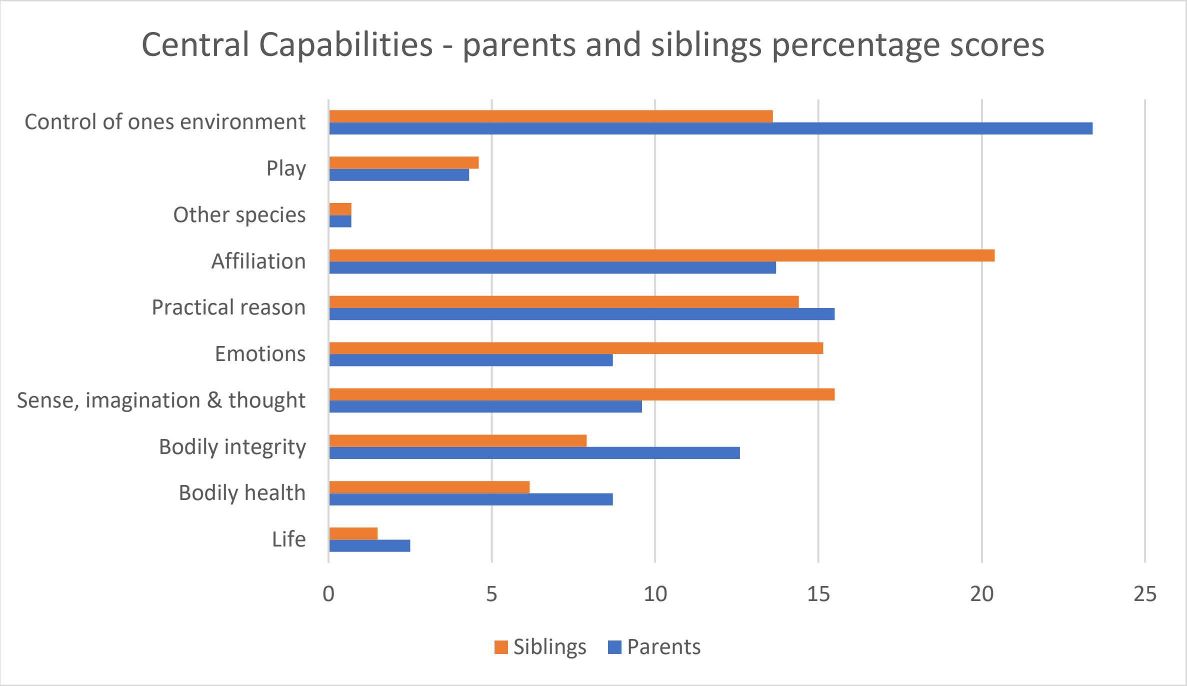


Figure 20: Nussbaum central capability framework: Comparison of sibling and parental data



iv. Younger siblings’ Data

These data could not be coded in the way parents and older siblings data were, so the content is considered in the round; taken from contemporaneous notes regarding what younger siblings reported about what they enjoy about life, what they find challenging and what matters to them. These data are summarised in Figure 21 below.

Figure 21: Summary of young siblings’ focus in relation to QoL

- Having a normal life
- Their place in the family in relation to their disabled sibling
- Strong sibling bonds
- Importance of family
- Friendships
- Attitudes of others towards disability
- Leisure activities and holidays
- Stigma and discrimination
- School life

Younger siblings’ expressed views were much more based in the present. They were already conscious of differences in their experiences of life compared to some of their friends; and could see what is different about life for their disabled siblings. Their thoughts and ideas around their experiences of living with a disabled family member were less well-developed than older siblings, however some of the same thought processes were clearly developing about being a protective influence for their sibling, gradually adopting some responsibility born out of their deep sibling bonds and shared family values.

All of the siblings both younger and older who were directly involved in the study, mostly indicated acceptance of the way things are within their families, and whilst they voiced some frustrations, they talked of being able to live fairly typical lives because their parents usually make this possible.

5.5. Data analysis of Education, Health and Care Plans (EHCPs)

In this section the findings in relation to the analysis of EHCPs is discussed.

The Children and Families Act 2014 (CFA 2014) established a new process for assessing the needs of children with special educational needs (SEN). This has become a fundamental part of the support system for parents of children with SEN. Those children with the most complex needs can be eligible for an EHCP. Once a child with an EHCP is placed with a school or nursery, educators are required to use their ‘best endeavours’ to meet their needs as defined in the EHCP. These plans must be actioned and reviewed regularly. EHCPs provide entitlements and enforceability through tribunals. Children without EHCPs do not have protected SEND provisions. These plans establish some level of choice and control for children and their parents. An EHCP is therefore, a critical document; it is intended to support the best possible outcomes for the child and prepare them for adulthood. In this context, this research has been designed to investigate the formal system with which the families in this study interact.

All of the families within the cohort have a learning-disabled child who has been assessed as having support needs complex enough to warrant an EHCP. These plans can both positively and adversely affect children’s quality of life, depending on how well they are drafted and implemented.

National research by Adams *et al.* (2018) evaluated 25 EHCPs and found weaknesses that included:

- Poorly coordinated provisions across education, health, and social care.

- Failure to secure and document young people’s contributions.
- Lack of inclusion of informal support.
- Weak representation of a future focus on outcomes.

A criterion for participating in the research included that each learning-disabled child had an EHCP in place or was being assessed for one. Consent was sought from the outset for parents to share their children’s EHCPs, enabling analysis of how well the plans met the provisions of the legislation. How EHCPs are drafted and implemented not only offers insights about family choices and control; they also provide insights into the power relationships amongst parents, professionals and children.

Six of the nine families shared their child’s EHCPs. Of the three who didn’t,

- One child was still being assessed.
- One young person no longer has an EHCP, having reached 19 years of age (although eligible to have one until 25 years of age).
- The third family were awaiting a review during the study and did not want to share until it was updated.

In analysing the data, it is first important to have contextual understanding of EHCPs. They are divided into eleven key sections, A–K, covering assessed education, health and care needs, outcomes and agency responsibilities. What each section addresses can be seen in Table 20. The most critical aspects of the plan, the key educational sections, are defined in **Sections B**, **Section F** and **Section I**. They are particularly significant because they are mandatory and are the only legally enforceable sections, along with **Section E** (the outcomes section) in any Right of Appeal to the SEND Tribunal. Appeals to tribunals regarding the provisions in the plan and how they have been implemented are an important part of the process. They enable families to exercise some control within the system.

Enforcement limitations can significantly affect families’ ability to achieve their desired plans. If important aspects of the plan are not included in the mandatory sections, the child may not receive the services that parents believe they need. Some families in this study recognised the significance of these restrictions, whilst others were less aware; however, this is an important point to understand because it can affect how the plan is crafted and what is treated as an education outcome.

(*N.B. Since April 2018, a national trial allowed families to request that recommendations for health and social care be considered. Tribunals can make judgements on these, but they are not enforceable.*)

For this research, each EHCP provided was individually analysed using a set template developed specifically for this study. Figure 22. presents the analysis template, and the data on how many plans met the SEND Code of Practice criteria; This analysis considered how well each section of the EHCP is met. It presents an overall narrative summary of each plan that was analysed. In evaluating the EHCPs prior professional knowledge was applied.

Figure 22: Analysis of EHCPs

Evaluation questions applied to EHCPs	**Criteria**	**Cohort of 6**
General Info and photo	Is it included?	5/6
Section A Parent/child views	Are parents' views included? Are young person's views included? Is it possible to determine who drafted this Section?	5/6 5/6 5/6
Section B * *Child or young person's Special Educational Needs*	Are the needs stated? Are they specific? Do they relate to what I know about the child? Are they needs or conditions? Is the impact of these clear?	6/6 6/6 5/6 5/6, needs 6/6
Section C Health needs related to the person's SEN	Are health needs specified? Are they needs or conditions? Is the impact of conditions clear?	5/6 4/6, both 3/6
Section D Social care needs related to the person's SEN	Are social needs clear? Are they a list of conditions or specified needs? Do they reflect the Chronically Sick and Disabled Persons Act 1970 (CSDPA 1970?)	0/6 1/6 1/6
Section E SEN outcomes	Are the outcomes stated? Are they outcomes or outputs?	5/6 4/6, outcome-based
Section F *	Is what will be provided clear? Are the services specific?	5/6 5/6

Special Educational Provisions	Are the outputs SMART? Is it clear who is responsible?	4/6 4/6
section G Health provisions	Is what will be provided clear? Are the services specific? Are the outputs SMART? Is it clear who is responsible?	2/6 1/6 1/6 2/6
Section H 1 Social Care provisions resulting from Section 2 of the Chronically Sick & Disabled Persons Act 1970 (CSDPA 1970)	Is what is to be provided clear? Does it reflect the CSDPA 1970? Is social care recognised?	1/6 1/6 2/6
Section H 2 Social Care Provision reasonably required	Is there supplementary provision? Is the legislation being applied clear? Is what is to be provided clear? Is it SMART?	0/6 1/6, partial 0/6 0/6
Section I* *Educational Placement*	Is placement specified? Is there any accompanying info regarding the logic?	5/6 0/6
Section J Personal Budget	Are a personal budget or direct payments stated?	0/6
Section K Appendices, Advice and Information	Are there appendices? Are they relevant?	4/6 4/6
General commentary	Do outcomes lead from assessed needs? Are targets SMART? Is funding clear? Are responsibilities clear? Is the plan strengths or deficits based? Is there evidence of a waking day curriculum? Any comments regarding the code of practice? Comments regarding the nature of the professionals involved, multidisciplinarity? Overall rating of plans in the round	4/6 2/6, partial 1/6 1/6, partial 6/6 strengths 2/6, partial 0/6 2/6, fully multi-disciplinary 1/6, partially multidisciplinary 1/6, Full compliance 3/6, good compliance

		1/6, adequate compliance 1/6, non-compliant

Sections with * and italicised are the mandatory elements of the plan that can be appealed at tribunals.

A summary analysis of each plan is given in Figure 23 below with a compliance rating developed by the author applying the following criteria:

Full compliance: All Sections of the plan are addressed, targets are SMART(Specific, Measurable, Achievable, Relevant, Time-bound). The child has had direct involvement. Who is responsible for funding and how much this will be has clarity. Placement is named.

Good compliance: all or nearly all Sections of the plan are addressed, targets are mostly smart, evidence of consultation with child for their views though not necessarily direct involvement. Who is responsible for funding is apparent but level may not be clear. Placement is named.

Adequate compliance: Most Sections of the plan are addressed though some may be missing and targets may not all be SMART. Little evidence of the child's involvement but parents clearly inputted into the plan on the family's behalf. Funding apparent but who responsible not always clear. Placement type named actual placement not necessarily specified.

Non-Compliant: Few Sections of the plan complete. Little evidence of parental or child's involvement in the plan. Aims and targets may be SMART but are limited in what they cover. Who is responsible for funding unclear.

Figure 23: Commentary regarding the analysis of EHCPs
EHCP 1: Good Compliance
A very comprehensive plan with substantial detailed information about the child and their needs. Parents are engaged with the process and one uses their teaching expertise to ensure that the plan is very specific about how their child is supported. Social care does not feature and it is suggested that the family do not meet these criteria. Parents may have carer needs but this is not recognised (although the council's guidelines refer to considering the Care Act 2014). Some aspects of need may change as the child gets older. This is an

example of a plan written such that if certain provisions are not available, it would be appealable. Parents know the systems and there is little room for interpretation. Issues of risk are not emphasised. The child has conditions that can be quite dangerous if not managed well, e.g., eating and mobility. Questions of how risk is managed in school settings are not addressed. These health risks should be spelt out in the EHCP.
EHCP 2: Good compliance
This plan has many strengths. The young person's needs are well described and their personality comes through. What matters to them and their parents is clear. The plan is education-based but lacks detailed health and care consideration. It focuses on enabling the young person to get the most from school and not on wider aims. The care element of the plan is non-existent and will probably lead to issues later on when preparing for independence. It makes no reference to planning for independence from Year 9. The plan is very strengths-based; when describing the young person's challenges, they are presented as things that can be supported rather than as deficits. It considers what the young person can do well to build on. If this plan considered health and care in the same way as education, it would be an excellent plan in many respects. It is not at all clear who will fund additional supports, and how. This is not referenced at all, which makes it difficult to appeal.
EHCP 3: Adequate compliance
The plan has a global overarching theme that is embedded in ensuring a good quality of life for the young person; it considers health, learning, social and family needs. The introduction by the parents gives a very good pen picture from which the plan should flow, which it does to a degree, but some non-specificity within the plan means professionals can argue that certain things are not their responsibility. The college is silent on the targets about maintaining family relationships from a distance and there is nothing about programmes, social stories or maintaining contact with home. Despite the importance of technology for this person to communicate (e.g., iPad or video calling), these needs are not stated or funded. The plan is also silent on social skills-based learning. It is very difficult to see from the plan, other than health input, what the specifics of the day hold for this young person and how these link to their stated outcomes.
EHCP 4: Full compliance
An excellent plan that evidences an understanding of the young person's needs, who is involved and what is trying to be achieved. Young person and parents both involved. The way the plan is written suggests that the parents maintain good relationships with agencies and they have been able to access health and social care services. These are noted in the plan but do not seem to be generated through the plan. For example, given this young

person’s high levels of medical need, NHS services are sourced through GP and CCG. The risks to the young person are not entirely spelt out, e.g., they must be careful about what they swallow as the wrong foods can be life-threatening, which is not stated in the plan. The family have a social worker who has applied CSDPA 1970, the Children Act 1989 and the Care Act 2014 to acquire what the young person needs. The plan is constructed such that if the parents wanted to appeal anything at tribunal, the professional responsibilities and funding are well set out. Of the six plans assessed, this is the closest to a complete and comprehensive plan.
EHCP 5: Non-compliant
A very narrow EHCP that focuses on educational attainment and enabling the young person to participate in education and meet education goals. It is very present-focused. Other than plans to sit exams, the wider goals are unclear, such as moving on to the next placement or independent living and employment. It is a positive plan in the sense that it gives a sense of purpose and belief and is encouraging and fair, but there is little sense of the young person; the plan is mechanistic. There is little evidence of parental involvement; and whether there is any wider multi-agency involvement is unclear. It would be very difficult to use this plan to obtain services from other agencies or challenge the lack of provision. Its lack of specificity would make it difficult to appeal to tribunal should the parents or child ever need additional services.
EHCP 6: Good compliance
A comprehensive plan that is well laid out and very clear in what is being sought. It is predominantly focused on education outcomes and less so on health outcomes, although these are acknowledged and linked to education supports. The plan is silent on social care aspects, deeming them non-applicable. There is little looking to the future on how social care outcomes may need to be considered or needs assessed as the child gets older. The objectives are clear, outcome-based and broken down into specifics about how each will be supported. The plan is unclear about funding, although responsible agencies are stated. It gives a good sense of who the child is and how they can best be supported. It is generally strong except in its disregard of Care Sections H.

Aggregated findings from the six evaluated plans are summarised below.

- Only one plan comes close to meeting the full set of requirements. One of the plans, whilst titled an EHCP, is mostly a school-based academic plan.

- All of the analysed plans take a strengths-based approach, although in 2/6 plans this is very general, taking a broad rather than specific perspective.
- The statutory Sections, B, F I, and E which focus on education needs and outcomes, are the best-developed Sections in all six plans. They appear to have had particular attention paid to them, probably in recognition of their enforceability.
- The adequacy of other plan Sections is more variable, particularly those covering care. Some are almost silent in their aims and statements of the type of provision to be delivered.
- The EHCP code of practice states that all Sections must be specific and quantified. 5/6 plans lack specificity in some, although not all, Sections. A lack of specificity compromises legal enforceability. It is very difficult to challenge a plan with general language like 'access to' or 'benefits from'
- Evidence of the direct involvement of the young person in the development of their plan is variable:
    - 2/6 plans, parents report their children's views.
    - 3/6 plans, children appear to have had meaningful involvement.
    - 1/6 plans, the child's views are not considered at all.
- In 5/6 plans, there is evidence of parental involvement but in one plan the Section on parents' views is completely absent.
- Health care needs (Section C) are generally well understood, but the Sections on health outcomes (Section G) are more variable and do not always match the identified needs.
- The least-developed Sections overall are Sections D and H1, which refer to social care assessed needs, provisions and outcomes. In only one plan is social care properly considered with evidence of the assessment of the young person's needs specified under the requirements of the CSDPA 1970.
- There is little evidence of consideration of other relevant children's legislation in H1, which is intended to integrate with EHCPs. This includes the Children

Act 1989's framework for assessing children in need, which only features in one plan.

- Section I of the EHCP is meant to name the actual education placement for the child. Five plans name the establishment one plan only the type of placement. This lacks specificity making it harder for a parent to challenge in a dispute.

The SEND Code of Practice sets out statutory requirements for how plans are developed and who should be involved. These include parents, headteachers or SENCOs, medical professionals, Educational psychology, social care and hearing and visual impairment specialists, where relevant.

Parents, headteachers and SENCOs were involved from the outset in all six EHCPs evaluated, but the participation of medical professionals, educational psychology and social care is highly variable and inconsistent. In relation to social care in two instances involvement was declined; saying family not known. This fails to recognise that there may still be a need for a statutory assessment.

With the exception of one plan statutory agencies involved with these families are insufficiently following the SEND Code of Practice across all domains or considering children's holistic needs. The plans reflect a dominant focus on educational attainment and outcomes. Health needs are addressed where they create barriers to learning only partially for some children, although well for others. Care support is poorly addressed in all but one plan. Social skills for life are not recognised in most of the EHCPs analysed, although all plans indicate aspirational outcomes for independent living, social relationships and well-being. This might not be problematic if other legislative systems designed to meet children's wider needs worked well and are integrated with EHCPs; however, parents' and siblings' narratives in this study suggest that this is not the case, as is discussed in subsequent chapters.

Finally, a key element of Section III of the CFA 2014 is that parents and children should be involved in a collaborative, co-productive process offering them more choice and control in delivering their goals and aspirations. The analysis of these EHCPs reveals that, in drafting their plans, professional partnerships inconsistently involve parents and do not consistently involve the child to whom the plan applies. This does not inspire confidence that professional agencies are applying systems of co-production which are encouraged within the Codes of Practice.

5.6. Conclusion

This chapter has presented an overarching analysis of the collected data. The analysis begins to describe families' views about quality of life and what matters to them in relation to this, and the importance they place on governance and controlling their environments. Data cross-referenced with UK government, and Nussbaum's frameworks indicates that Nussbaum's social justice based framework is more comprehensive regarding what in families' views makes for a good QoL. The data and thematic analysis provide clear insights as to families' stated priorities

The analysis of EHCPs also provides insights into what professionals and families prioritise in terms of outcomes for a good QoL providing indications of the level of choice and control that families can exercise in achieving their desired outcomes which can be limited by their lack of meaningful involvement in the EHCP process . There is evidence that a principle of professionals co-producing EHCPs with families in a joint endeavour is inconsistently applied; and whilst most EHCPs were strengths-based, which is a clear positive, they were also heavily education-focused with more limited evidence of the holistic consideration of children's wider needs. The following chapters explore the findings and their implications in more detail

Chapter 6: Discussion: Quality of Life and the System

6.0. Introduction

The main research question seeks to understand the choice and control that families feel they can exert to achieve a good quality of life (QoL) both for their learning-disabled children and the rest of the family. Before discussing choice and control, clarifying what families define as a good QoL is valuable. All of these families recognised that they live within social and community-based networks that provide affiliation and support well-being. They additionally recognised the importance of their interactions with the system as exemplified by government institutions, economics, professional organisations and aspects of community. This involves for families navigating many family and economic policies, legislation, Codes of Practice, agencies and professional relationships to access services for themselves and disabled family members. These interactions can all affect their overall QoL. What families reported about the system and the benefits it provides are discussed; as well as how it can put at risk a family's equilibrium and well-being when it is not working well. In this context Habermas's characterisations of the lifeworld interacting with the system becomes relevant.

In this chapter, family definitions of QoL are explored as well as their critique of the system. In exploring the workings of the SEND system, discussed is whether family data indicates that this has become overly dominant; while other systems, including social welfare and health-based approaches, have become minimised over time. Whether this is proving to be to the detriment of children's and families' overall well-being is investigated. Additionally, evidence from families that a focus on purpose rather than employability could offer a more suitable strategy for life; and that principles focused on welfare can improve outcomes, is explored.

6.1. Defining Quality of Life

In general, when asked about what quality of life means to them the families in this study described the importance of having a home, family, friendships, good health, enough money, interests and activities, with control over their own lives. No singular definition arose from either parents or siblings, and they mentioned many different facets of life. Their appraisals were partly affected by their preoccupations in life at the time of the conversations and different emphases were apparent across the dataset. In chapter 5, there is discussion about what the data drawn from parents' oral histories and siblings' narratives tells us about family perceptions of QoL. The closeness of fit emerging from the family interviews with Nussbaum's capabilities framework was highlighted. When asked directly though, 'What does QoL mean to your family?' around a third of parents and nearly all siblings framed their initial answers around meeting their learning-disabled family member's needs, rather than exploring an overall conceptualisation for the whole family. This is illustrated in the following comments, first from Marcus, the father of an autistic son:

> *'I think a good quality of life would be (him) living near to us, preferably in accommodation that we provide, in an environment that will enable him to do interesting activities and things that interest him, so, for instance, gardening.'*

And secondly from Gemma, whose daughter has Down syndrome, who said:

> *'Quality of life? Whatever she wants to do, really, like I'm not really a person who sort of, like, has ideals of what I would want to happen, and as long as she's happy and supported and progressing.'*

Two brothers from different families reflected this same focus on framing QoL through their siblings' needs. Matthew commented:

> *'I'd like my brother living on the same plot of land happily in his own little house with a little plot of land for himself to farm. I would try and live as close as possible.'*

And Luke remarked about his sister:

> *'For a good life…it is important to let people with disabilities be independent as far as possible and striving for more so that they can live a normal life like anyone else. And things around relationships, too, to be able to have the relationships and friendships that they want to have.'*

All of the narratives demonstrated that families ultimately seek for their learning-that they have a duty where they are recognised as full citizens with meaningful stakes in society. No limits on aspirations are assumed by families for any family member; the importance of all family members having realisable dreams is emphasised. Stuart, the father of a 12-year-old, commented in this context:

> *'I think purpose and meaning, that sort of quality of life, is really what's important.'*

6.2. Parents' views

Parents were generally able to articulate their priorities for a good QoL, but they also indicated that their goals are not always achievable. They described things that make them happy or frustrate them; what is good about life and what is challenging. Conceptually, several parents referred to Maslow's (1943) hierarchy of human needs in their analysis of QoL, relating this to what is important for both their disabled children and the rest of the family. They did not limit or differentiate who in their family units should be able to achieve the highest levels of Maslow's hierarchy; self-actualisation is a goal for all. Some parents argued, however, that whilst families believe in universal rights to self-actualisation, the system within which they operate is less supportive of this goal. Marcus commented:

> *'When you look at Maslow's bit of self-actualisation, that bit that is meaningful at the top, it is almost like the system thinks that so long as you get the bottom layers of Maslow's needs fulfilled, the top layers don't matter.'*

Seeking equity and the right to achieve purpose and self-actualisation is significant given the context of known discriminatory attitudes towards learning disabilities. Barriers founded in discrimination can prevent access to mainstream activities including education, leisure and employment, preventing a child from reaching their full potential.

Parents highlighted the Special Educational Needs and Disabilities (SEND) system as the main formal system for accessing services to support good QoL outcomes for their learning-disabled children. They perceived this as having strengths and weaknesses, but clearly do not feel that it is always responsive to generating a good overall QoL. Within their narratives, they described how the system both supports and limits them.

i. Intrinsic and extrinsic worth

Parents frequently commented on the negative attitudes conveyed towards disability within the system and implicit ideas about an individual's worth.

Parents quickly picked up in their conversations on ideas that are reflected in Rojas's (2004) work regarding intrinsic and extrinsic worth. He highlights the worth of all people in his commentaries on QoL, which are highly pertinent to this study. All parents affirmed the intrinsic worth of their children's lives whilst recognising that society often devalues disabled people. They also highlighted their disabled children's extrinsic worth in the contributions they make to the overall family unit's quality of life, as well as other people, including friends and the wider community. Stuart commented:

> *'You know, our child has got a fantastic quality of life and it has been good for us, good for her siblings. I mean, overall, we've got lots of challenges...but she has raised the bar actually, she has just raised the bar on the quality of our lives, for us all, she is a good example of happy, tolerant living and she's inspiring all of us.'*

This assessment of the family being enriched and its members becoming better people is shared by another parent Claire, who talked about her son with Down syndrome:

> *'I feel as a family, we are now a different family… I am not saying as a family, we were not good, but I think we are becoming a better family in a way in terms of empathy and caring, and if we are out somewhere in a group and there are children my kids don't know, and there is somebody with a special need, you can bet your bottom dollar that my lot will gravitate towards the child with special needs.'*

In the literature chapters, discrimination towards disability and the use of negative and ableist language is discussed. Parents highlighted experiences of this in their narratives and drew out the impact this can have on QoL. Gemma commented on her anger with wider society in this context:

> *'People need to stop using 'special needs' as an insult or what they think of as humour.'*

She made subtle points about how language conveys issues of lesser worth:

> *‘It is a common practice that parents who have a child with a disability are praised for raising their child. This makes me incredibly uncomfortable. If you look a little deeper into why these comments are made, you can see a thread of prejudice. It’s difficult to put into words, but it centres around the idea that people with disabilities are not an integral part of society.’*

ii. Developmentalism

In Chapter 3 the concept of developmentalism was discussed. In this context, some parents expressed concern about how their children’s QoL is measured against societal norms and expectations. Parents believe that societally there are discriminatory attitudes towards their disabled children, linked to their offspring not always meeting the expected developmental norms. They argued that having negative attitudes towards those who need additional support because they are perceived as not meeting typical milestones is ableism and must be challenged.

Two mothers argued that not meeting developmental norms devalues their children in some professionals’ eyes and this can be rooted in eugenic attitudes. These parents expressed their anger that they had felt pressured by professionals to consider terminating their pregnancies where Down syndrome (DS) had been identified. They believed this was because their children would not necessarily expect to meet ableist norms. Parents with a child with DS highlighted negative, deficit-based language in information leaflets that they were given when their children were born; these suggested that their child would not develop normally and their QoL would be poorer. Annaliese commented:

> *‘I understand that they have a duty to give me information… What I think is unfortunate is that the leaflet is full of things like, she will die before she is 65 because her life expectancy is less; she is more likely to get leukaemia, dementia; the list goes on.’*

Linked to conceptualisations of ‘normalcy’, some parents also argued that everybody is likely to experience aspects of disability during their lives, whether they are born with disabilities, experience injury from accidents, become chronically sick or age. This is normal. Several parents argued that society must recognise this and be more empathetic towards disability to all of our benefits. Stephanie, whose son has DS and autism, commented:

> *‘I mean, people have heart attacks, they have strokes, they have car accidents, they get an infection, meningitis, they lose limbs, you know, disease, they lose sight. So, it is all around us and you can’t just separate people with disabilities into a different world because that is not ‘our world’. Because ‘our world’ is everybody.’*

This is her rallying call to challenge and address ableist attitudes within society and, ultimately, improve everybody’s QoL.

Other parents recognised the reality of a societal focus on developmental stages but argued that an important part of ensuring that their child is included in perceived normal expectations is to support them in meeting milestones. Julia, the mother of a child with DS, commented:

> *‘Quality of life is really important; it was always important for us; we decided right from quite early that we would always have age-related expectations for her.’*

Darren, the father of a child who also has DS, recognised that development and skills acquisition are important but argued that time is needed to achieve them. He believes that professionals should not give up on children or problematise them because they are not meeting chronological milestones, but should give sufficient time; otherwise, children are harmed. He remarked:

> *‘that's one of the first things you sort of learn about, with Downs syndrome; that they will get there. It'll just be probably slower and they will do it in their own time…she'll get there when she is ready.’*

Other parents recognised how life will change for their child and plans will have to be adjusted during different life stages and as their disabled child encounters different phases and developmental stages while they grow up. Different family members will be affected in different ways. Diane commented:

> *‘The quality of life thing! You know, it’s actually… it’s having a balance, and I don’t think we are very good at having a balance and life changes. Like every time he gets older you go on to the next stage so you stop what you were doing …and then you start doing something else.’*

Parents demonstrated that they are constantly thinking about their disabled children's needs, anticipating the next life stage that they will have to navigate and how they will support their child in that process. One mother described planning five years ahead because she has found that failing to anticipate needs early becomes problematic. Professional support systems are insufficiently responsive without a long lead time to meet support needs.

There is a sense in conversations with mothers in particular, that they operate in a constant state of hypervigilance. Hypervigilance over long periods can seriously affect a person's quality of life, affecting their health, creating problems with sleep and leading to an inability to relax. All of the mothers in this study are particularly strong advocates for their children and spend significant time and emotional energy planning and problem-solving. Seven of the nine mothers acknowledged that their mental health has not always been good and described having received clinical mental health supports since the birth of their disabled children, including CBT, counselling and medication. These mothers felt that their needs are insufficiently understood. Their narratives emphasised the pressures that they all face as they strive to attain the best lives for their children, sometimes at the expense of their own well-being. Mental health and wider family and marital relationships can all be put under strain, although mothers reported that they gain much support from spouses as well. Diane explained the impact on her family:

> *'[It] is the worst degree of grief you could ever feel… because you grieve for the son that you think you should have and for a long time. I expected to have a son who I thought would grow up, get married, get a job, and leave home and so on, and all of that comes crashing down behind your ears and nobody gets in touch with you. No health care professionals, nothing, you are left to manage it.'*

Parental narratives evinced their common goals of achieving a good QoL for every family member. They focus on trying to balance every family member's needs but tend to be preoccupied with the needs of their disabled offspring. Some ameliorating factors to addressing the strains described are the joy and pride parents feel in their children and working with good-quality, well-trained professionals who build supportive working relationships. This is discussed further in a later section on families' responses to the system.

6.3. Siblings' definitions of quality of life

Direct social research on the views of siblings is sparse (Hastings, 2014). Exploring the views of all children within these families was a key consideration in this study and direct involvement was consequently, incorporated into the methodology. This has provided rich data on young people's views. Interestingly, older siblings tended to give more specific answers than their parents when asked directly about QoL. Like their parents, however, the initial framing of their responses was predominantly in relation to their learning-disabled sibling. They then moved on to reflect on their own and family needs in a more rounded way. The greater clarity of their responses about QoL may relate to their life stages. All of these young people are making their own transitions to adulthood and working out what they want from life. Peter, an adult sibling, provided a comprehensive analysis, describing first what he believes is important for his younger brother and then moving into wider conceptualisations:

> *'Often, in these situations, it is you or I that's defining what is the good quality of life for my brother when, actually, you know, it's his life. So, we should be trying to ask him and interpret that from him. But I think it's obviously, being safe. having opportunities, not being limited, and that his medical conditions don't take over. That he's still very much able to be involved in society and be with his friends and have those experiences. And that he's supported when there are challenges and difficulties like that; as we discussed, with their kind of societal model of disability.'*

He went on to talk about measuring QoL and moved into reflections that he felt applied to all family members, not just his brother. Principles of personalisation, inclusivity, and choice can be drawn from his commentary:

> *'How do we measure it (QoL)? A lot of people think initially that while the society that we live in will probably think that economic considerations come into that…definitely, for me, it is more about the relationships and people. And feeling like you have a purpose, that you're loved and that there are going to be bad times as well as good times. It's not about being happy all the time.'*

Other siblings reflected similar hopes for QoL and how it should be their siblings' absolute right. In talking about his sister's future, Max reflected the family values of the importance of promoting a normal, inclusive life, recognising that systems to support this are crucial. He commented:

> *'People with disabilities (need to) be independent as far as possible, because I don't know if it is just that the Government says, 'Oh, that is good enough', if someone with disabilities is just living with their parents, because that means they have got a roof over their head and food… I would want them to live life like I can live it.'*

Strikingly, all sibling narratives featured strongly held beliefs that learning-disabled siblings should be able to aspire to all of the same life goals as non-disabled young people. Whilst all of the siblings recognised their disabled siblings' additional support needs, they did not see these as barriers to leading an ordinary life. Siblings are highly aspirational on behalf of their learning-disabled brothers and sisters and see them having their own homes, purposes, friendships and relationships as absolutely possible. Luke commented:

> *'I'd personally like her to be as independent as possible, and to just be living her own life, really, not having to rely on the government for money and for her to be able to work for herself. Because that is what she wants to be able to do...and that may be like, being a baker or something. I feel like my sister wants to be independent, so why not?'*

6.4. Where families meet the system

The UK policy narrative, as discussed in Chapter 2 and as it applies to disabled children, is focused on children being supported within their own communities and living with their families wherever possible. A disabled child's fundamental human right to access education is strongly emphasised. This should feel coherent to families who expressed strong views regarding their disabled children's entitlement to lives of choice; and that their children's independence and aspirations should be supported.

Whilst parents described, within the context of their lifeworlds, how family relationships, friendships and the wider disability community provide substantial mutual support, they also recognised that they need to draw on 'the system' for services to enable a reasonable QoL for their families. Learning-disabled children with additional support needs are predominantly supported through the SEND system. Families pursuing overall family well-being recognised, however, that they will at least occasionally, or even substantially require support through NHS services, social care and employment and benefits systems. Parents, in particular, recognised that they must learn to navigate the multiple structures and systems aimed at supporting children and must understand how professional cultures, jargon and societal attitudes intersect.

Sadly, siblings and parents tended to believe that professionals within the system are generally more limiting in their aspirations for disabled children than families are themselves; and that professionals are more likely to underestimate their disabled family member's capabilities. This means both parents and adult siblings see their roles as being strong advocates. Julia, a mother, stated:

> *'One of the horrific parts of the SEND system is that I never think of my daughter in deficit terms until I have to interact with the system. It sucks everything out of you when you engage.'*

This is a recurrent theme within family narratives that family members are not always confident in the system's ability to meet family needs. Marcus, a father, commented:,

> *'The system doesn't work...well, the CCG and the local authority don't cooperate; they blame each other; they don't talk to each other much; you are dealing with a disparate group of individuals who are basically trying to provide the minimum that they need to provide.'*

Angela, another parent, offered similar sentiments:

> *'The system, you try and make it work but ultimately the system should not be like this. We have been trying to make it work for us for 20 years, and we feel quite tired. I think also there has been no learning in the system, it has never learned how to be better.'*

And Chand, a father, further commented:

> *'You see other people and theirs is the consistent story, there is this big, big hole in the system.'*

Adult siblings were equally aware of the need to understand the system and many reported that from an early age they had recognised that they will have to navigate it in the future to support their siblings; particularly when their parents are older and more infirm; or after they pass away. Matthew commented:

> *‘I see now that I have a great responsibility ahead of me, because, of course, as my parents get older, I will have to take up the mantle of caretaker because my brother does not have much in the way of independent living or skills. He needs care for the rest of his life, and I realise that is the sort of responsibility I will have to hold with the system and make sure he gets that good quality of life down the line.’*

Both parents and older siblings believed that to achieve a good QoL, they must understand and learn to navigate systems. Parents in this study all demonstrated great resourcefulness and problem-solving skills and clearly they draw hugely on their own emotional, practical and financial resources, becoming true experts by experience in their children’s care. As they develop expertise, they make it their business to understand how the overall system is structured, how it involves different agencies and how it can support their endeavours to achieve the best outcomes for all of their children. Whilst all parents, without exception expressed their frustration at times with the system, they equally recognised the importance of working with it and being prepared to challenge it at times. Julia, a mother, commented:

> *‘During those five years, we did a lot of research; we spent time looking at stuff on the internet about the system. We are very resourceful people.’*

In their endeavours to understand structures and services, however, all of the parents pointed to the lack of available information provided in accessible and sensible formats that describes how things work. This is despite statutory information systems like the ‘local offer’, a local authority-commissioned information repository about SEND support and services required under the provisions of the CAF Act 2014. Parents pointed particularly to the lack of good-quality information made available at the point of diagnosis, noting that materials are often out of date or convey negative messages. This is particularly true for families with children with Down Syndrome. Parents often commented on the depressing and obsolete nature of the literature. One mother, Julia, described:

> *‘We had been given leaflets from the hospital which were just awful because they were very out of date and full of bad haircuts and awful jumpers…those leaflets just tell you about things like if your little baby has Downs syndrome, they are more likely to get Alzheimer’s when they are 50, all of those things that you just don’t really need to know about.’*

Another mother pointed out that for all people, disabled or not, life is full of health risks and hazards, but we do not highlight these to all new parents, nor should we when a child with Down syndrome is born.

For families with autistic children, the issue is not so much that information is out of date but that there is a lack of available information, particularly at the point of diagnosis. Diane, a mother, commented:

> *‘The paediatricians kept saying, he is complicated, isn’t he? Well, you are doing a good job. And that was it and nothing else, so we just thought, that is no help at all. I mean, we read every book going and watched every podcast and YouTube and we kind of clued ourselves up.’*

Every parent highlighted difficulties with information access and some argued for a more comprehensive universal directory of information to provide families with a good starting point. Annaliese discussed her very poor experiences with information-sharing and concluded:

> *‘There is no big bible you can go to and have all this explained to you. You need a good information system, like a directory; I think it would make a lot of difference for a lot of people. And I think, you know, then you've almost got a fair system.’*

Parents commented that, overall, they learn about the system and what they need to know about it through a process of trial and error. They realised the importance of understanding the structures involved in service delivery and use a range of resources including the limited professional literature, the internet, books, social media and word of mouth via affiliations with other parents and parent groups.

All parents in this study recognised the significance of the SEND System for their children. Many demonstrated significant knowledge about how it works, including its limitations. In this study, all parents described the SEND System as the main route to access a coordinated multi-agency plan for their disabled children. All parents were aware of the Children and Families Act 2014 and the SEND Code of Practice. Some parents have made it their business to know this Code of Practice at least as well and often better than professionals in the field. In this respect, they feel they can exercise shared power. Julia commented:

> *'We will do lots of reading; I've read the law. I know the Code of Practice inside out, and it means we can practically write our own EHCP.'*

Families evidently seek a system that provides good information about what is possible and then for professionals to collaborate with them to achieve the right outcomes for the whole family. Family narratives affirmed that to meet their disabled children's needs, they want more integrated services across education, health and care, with a more rounded approach to planning. They also seek professional recognition that supporting complex needs is challenging for families and that they cannot do everything themselves.

Whilst these parents understand the importance of the SEND system, two-thirds of them recognised that they are much less confident in their knowledge of the roles and purpose of other parts of the system aimed at supporting disabled children and rights of referral, for example through the Children Act 1989 (CA 1989). This system provides access to social work provisions. Four of the families remarked that they do not fully understand how eligibility is assessed for local authority social work.

Three families have links to local authorities' children's disability teams. Two of these families have found these to have more specialised and holistic knowledge of disability, which has benefited their children's plans. One family was less positive. All parents described the difficulty of accessing social work services because the eligibility criteria are stringent or opaque. Even families whose needs are obvious reported challenges of access. Diane described the process:

> *'I contacted social services and asked for a social worker. I was passed from one social work department to another. The physical disability said it wasn't them, the learning disabilities one said, 'Oh, well, he is not with me because he has epilepsy', so I went to a normal social worker that just covers children, 'Oh, no, he is not with us because he has got epilepsy and autism and learning disabilities, so he needs to go to the Learning Disability Team'.*

After threatening to lodge a formal complaint, Diane's son was finally allocated a social worker, and from that point, the family were very satisfied with the support they have received from social workers. Diane commented:

> *'The social worker supported us right up until he reached 17 and then he was transferred to [the] adult section, who have been just as good.'*

Within this cohort of families, only the children with the most severe and profound levels of learning disability have been accepted for social work services. This raises interesting questions about onerous thresholds, as all learning-disabled children in this group have complex support needs. Some families recognised that particular points of transition for their children would be aided by the involvement of social work, such as preparing for adulthood and transitions to independence. Whilst the CA 1989 provides for such scenarios, families nevertheless reported that they struggle to access support, and some have had to resort to formal complaints systems to access social work services either through Local Authorities or through contacting regulators (Ofsted and CQC) and, in the most extreme cases, referring to the local government ombudsman or tribunals.

Eight of the nine families in this study were acutely aware of regulatory systems that are designed to hold agencies to account; and most were aware of their formal rights of appeal. Some parents had exercised or threatened to exercise these rights for leverage within systems. However, exercising their rights has not always delivered satisfaction or confidence with the process. Marcus described:

> *'We went to the ombudsman as a complaint, that produced a report of fault; the local authority still don't produce anything, so we had to send the report to the secretary of state; I can't remember under which section now, but the local authority seems to have a curious nonchalance. They got a report, so what! The local authority as officials seem to be people without accountability.'*

All nine families in this study reported many barriers to achieving a good QoL for their disabled children. They each described how things can ebb and flow, with periods of calm and then periods of crisis and, occasionally, feelings of equilibrium. Family life is organic and dynamic and throughout this research, all nine families experienced peaks and troughs; exacerbated by the impact of Covid-19 in addition to the usual stresses of daily life. Parents reported wanting professionals to recognise and understand how family dynamics shift and change, altering their support needs in turn. All of the parents and siblings involved in the study acknowledged that both individually and as a family unit, they have experienced periods of stress, pressure and isolation. Some couples reported huge pressure on marital relationships. Life is not always good. Families do not attribute this to having a disabled family member so much as how the system creates barriers and lacks compassion in its response. Chand remarked:

> *'I think there are a number of angles; one thing I've always thought is that there is a lack of support. When you hear your child has these conditions and then you see your child is not growing like any other child, then that is a shock to the system. It can be very daunting, and if there is support around that, then that at least (can) help. I think, though, that aspect is completely missing.'*

That the pressures are sometimes extreme is evidenced in part by family reports of:

- mental ill health, particularly of mothers, but also adult siblings;
- mothers giving up fulfilling careers to become full-time carers;
- fathers avoiding promotion to stay close to home to provide support;
- stress experienced in marital relationships;
- expressions of distress and anxiety from disabled children who struggle with communication;
- experiences of professional stigma and discrimination and perceived differential treatment;
- lack of opportunities for culture and leisure that provide needed respite;
- lack of sleep for some parents;
- a disproportionate draw on family income and resources used to supplement or enable disabled children to access provisions;
- purchasing education resources, health equipment, therapies and respite services so disabled children are included.

Families reported during times of intolerable stress, things begin to break down for them and they seek support from the system, but the response can be lacking. Over half of families sadly reported experiencing discrimination and institutional ableism within professional relationships. This becomes a barrier and builds mistrust. Gemma, whose daughter has Down syndrome, described her experiences:

> *'I think there is embedded ableism. I think it's embedded prejudice (it is) unconscious, but it does feed into their daily work. The way they deliver the diagnosis, the dramatic pauses, like, 'Oh, you need to consider termination!' (They've) got really antiquated ideas.'*

In reality, whilst these families recognised that there are huge rewards to caring for their children, there can also be extreme pressure. The system needs to better respond to this. Families reported that a lack of support and frustration with services becomes damaging to the well-being of all family members and destabilises family units. Older siblings particularly acknowledged negative effects on their own mental health that are linked to the weight of responsibility that they feel. Peter described this:

> *'I've kind of had a few other personal mental health things that I've gone through. Actually, I'm trying to disentangle myself from those, and trying to identify what actually will be healthy for me…and with my brother, I started wondering, well, actually, you know, I don't necessarily have capacity to take that on.'*

Adult siblings sometimes feel conflicted. They observe a system that not only does not work well for their disabled siblings but is also lacking for their parents. They want to provide love and support, but as they become adults themselves, they have their own lives to lead and feel restricted by the responsibilities they feel towards their families, particularly as their parents age and become less fit.

These families presented as resilient. Whilst they are moderately optimistic and fiercely determined to support their disabled children in achieving a good QoL into the long term; they also believe that they need the system to partner with them and be responsive during times of transition, crisis, or unexpected change. Families would concur with Ryan (2021, p. 159) when she comments:

> *'Don't assume that families that seem to be coping at one point will remain buoyant…relationships, effective support and community engagement are as important to learning-disabled people as pretty much everyone.'*

6.5. Family Support

It would be hard to argue against the importance of a physically and mentally healthy and resilient family unit for supporting a disabled child. Enabling families to maintain their well-being points to the necessity of supporting them properly. Professional systems have an important role to play in this. Parents recognised their roles as primary carers for their children, but that the complexity of their children's support needs will also require input from professionals who are skilled and knowledgeable about disability. Parents equally recognised that there are wider family needs and reported the requirement for a support infrastructure that will permit them to sustain normality in their own lives, including maintaining employment, having time for their other children and allowing themselves to emotionally recharge and maintain overall family health.

At a macro level, government's approach to family policies is important. At a meso level, families seek good, local, community services. Likewise, at a micro level, in accessing support for their disabled child, parents highlighted the importance of good relationships with professionals. They seek from professionals clarity about their options and practitioners who will listen, hear and work with them at the right times. These macro-, meso- and micro-level considerations indicate where families' lifeworlds interact with the system. Supporting a child with complex disabilities involves a complex range of considerations. Families argued that the system needs to better understand the role of family in this context and work to better meet both individual and family needs.

As previously stated, parents recognised that the SEND system predominates in providing support for their disabled children. This is an education-focused framework directed at educating children to prepare them for adult life within a macro model that promotes economic productivity. Whilst SEND legislation recognises the need for integrated education, health and social care as part of holistic plans, as previously described only the education elements of an EHCP, not the health and care ones, are legally enforceable; this highlights government policy priorities.

Parents reported that once their child is engaged within the SEND system, agencies with health and social care responsibilities often limit and gatekeep their involvement, with sometimes negative effects. Parents described struggling to get these agencies to work within the provisions of other children's legislation, such as the Children Act 1989 or the Chronically Sick and Disabled Persons Act 1970. The SEND system, however, is reportedly overwhelmed by increased referrals (LGA, 2022). Parents discussed delays in accessing provisions set out in the SEND Code of Practice, and how statutory timescales are frequently breached.

In addition to overwhelming demand, there is a question to explore regarding the dominant application of SEND policy with its focus on education and employability in the context of complex learning disabilities, whilst underemphasising social needs. There is strong statistical evidence that young people with severe and profound learning disabilities struggle to enter the employment market. In England in 2019, 0% of profoundly learning-disabled people of working age held paid employment (Mencap, 2019). Four young people in this study have such profound needs that they are unlikely to ever enter the paid employment market. Three others will need significant support to access paid work. Two children are too young to gauge their employment outcomes, but their complex learning disabilities mean that they will likely also face employment challenges; unless there is significant societal change.

Families described their desire for their children to have a stake in society and recognised that paid employment is one way to achieve this. In recognising their children's employment challenges, though, parents argued that their child's stakehold may need to be achieved through means other than paid employment. In mainstream education, successful outcomes are measured through neoliberal polices based on qualifications and prospects for further education and employment (Clack and Paule, 2019). Although some learning-disabled children in this study were undertaking qualifications, they struggle to participate fully in a curriculum focused on qualifications for employment. They are unlikely to achieve GCSE levels in Maths or English, a prerequisite for most paid employment. Parents are concerned about how their children will integrate into wider social systems. All of them believe that their children need purpose in their lives. In adulthood, this may not be achieved through a paid job or career, which therefore entails a stronger focus on achieving social outcomes.

Despite the associated challenges, many of these parents have not given up on their children becoming employed as adults. They spoke openly of using family finances to create jobs in a protected environment. These plans ranged from buying a corner shop, or testing software for children's educational resources, to setting up a horticultural plot, or joining the family's landscape business. Whilst all of these families strive to support their disabled offspring's eventual employment, they also recognised that their children's social worlds may become more important. They are, therefore, strongly focused on developing life skills and social interests.

Whilst not seeking to limit children's opportunities, the current system outcomes suggests that radical change is needed. For children to achieve full citizenship, they may need to achieve purpose in ways other than employment, which highlights the importance of developing social outcomes. The meaning of 'social' here is underpinned by conceptualisations of 'social functioning' where 'through social intercourse, individuals learn skills in interaction with others, and accomplish what is needed for living in direct or indirect exchange with others' (Dijkers, Whiteneck and El-Jaroudi, 2000, p. 64). If this argument is accepted – that social outcomes are significantly important for children to achieve their potential – then the system needs to be able to support not only the children's education but also their social worlds.

6.6. The role of social care

The social world is emphatically the business of the social work profession. Social theories form the basis of social work pedagogy and quality practice (Garrett, 2013). BASW, the independent professional membership organisation for social work, describes social workers as being uniquely skilled in accessing a wide range of practical and emotional support and services to meet individuals' needs and aspirations. Social work knowledge and skills can support people's achievement of desired outcomes and BASW argues that social work plays a role where ambiguity or complexity is greatest.

That social work can play a valuable role in supporting learning-disabled children with complex support needs is evident in the case study set out in Figure 24, below. This young person's plan, as described by his parents, is focused on social and health outcomes, and his social worker has played a significant role.

Figure 24: Case Study: Social transitions to adulthood

Fraser has complex autism, epilepsy, speech and language delays and chronic physical health conditions. Throughout childhood, he has needed high levels of support. A multi-disciplinary team of professionals has supported his education, health and social needs, including a SENCO, paediatricians, speech and language therapists and a children's disabilities social worker.

As Fraser approached 16 years old, his parents, Diane and Tony, alongside the professionals involved, recognised that he would not be able to access paid employment. In his final two years of college, plans focused on the transition into adulthood ensured that Fraser has access to purposeful social activities, opportunities for friendships and affiliations, and that his mental health would be well-supported. He has episodes where his difficulties in communication affect his behaviour and moods.

With the support of Fraser's social worker, Diane visited several adult day centres and post-18 colleges. She worked with Fraser's social worker to support him and identify the right plan for him. Their planning focused on Fraser's health and social needs; where he would live and how he would spend his days purposefully once he left college whilst also ensuring access to health provisions to meet his chronic health needs.

Fraser had reached the limits of what formal education could offer and so the focus moved to social outcomes. His children's disabilities social worker worked closely with adult social care, achieving a smooth transition to an adult social worker before his eighteenth birthday. Fraser now has a post-education plan of mixed activities, including attending a centre where he pursues leisure and sport and has access to friendships and a skills-based programme to build as much independence as possible. He sees a long-term carer/befriender at least one day a week who supports him in accessing activities that interest him and reinforces the social skills work undertaken at the centre.

Fraser will always need full-time care and will live with his parents. During Covid-19 lockdowns, both the day centre and the carer programme were paused. There was marked deterioration in Fraser's mental health. Parents reported that the social worker remained very accessible and visited regularly to work out strategies to keep Fraser well and help his parents with coping strategies as his behaviour could be challenging. A positive and co-productive working relationship between Fraser's parents and social worker was in place. Diane and Tony both described social work support as invaluable to maintaining stability for Fraser and achieving a good QoL for him.

Fraser's parents as evident from the case study in Figure 24 believe that community based options are essential for their son who they adamantly maintained will never be placed in residential services. Professionals and activists have argued that care within large institutions is a revocation of children's rights. Davidson *et al*. (2017) discuss how community based professional social work teams are needed to offer skills in referral, assessment and care planning in supporting family based care. This is highly applicable for families of learning-disabled children. Evidence in this study indicates though that successfully engaging social workers in supporting family circumstances is often challenging. Around half the families described how social work involvement is limited in scope, and quite transactional; this is ill suited to the support of long term needs arising from complex conditions. Two families described more positive experiences of community support services but none of the families had much confidence in the quality of respite or alternative care provision. One family had drawn on full time institutionalised care but felt deeply conflicted by it and did not see it as a long term solution.

6.7. Achieving life outcomes: understanding disabled children's needs

All of the children in this study have complex needs and their main route to professional support is through their EHCPs. The stated purpose of EHCPs is to secure the best possible outcomes for children and young people across education, health, and social care and prepare them to transition to adulthood. The SEND system is individual-child-focused, not family-focused. Family support models however form part of the pedagogy of social work, and like Fraser, many of these young people will benefit at times from social care support.

Parents in this study expressed reasonable to high levels of satisfaction with the education elements of their children's plans. They reported that achieving plans can be challenging though and sometimes involves fighting the education system and threatening the use of SEND tribunals. Although they reported that the EHCP system is not straightforward, they contend that over time, they have been able to achieve plans for their children that mostly meet their education needs.

Satisfaction with health assessments within EHCPs and targeted support, such as speech and language therapies or physiotherapy, is more variable. Parents generally expressed concern about the quantity and accessibility of health-related provisions rather than their quality. For complex health conditions, some health provisions are accessed outside of EHCP through GPs; for example, accessing an eating disorder service or sleep clinics.

The parental narratives exhibited a particularly striking lack of engagement of social care practitioners. Only one EHCP included a care/social assessment with stated outcomes that were at all adequate. When parents were asked their views about the lack of consideration in the care sections, four of them did not wholly recognise its place, understanding social outcomes to be their responsibility as parents. Whilst they recognised that their children have social worlds, they mostly believed it falls to them to achieve access. Annaliese, a mother of a 12-year-old, remarked:

> *'I must admit I never assumed that I was going to get anything. Other than support in education and the health elements that support her in education. The rest, I thought, was our responsibility.'*

Four of the nine families reported experiences of departmental silos where education and children's social work fail to cooperate with each other. At least three families reported that social workers have declined to be involved in the EHCP process because they have had no prior contact via Children Act 1989 provisions. This even included stages when transition to adulthood plans were being developed. Social workers under the SEND Code of Practice, at the very minimum, have clear responsibilities to support independence into adulthood. Two families reported that social workers have argued that because the child's needs are assessed through

SEND, they were not required, thereby failing to recognise their own statutory responsibilities.

The age of a child affects when parents are more likely to seek social care services in support of social outcomes. Younger children's social worlds are very family-based, although support with leisure and extracurricular activities and accessing short breaks for respite may be valuable; only one participating family has done this.

There is a mixed understanding within the parental group about the role of social work generally, and in supporting the care elements of an EHCP, specifically:

- two families believed that social work would not be involved unless there were safeguarding issues;
- two families understood social work as broader than safeguarding alone but had been unable to engage social care services for any family support work. Support was declined due to eligibility criteria;
- two families demonstrated a clear understanding of the wider context of social work and were positive about the contributions social workers had made to their children's plans;
- one family has had a social worker for many years but had not found the relationship supportive;
- one family has had no contact with social work throughout their disabled son's childhood, but parents believe social workers have a role in planning for transition to adulthood and were awaiting contact, although their son is already an adult;
- one family saw no role for social work currently, as their child is very young and their health visitor is meeting their needs.

Circa two-thirds of the parents perceived the role of children's social work in the context of their families as only helping them to access respite care and, in some cases, direct payments. Fewer than half of the parents understood social workers' roles in accessing wider advice, advocacy, family support and services. Those that had experienced constructive and proactive social work articulated how this has improved the family's well-being. Diane commented:

> *'It made a difference that our social worker could command an MDT [*Multi-disciplinary team*]. Whereas I had to fight every person, she could command it. She became my link that was always missing. Where she could speak to somebody or she could arrange something else, she arranged funding for us without a hick and it has been brilliant.'*

The older the child, the more likely parents are to see a role for social work. They recognised that their child will have unique views and that they should be entitled to support with more private aspects of their life outside of their family networks; for instance, with relationships, sexuality, welfare entitlements and finance. Some parents also recognised that whilst they have the motivation to support their child in achieving social outcomes, they sometimes lack the requisite knowledge and skills that social workers have, for instance to identify the right sort of accommodation for adulthood.

6.8. Community and residential programmes

Having access to the right skills to achieve social outcomes within a community setting is important. In Chapter 2, reference was made to criticisms of residential special schools for learning-disabled children on the grounds of separating them from family. However, residential special schools can offer advantages which are less easily replicated by services in the community. Good-quality residential special schools provide input on social functioning skills that link with the requirements that could be contained in the care sections of an EHCP. This is often referred to as a 'waking day curriculum'. Whilst the term is imprecise, it recognises that learning-disabled young people can benefit from programmes designed to develop resilience, raise self-confidence and improve mental and physical well-being. These can focus on travel training, safe internet and social media usage, understanding money, laundry, cooking, shopping and how to access leisure – all crucial skills for life. Mainstream schools rarely have a waking day curriculum that covers these aspects of social development. In residential schools, these can be delivered after school hours by care staff.

Whilst some of these social outcomes can be developed within families, the system minimally recognises how expert parents are expected to become across many aspects of their children's lives. Teaching strategies are required for social skills development, and social skills training can be intensive. Dividing outcomes into stages and, often, engaging in repetitive learning puts pressures on families that already lack time or capacity given the other demands they face to support their children with medical appointments, reviews, etc. Angela reflected on the time pressures parents feel:

> *‘I had to give up work because sorting all of this out was a full-time…it was just a full-time job, managing, nobody could possibly manage and deal with all of this stuff and so I gave up work.’*

Children should not need to attend residential school to achieve social outcomes that could be addressed within the community. There is however an emphasis on learning-disabled children accessing special education provision and it becomes a driver for their placement in residential institutions. This may arguably meet a necessity principle but is unlikely to meet a suitability principle (Cantwell *et al*. 2012).

The system therefore currently presents a number of problems including:

- focus on education outcomes dominates rather than on family life and social outcomes;
- lack of investment in community based support services puts stress on families;
- lack of social work engagement.

Social context needs to be better recognised and better community supports developed. Families in England during the first decade of the 21st century had access to Sure Start Centres that had the capacity to teach skills to achieve better social outcomes, but this provision is no longer on offer.

To understand why social care is not more involved, it is important to consider the separate eligibility criteria for SEND and children’s social care services. Each local authority is required to publish this information on their websites. To aid insight, an analysis of the information posted about structures and eligibility for services on the seven authorities’ websites where these nine families live was undertaken for this study during the data analysis stage. This found that SEND Information is relatively accessible.

6/7 local authorities explain the purpose of their SEND team and its statutory obligations to assess, meet and review the needs of children and young people with SEN.

- 1/7 local authorities provides no specific information about the role of the SEND team on its website, although it provides a contact number.
- 6/7 highlight engagement with families and explain professional support roles.
- 7/7 of the local authorities provide referral information.

By contrast, children's social services information connected to disability services is less accessible.

- 3/7 emphasise their main responsibilities as being safeguarding and protection.
- 4/7 focus on disabled children only, not on wider family support,
- 3/7 note that siblings may also need support as carers and could be eligible.
- All state that only very severe and profound disabilities will meet the eligibility criteria for service.
- All stated that a pre-assessment will be required before a Section 17 'child in need' assessment begins – an assessment to consider an assessment!
- 3/7 refer to the now obsolete Every Child Matters (ECM) outcomes.
- 2/7 local authorities do not appear to publish information about the role of their disabled children's team.
- 3/7 make no reference to support for the transition to adulthood.

Whilst this is a basic analysis of seven local authorities, it is useful in illustrating the information that parents from these families would initially find when seeking insights about the services their own local authorities provide. In all seven authorities, children's social work departments emphasise safeguarding in their information systems. It is unsurprising then that one of the parents, Annaliese, commented:

> *‘I assumed social care was only for those that didn’t have the sort of family environment and are on the social services awareness list, rather than for families like us.’*

Local authorities it seems, either by design or default, push families of disabled children down the SEND route for support. DfE data also indicates that significantly more EHCPs are agreed by local authorities than ‘child in need’ assessments for disability reasons. EHCPs, as the fifth and final stage of support for SEND, represent only one section of the overall numbers of SEN assessments, so EHCP figures reflect only some of the families seeking support for their children through the SEND system.

Figure 25: UK government data on child in need referrals and EHCP applications

Year	Child in need assessments	EHCP Applications
2020/21	Total for all disabilities: 49,310	Applications for EHCPs: 75,951
2020/21	For learning disabilities: 20,465	New plans agreed: 60,097

An additional factor that parents cited as a barrier to accessing social work support is what they believe to be a level of gatekeeping, with high eligibility criteria in place to manage demand. Even some of the more complex issues experienced by these families have not been deemed sufficient to warrant support. One parent described how her child could not walk properly without orthotic boots, restricting her ability to start school. This mother, who claims universal credit, was advised to buy expensive Doc Martens instead to support her child’s ankles. Another family also reported being unable to access essential orthotic boots. Provision for this should be possible through the CSDPA 1970.

Parents recognised that austerity cuts limit local authorities. The Local Government Association, in 2019, stated that by 2021/22 there would be a funding gap for children’s disability services of £1.6 billion. Increased demand is attributed to the expectations of the CFA 2014 and the increased life expectancy of disabled children due to medical advances. Several parents referenced their belief that service accessibility is mostly based on affordability, not need. Marcus, a father, reflected:

> *‘From the local authority’s point of view, they hope if they play hardball, they are going to have cases where parents will go away during the process. Sadly, though, is it right to be hard-nosed when you are talking about vulnerable young people? I mean, there is something about the taxpayer and value for money and spending wisely to get the best, but in the middle of this is people. So, being hard-nosed about an individual, is that the system we want?’*

6.9. Children’s social policy considerations

Successive UK governments’ focus on neoliberal policies, which was discussed in Chapter 2, is linked to financial considerations. Whilst neoliberal managerialism has influenced policy across whole UK state governing systems, it has also become tied to the lives of individuals (Read citing Foucault, 2009). This has had particular ramifications for children’s social work. Neoliberalism has diverted the focus from welfare principles toward managerialism (Briskman, 2009) after trust was lost in the welfarist philosophies of social work in the 1960s–80s. Welfarism was rejected in part because of public and media outrage in response to several tragic child deaths through abuse and neglect by parents or carers, including Maria Colwell (1974), Victoria Climbie (2000) and Peter Connelly (2007).

These cases and others proved pivotal in changing structural approaches to social work, and the purpose of the children’s social work system was redefined. It has evolved towards one of child safeguarding rather than family welfare (Parton, 2014; Purcell, 2020). Social work has become more risk- and protection-focused and notions of therapeutic family support models for children outside of safeguarding systems have been diluted. This has ramifications for families with disabled children who may need welfare-based support.

Learning-disabled children with social needs are not ‘seen’ enough by a social work system that is primarily focused on child protection. Child protection is relevant for disabled children; the NSPCC contends that they are more vulnerable to abuse and neglect; however, an undue emphasis on risk and protection is at the expense of wider considerations of well-being, and a social care system that insufficiently recognises the circumstances of learning-disabled children. These children face challenges in their day-to-day lives and their families experience emotional effects; they will, at times, need professional social work support.

Clements and Aiello (2021, p. 4) argue that the lack of disability-specific guidance concerning assessment and care planning for disabled children is causing significant harm to children and their families. The safeguarding focus of national and local social care policies in England creates a default position of parental failings for those assessing disabled children. This approach locates the problems associated with a child’s impairment in the family – a phenomenon that Clements and Aiello call ‘institutionalising parent carer blame’. The result is a ‘one-size-fits-all’ approach to families, regardless of circumstances (Clements and Aiello, 2021).

Two families in this study described experiences of parent blame when they persisted in seeking services under Section 17 of the Children Act 1989. They felt that they were being judged as being unable to cope. One family’s persistence in insisting that social workers recognised their child’s needs, led to conversations about considering Section 47 of the 1989 Children Act – the ‘duty to investigate’ for reasons of neglect. This alarmed them; and is an extreme and disproportionate response to the issue being discussed. Parents were seeking access to their child’s rights to services in their transition to adulthood. This parent believes they were being blamed unreasonably for needing a service that they cannot reasonably provide themselves.

Analysis of the social policy context for disabled children does evince the government’s intentions of encouraging support for disabled children within the SEND system, rather than children’s social services; except in the context of child safeguarding. These intentions are not explicitly stated, but a policy of nudging agencies towards the primacy of the SEND system to coordinate disabled children’s plans seems evident. Decoupling the coordination of disabled children’s plans from children’s social work services can be identified through several developments since the enactment of the CFA 2014.

1. The evaluation report of the pathfinder programme for the implementation of the EHCP process, published in 2014, refers to the new system as ‘part of a new family pathway where the (new) family-centred way of working could lead to better quality plans as it would enable professionals to develop a more comprehensive understanding of the child or young person.’

2. The social work inspection regime before 2013 treated disabled children as a priority group. Since 2013, the Children's Services Department's single inspection framework and evaluation schedule for inspecting services for children in need of help and protection focuses on looked-after children and care-leavers. Disabled children are no longer a specific line of inspection.
3. Disabled children as a particular inspection category are handled under a new Ofsted inspection system for SEND that was implemented in 2015 and is currently being updated.
4. In January 2021, the DfE launched a review of children's social care, describing it as a 'once-in-a-generation opportunity to reform systems and services' by tackling practice and outcomes. When organisations representing families of disabled children asked if disability would be included in the scope, they were informed that it would be handled through SEND reviews. The subsequent review report did not address disability .

It is difficult to gauge whether the disengagement of learning-disabled children from the priorities of children's social work is ideological and deliberate; or an unintended consequence in which disabled children's social needs have been overlooked through a preoccupation with safeguarding; but it feels very real to these families. A factor that puts services for disabled children at odds with children's social care is that their needs are likely to be long-term, often lifelong; but children's social work departments are largely organised and measured on their ability to move children and families through the system to a clear exit. This means undertaking limited-term contacts and not open-ended interventions. This is not helpful for children with chronic health conditions and long-term disabilities.

Families were asked directly during fieldwork what their key messages for professionals about disability services would be. All of the families expressed that they want more holistic services and better access to information to help them understand the pathways to different provisions. Around half of the group described how they would value an individual who understood the whole children's services context, including legislation; somebody who could help to coordinate plans, advocate and help them navigate the complex system. Two families that already had such an advocate in the form of a social worker, valued it tremendously. Parents want a human, not a bureaucratic response. They find the system confusing and the different professional cultures challenging to make sense of. In effect, parents argued for an integrated system that would work in a process of meaningful partnership with co-production.

6.10. Conclusions

In this chapter, I have explored what quality of life means for families, identifying that they seek the same outcomes for their disabled family members as for themselves; to have a fulfilled, purposeful life where they are loved, feel safe, cared for and can realise their aspirations. Whilst families reported that they draw hugely on their own resources to pursue their best possible lives, they also recognise that they are dependent upon what they described as the system: the range of government and professional bodies that can both support and inhibit achieving that good life. Families identified that the SEND system is the main route to services for their learning-disabled children, and that it primarily focuses on education, not wider family needs. The SEND system does not address social outcomes well, nor does it focus particularly on achieving wider purpose where paid employment is unlikely to be achieved.

Parents indicated that the system is complicated and many would value better information and more holistic and collaborative professional relationships. This would help them to navigate all of the relevant systems to achieve the best outcomes for their families.

Chapter 7: Findings and Discussion: Relationships and Developing Co-production

7.0. Introduction

This chapter explores the second element of the main research question; how families exert choice and control to achieve a good quality of life (QoL). In Chapter 6, it is highlighted that families emphasised relationships and control of one's environment as highly significant factors for achieving a good life. Parental and sibling critiques of significant relationships included the personal: couple relationships; parent/child relationships; extended family; community, including friends and neighbours; and professional relationships including multi-agency practitioners.

Families argued that problem-solving and achieving better outcomes can be founded both on the support gained from extended family and friendships; and from professionals. Positive relationships support the achievement of life goals but negative relationships become barriers to achieving a good life. Parents and siblings recognised in common, that different types of partnerships offer different things in achieving family aspirations. Whether supportive or riven with conflict their importance to quality of family life is immutable.

Later in this chapter, the high level of condition-specific knowledge and problem-solving skills, resources and commitment that families bring to partnerships are discussed. In their narratives parents and siblings demonstrated their abilities to analyse challenges; scan and understand their environments; inform and educate themselves; develop networks and identify solutions. Through this, strategies to achieve what is important to the whole family unit, are developed. Where family lifeworlds meet the system though, families recognised that to attain QoL goals, navigate more difficult times and achieve security and well-being, professional partnerships are necessary.

In this chapter, co-production (see Chapter 3), and what this actually mean for parents is explored. This includes what families recognised as the benefits of co-production in offering different types of positive, collaborative relationships with professionals where knowledge, skills and resources are pooled in a system of common purpose. Equally the mismatch between theories of co-production with families' reported direct experiences is discussed. Understanding how families work with professionals, as well as how they harness wider relationships, provides insights into how they exercise choice and control to achieve good outcomes, and is explored in this chapter.

7.1. Relationships within the lifeworld

i. Couple relationships

Particularly important to family life within this particular cohort is the nature of the couple partnership. Parents recognised the importance of their relationships with their partners, the strengths it can offer and the impact of stress on their relationship; created through constantly fighting what they perceived as an unsupportive system. All of the participating couples are in reportedly stable marital relationships. Many parents reflected on the resilience this gives them, but also the challenges they encounter to maintain healthy marital relationships. Angela commented:

> *‘We have quite a strong marriage, and periods where we have had, like, a little oasis of support. We have had some really terrible times; it has been really hard. It is not easy now, but just to have some time and fun together would be good; we are still married, so that is a miracle! I have a good marriage, so we are lucky.’*

Another parent, Chand, commented:

> *‘There is definitely an element of the impact of it all and not having the support and the impact it has on the relationship. I know a few more families who have split because of that and found it difficult.’*

All of the couples discussed the adjustments they constantly have had to make in their relationships, and how this has not always been straightforward. Whilst the couples have remained together, the majority recognised that the stresses they face put their relationships at risk and they have needed to focus on maintaining a sense of themselves as a team managing challenges together. Around half of the parents pointed to the lack of support and recognition from professionals about the impact of their child’s situation on marital relationships and how this creates risks for family cohesiveness.

ii. Sibling relationships

Familial relationships overall within all of the families in this study are very strong; with a clear sense of family identity and shared values evidenced. Every individual in the family matters and is considered inclusively in family well-being. However, in addition to marital pressures, parents also described the pressures on other children within the family. Two mothers described how their young adult daughters have left home to preserve their own mental health and well-being.

In all nine families, the parents are the main carers; however, in eight families with multiple children, siblings also play a significant and supportive part for their disabled siblings. Most of the parents and siblings understood that siblings do not have to be what professionals term ‘young carers’, only ‘good’ brothers or sisters. This is part of a family culture of looking out for each other in kinship. Luke, whose sister has Down syndrome, highlighted this:

> *‘My parents have always said that I am not her carer, I am her brother. I always try to look out for her, but that is a brother thing.’*

A small number of siblings did refer to themselves as carers but mostly reported this as something positive. Amongst older siblings it is very evident that they have an understanding they are likely to have a continued support role throughout adulthood as their parents age and one day are no longer there. Peter, a sibling, commented:

> *‘You just have to wait and see how time pans out. But yeah, I do recognize that I am, as well as a family member, I'm clearly a supporting resource to my parents and my brother as well, and I will need to have a conversation with my parents about the future.’*

In terms of the future, parents had varying expectations. Some expressed very clearly that they do not expect their non-disabled children to be anything but advocates for their disabled siblings. Stuart remarked:

> *‘We will look after Zara financially for welfare. I don’t want Max and Florence to be burdened. I wouldn't expect that they would need to have Zara living in their house, for example. We wouldn’t want to limit their total freedom to go wherever they want to or wherever their partners or themselves might want to go and work, but that's family!’*

However, another parent described her expectation that her son will step in when she is no longer there:

> *'I don't know how long Phillip is going to live. It is difficult stuff, but he's got his brother and that, if we go, he's got his brother.'*

Other parents have formalised arrangements for the future and included their children in those plans. Diane explained:

> *'Fraser, for the rest of his natural life, will have our home; whether we are here or not, he would never have to leave. Joanna* [his sister] *is named on the power of attorney and that was her choice, that she would oversee, not solely though; we have somebody else as well.'*

Each of the participating adult siblings saw a future role as advocates and, in some cases, at least part-time carers for their disabled siblings. Many accepted this and some have an implicit pact with their parents to own their future responsibilities. Some are anxious about how this may limit their future options, but rather than reject the expectation, they instead reflected on how all needs can be balanced. Matthew commented:

> *'I would try and live as close as possible. But it seems, my jobs will keep me tethered to London more or less permanently unless I quit one of them. The thing about the teaching job is that it is mobile, you know, you can sort of take that and move somewhere else because it is transmissible.'*

There is a high level of correspondence between what parents described in the research as their expectations about siblings' future involvement and what siblings themselves said. There was little evidence of rejection of parental expectations. Those siblings whose parents expressed lower expectations of proactive involvement also described a much lighter touch regarding future advocacy for siblings than those whose parents had greater expectations. Both sibling and parent narratives emphasised that other children in the family see roles for themselves in protecting their disabled siblings' long-term interests. Their expected involvement varies, but all of them described responsibilities in this regard. As Peter mentioned:

> *'As well as a family member I'm clearly a supporting resource to my parents and my brother.'*

Tensions are evident in the competing needs of offspring; however, the level of support and resourcefulness that siblings offer in the context of family life is indisputable. All of the parents ultimately seek independence for all of their children but caring for each other is seen as something family members simply do. This is pretty typical of their overall understanding of family life, whether there is a disabled family member or not. The warmth of the relationships within these families is evident. They clearly share values underpinned by emotional ties that lead to a common understanding that they all care for and express concern for each other. This care is not about disability but about what family members do in kinship. Julia described her and her husband's message to their son:

> *'We have always expected him just to be her brother and to love her.'*

7.2. Community relationships: identity, collaboration and support

Some families within this study commented that they identify strongly with other families with disabled children within their particular disability community. They related in a way that is reflective of Solomon's (2012) descriptions of horizontal identity. By associating with other families with similar experiences, they find a source of collaborative support. For other families, this level of identity, collaboration and support was less evident. The families in this study who have a child who has Down syndrome maintain stronger community affiliations than those families with autistic children. Whilst the parents of autistic children involved in this study reported that they draw on advice from organisations such as the National Autistic Society, they stated that they draw less on other families for support. The research cohort is not large enough for this to be a generalised finding but families with experience of autism appear to be more isolated from wider community support systems.

Those families who do link with disability communities do so mostly locally, enjoying reciprocal opportunities to share knowledge and resources. Some parents reported having been prepared to travel 30 to 40 miles to meet with groups of other families with common interests, particularly around Down syndrome. They commented that generalised disability support groups are less helpful. Two mothers described very upsetting early experiences of referrals to general disability support groups by professionals; and that these groups were very poor at recognising differentiated needs, treating disability as a homogeneous identity. Around two-thirds of the families have also engaged with charitable support groups. Parents engaged in these relationships more so than siblings. Siblings tended to see these links as something parents value but that they valued less.

In addition to face-to-face relationships, some parents draw on social media; particularly open and private Facebook groups and Twitter. They share information and advice on social media, and sometimes crowdfund for services or equipment that they need. Parents get to know other families virtually and gain strength from the interaction. Social media platforms open up much bigger and more diverse communities of support than local networks can provide. One mother, for instance, described how one of her best friends and allies is another parent she met through Facebook who lives 200 miles away and whom she has never met in person.

Knowledge and understanding gained from these disability community networks, which provide insights from other parents' experiences, are sometimes used as leverage in challenging professional assessments and advocating for particular services.

Parents also reported examples of collaborative problem-solving with other parents. Developing their own services and working with other families to set up charities. In some instances, these charities have subsequently become agencies to which professionals then refer other families.

7.3. Relationships within the system: professional relationships

Families do not seek to depend on any state systems; however, they recognised that at times, they need additional support from outside the family unit and their immediate community to access services. This is where the importance of relationships with professionals comes to the fore. Both parents and siblings recognised the inevitability and necessity of engaging with professionals who are key to accessing some services. Both parents and siblings indicated the importance of how individual professionals involved with their families understand their wishes and aspirations and work with them to deliver these. They see professional roles as significant in enabling support for practical and emotional challenges whilst supporting the family in exercising choice and control.

Families also reported that they seek acceptance from professionals of their learning-disabled children as human beings; worthy of respect and valued for whom they are. They argued that disabled children should not only be supported through medicalised professional approaches based on notions of their impairments; they have as much right to a good life as any individual. In this context, parents described relationships where some professionals apply what they termed deficit models; the child's problems are seen as something to be solved rather than viewing the child's strengths as something to build from. Parents and older siblings expressed their desire for a focus on ability, not disability. They seek support that is provided on the basis of empowering and improving their disabled child's quality of life. This was evident in Julia's remarks:

> *'I wrote to the school and stated that my concern was the problematic and deficit-based language used by the school in relation to my daughter. I was furious. We regularly push back on deficit language; we regularly question, what have you done to support this? Stop telling us there is a problem unless you can tell us what you have actually done to help with this.'*

Parents and siblings described both good and bad experiences with professional relationships and attitudes. In their narratives, they strongly linked how their disabled family member is treated, with the difference this makes to the family's overall well-being. Each family works with many different professionals. They reported their views that professionals and parents bring different but complementary aspects to a working partnership. This includes family knowledge and resources combined with professional skills and service provision. The quality of the partnership between the family and the professional team is an important element for families.

Parents tended in their narratives to focus more on relationships and less on agency structures. The structural dimensions of the multi-disciplinary teams around their child did not matter to most parents. Parents wanted to understand how to navigate the system, but strong and trusted relationships, not structures, matter most because they are empowering in achieving the right outcomes. For parents good-quality relationships matter more than which team somebody works for. Organisations structure themselves according to government and local policies in ways that make sense to them, but relationships are sufficiently significant that parents admitted sometimes ignoring structures to go to the professional they perceived to be most helpful. Several parents described the strength and moral support gained from good professional relationships in sharing the load. Annaliese, a mother, described side-lining her community paediatrician, instead targeting her hospital consultant, whom she felt better understood the implications of genetic' conditions:

> *The community paediatrician; I wouldn't say she was ignorant, that would be harsh; she probably didn't know enough about Down syndrome, but she said a lot of things I found very negative. I found that incredibly difficult. I went back to Dr D, said I can't see this woman; I am really sorry. He was wonderful and he said 'No problem! You come back to me!'*

When relationships work well, they are seen as affirming. Just what a difference these can make is illustrated in Figure 26, where parents describe their experiences .

Figure 26: Parental examples of positive professional interactions

Claire, mother of a son with DS:

He had a lady working with him, Mrs S. And he loved her. So, it was Janet in the morning and Mrs S in the afternoon, Janet left and Mrs S said, 'I want him full time'. For my son that continuity for him of one person was what worked. He was in class and he thrived. She is so lovely…she is a family friend now.

Angela, mother of an autistic son:

We met this lovely team; they said they normally had a twelve-week programme but he is not going to fit the twelve-week programme, so he can come every six months, and he went there for seven years.

Diane, mother of an autistic son:

They put me in touch with a social worker out of their department who was just brilliant. She was horrified by what I had had to do to get a social worker and she supported us wonderfully, right up until he reached 17.

Annaliese, mother of a child with DS:

I knew [the diagnosis] *was coming but I still didn't want to hear it; I don't think I cried, I just made these funny noises and just sat there in shock. Dr Davies was very good, he sat there and said nothing. He let me have my moment, and then he very calmly said, 'I know this isn't the news you were expecting to hear'. He didn't say 'I am sorry' for which I am now extremely grateful.*

Stephanie, mother of a child with DS:

My son was a baby; it was his brother's fifth birthday; we planned to have a party in the garden and have friends around and a magician and things. The nurses on the night shift *helped wrap all the pass the parcel prizes because I had them all in my room. And they said, you just go to sleep and we will do it between our ward rounds. They would just look at helping me do things.*

Chand, father of an autistic child:

I spoke to his professor who teaches him music and he said, 'Why don't we try and see if we can adjust the course for him?' He is good at music but would require theory. The professor said that he can tailor his own course; he can make sure he at least has an understanding, and he can decide if he wants to study there or not, so that's where we are at the moment.

Darren, father of a child with DS:

There's a lot of things that you are never ever told; we found out a lot through the health visitor. We have been blessed with a brilliant health visitor and she would say, oh, you can do this. Let's say I didn't realize it was a thing you could do!

Julia, mother of a child with DS:

I didn't tell them on the phone that she had Down syndrome then I rocked up and I thought, I have got to tell them now, it is just so visible. I got to the door and when the manager came out, she said, 'We will go in in a minute but I just wanted to come out and introduce myself', and I went 'Oh, is it OK for us to come?' And she said, 'Well, why wouldn't it be?' and I said, 'Well, she has got Down syndrome' and she said, 'OK, and what difference does that make? There are 30 children in there and they are all different, of course we want her!' And they were amazing, absolutely amazing.

What is significant in these parents' commentaries is how important it is for professionals to afford learning-disabled children the same rights as others. Most of the scenarios in Figure 26 evidence children being supported to participate in culturally normative activities. Parents want all of their children to be fully included in mainstream life, to go to nurseries, learn to play music, have birthday parties and be able to partake in family life. These examples demonstrate professionals enabling families to achieve goals that made family life better in those moments.

The warmth and empathy of professionals and their preparedness to adjust to make things possible is evident. Parents seek this from all professional relationships, and when it happens, they are hugely appreciative of constructive human responses. Ryan (2021) highlights the value of decency, respect and thoughtfulness in professional interactions. She describes the lengths that good professionals will go to as being both truly extraordinary and demonstrative of basic humanity. The parents in this research recognised the value of professional interactions based on trust, listening and reflection. They also valued the help to access services that makes their lives even slightly easier.

7.4. How family/professional relationships become challenging

Whilst parents cited many examples of good experiences with professional relationships, they also reported less-positive interactions; and negative professional attitudes towards disability. Parents and siblings alike spoke about professionals ascribing unwelcome disability identities. This included notions of ‘pity’ where professionals feel sorry for the family’s ‘predicament’ in having a disabled child. Pity was also linked sometimes to a non-empathetic attitude. One mother, Gemma, reported feeling blamed for her daughter’s ill health when she was asked what she expected when her child experienced physical illnesses linked to Down syndrome. Gemma contended that some professionals convey that parents should not be surprised by their child’s challenges and that they must accept these as their lot.

Such attitudes leave parents feeling disempowered, so they seek to reclaim control in many constructive ways. These include:

- understanding their legislative rights and keeping well informed;
- building relationships and networks using charm, dialogue and quid pro quos;
- becoming an insider, taking on governance roles such as school governorships and expert-by-experience contributions;
- becoming members of national working groups in health, education and social care;
- becoming ‘experts by experience’ trainers for statutory agencies;
- developing strong identities as activists;
- setting up charities to develop their own provisions;
- joining local authority parent consultation groups, offering them direct access to very senior staff within the organisation.

Parents reflected that adopting governance roles grants them a voice but also provides insights into the challenges agencies face. This gives them a more balanced understanding of the pressures, allowing them to weigh and decide what to push for regarding their children. This can create positive influences for change; Julia commented:

> *'I would meet with the Director of Children's Services and tell him supportively about policies, I was pretty much that critical friend.'*

Whilst six of the nine families explained that initially, they are more likely to take an ameliorative approach with professionals, they also reported being willing to consider formal measures. They pointed to the importance of accountability systems with options to challenge the system and seek redress. They use informal routes, including complaint procedures; democratic processes, contacting MPs and councillors; and contacting regulators, including Ofsted and CQC. They also highlighted more formal systems, such as the Ombudsman or SEND tribunals. Whilst some parents reported that complaining can create confrontational relationships, potentially leading to a stalemate, they also highlighted the need for governance systems that enable them to exercise their rights to professional accountability. Most parents sought to position themselves to influence, but if this does not work, they will apply alternative solutions or remedial actions through the various rights of redress. Figure 27 presents the ways these families have used accountability systems.

Figure 27: Routes to redress used by parents

Accountability system	**Families using systems (of 9)**	**%**
Informal complaints	8	88%
Formal complaints to LA	3	33%
Formal complaints to NHS bodies	2	22%
Complaint to regulator	2	22%
Equality and Human Rights Commission	1	11%
MP or Councillor	5	55%
Tribunal	2	22%
Ombudsman	1 on 5 occasions	11%
Number of families using more than one system	8	88%

7.5. Developing professional partnerships

All parents and older siblings within this study demonstrated high levels of skill and resourcefulness; they are ‘experts by experience’ in their families’ situations. Each family works with a broad range of professionals and a multiplicity of agencies within education, health, social care and the voluntary sector. They access both universal support and specialist services. Every family draws on statutory budgets over and above the generalised provisions for children.

Within the SEND system, many professionals perceive the costs of supporting learning-disabled children as unaffordable; with an increasing population of disabled children exerting enormous pressure on budgets. Austerity cuts since 2010 have led to many agencies struggling to meet their statutory responsibilities amidst multiple priorities. Statutory agencies and the government are seeking cost savings (*ISOS Report*, 2022). The DfE introduced in 2022 a safety valve scheme to incentivise local authorities to reduce costs.

Parents were keenly aware of austerity cuts and sympathised with the issues of limited budgets; but they also pointed to the lack of planning and preventative services, which incur unnecessary costs in the longer term. They described agencies’ fragmented service planning and lack of communication and hypothesised that statutory agencies are often overly focused on saving money and gatekeeping resources rather than meeting needs. Chand, the father of an autistic child commented:

> *‘They have had a lot of funding cuts, and I understand what a struggle they go through because they have to balance their books. Which is silly, really, because what you learn is that the more they support people now, the less they will need later. It is an investment, not a cost, and the less you support now, the more you can pay later.’*

It is evident that these parents contributed considerable amounts of their families’ financial resources to their disabled children’s plans. Commentaries on social media indicate that this is a common strategy adopted by many families and is used as leverage to obtain the right services for their children. It can include commissioning private assessments; and sometimes simply buying what is needed rather than fighting for it to be provided. Kuklys (2006) highlights the disproportionate amount of household income that is spent in families with a disabled member compared to families without a disabled member. For some families though purchasing services or equipment is just not possible due to their financial circumstances. Parents highlighted that using family finances to supplement services is not possible for all and expressed concern about this. Marcus commented:

> *'I can't rely on the system. I mean I am lucky enough; I am financially able to do things, but there are many people who won't be able to.'*

This draw on family income, combined with many of the mothers in this research feeling that they had to abandon their professional careers to be full-time carers, has certainly had a significant and negative effect on some families' finances. Gemma commented:

> *'I am a qualified teacher in special needs, but I can't work at the moment. It is hard; we have to go to food banks sometimes, and we have had to apply to the Family Fund for help with things or crowdfund.'*

There are numerous examples of parents paying for services or resources. One mother was so determined that her daughter should attend mainstream secondary school that she funded her daughter's curriculum resources to persuade the headteacher to offer a place. Another mother, Claire, who described family finances as tight, nevertheless funded necessary physiotherapy for her son:

> *'It was £45 a time, something like that. I mean I am very lucky, I have very generous family; my older brother paid a couple of sessions, we paid a couple of sessions; my parents paid a couple of sessions as well.'*

This same point about the expense of private provision and the inequality involved in otherwise being barred from services is made by several parents. Having financial resources that enable parents to make their own decisions is recognised by these parents as being helpful but also inequitable. Stephanie, who also privately funded physiotherapy, recognised this:

> *'What we would have done if we weren't able to afford that, I don't know. Even though you've got the DLA, I am a stay-at-home mum; I get carer's allowance and child tax credits and the highest rate DLA with care component. But it is expensive, so what do others do?'*

Whilst this research does not focus on financial metrics, it is evident that parents regularly financially contribute towards services to which their child is statutorily entitled. Each family has different experiences of funding and packages of care, with significant differences in levels of statutory expenditure. Families with children of similar ages with very similar levels of complexity, sets of issues and socio-economic backgrounds can have very different experiences of provision within care plans, as well as outcomes. These contrasts are outlined in the case study of two families involved in this research and presented in Figure 28.

Figure 28: Case study comparing two families' experiences

Families 1 and 2 are not named to protect anonymity.

- **Child 1:** aged 18, is autistic, has physical and learning disabilities, and is medically complex and has genetic conditions.
- **Child 2:** aged 15, is autistic, has physical and learning disabilities, is medically complex and has genetic conditions.

Funding

- **Child 1:** Well-informed estimate by parent of specialist statutory expenditure linked to SEND across their son's life, circa £3 million.
- **Child 2:** Parental report of specialist statutory expenditure linked to SEND, circa £500k.

Families' individual appraisals

- **Child 1:** High levels of statutory funding (£3m) but low satisfaction with outcomes. Child 1 is not in mainstream provision, having accessed special schools since leaving junior school. He has experienced institutional care. Parents express concern that this should not be a long-term option. Family is considering realising some of their own financial assets to create a home and some basic employment for their son. Social work involvement has been in place for some years but is perceived as gatekeeping resources role more than offering key working.
- **Child 2:** Lower spend (£500k), but high reported levels of satisfaction with child's plan. Child 2 has been maintained in mainstream secondary school, although he has high-level care needs with complex cognitive disabilities. He lives at home; plans are being developed for supported living post-18. The

family plan to involve him in employment in their business. Social work involvement has been in place for some years, providing key worker service in which the family express substantial confidence.

Impact on families

Family 1: Report levels of intolerable stress; highlighted by both parents and adult siblings. Mental ill health is evident for a number of family members.

Family 2: Report feeling stress but are well supported through friendships, community groups and professional services.

Outcomes

Family of Child 1:

- A late diagnosis led to delayed development for child which he has not been able to catch up on.
- Years of frustrated plans with poor or delayed assessments.
- Significant use of family expenditures to leverage or subsidise statutory provisions, including obtaining independent assessments to justify services.
- Distrust of professional agencies.
- Social work relationships are difficult.
- Family have successfully used formal systems of complaint, including the ombudsman and Ofsted.
- Negative experiences of the system motivated participation in this research; this family want the system to learn from what has gone wrong.

Family of Child 2:

- Early diagnoses of conditions
- Consistent and positive professional relationships, conceptualised as co-productive with key statutory agencies of education, care and health.
- Little requirement to use family income to subsidise statutory provision.
- Consistent provision since child’s birth.
- Long-term social work with positive relationships.
- No formal complaint processes have been used.
- Positive experiences motivated this family to be part of this research to demonstrate how things can and should be.

These case studies contrast familial experiences and highlight that good outcomes can be as much about good practice and confidence in professionals as in the allocated budgets. Family 2's experiences affirm something akin to a co-productive partnership leading to reported beneficial outcomes. Family 1, however, described professionals as losing sight of their son and his needs.

That relationships can start well but later become challenging is another factor that some parents described, as this father indicated:

> *'One starts off grateful for the extra help that seems to be given and then, as time goes on, one realises that actually, our son isn't getting anything to which he is entitled. There is a lot of turning of blind eyes by the local authority as to what his entitlements are. So, one transforms from being a grateful recipient to, I suppose, a fighter, enforcing and complaining.'*

7.6. Co-production

The families in this study, without exception, stated that they would welcome more collaborative professional relationships. Most families reported their experiences of mostly basic 'participative' models and sought more involved solutions. In Chapter 3, the policy rhetoric of co-production is explored. In the context of social care this is about working with and involving individuals and their families to ensure the best care and support possible. It recognises that service recipients and carers are not passive consumers but that their knowledge and insights can be involved in the design and delivery of services.

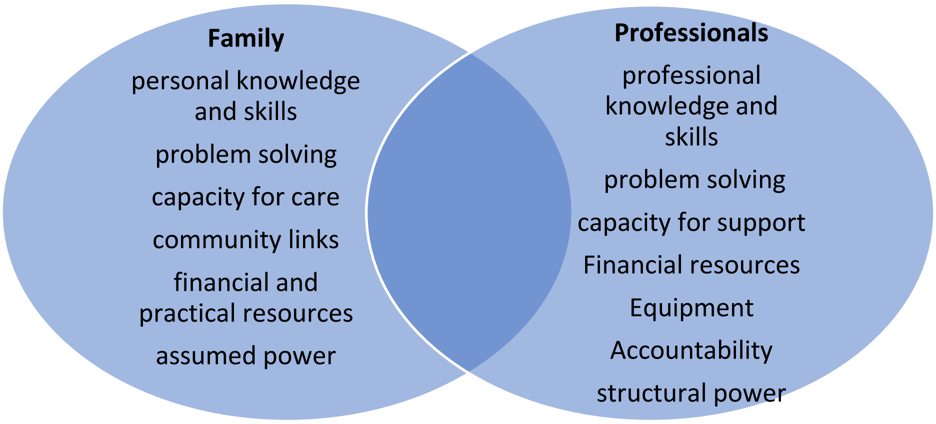
Parents in this study mostly described how formal power remains centralised, with professionals maintaining their positions of authority and keeping families subordinate. Opportunities for co-production are missed. Generally speaking, parents described that they can offer planning suggestions to professionals, but professionals can exercise a right of veto. Whether professionals view these families as partners or simply service recipients cannot be evaluated in this study. How families described professional relationships can be tested, however. Family narratives when applying Avelino's (2021) power framework reflected professionals asserting power over them rather than giving power to them. In exercising choice and control parents described ways to circumvent this, sometimes using conflict as leverage (e.g., making complaints), sometimes applying their own knowledge and sometimes using family finances to instigate their own plans. Whilst this may improve QoL, it can also result in parents funding services to which they are legislatively entitled.

Parents agreed that they would like to see more ‘meeting of minds’. Parents mostly agreed that co-productive partnerships where personal and professional expertise are combined with other resources could achieve better outcomes for their children. Fractured partnerships though, cause frustration. Angela remarked:

> *‘The Ofsted local area inspection for my local authority recognised there is no planning; there is no co-production in our area.’*

Around two-thirds of parents referred directly to the idea of parent/professional partnerships built on principles of co-production. Family narratives evinced what they believe each partner brings to the working relationship. Families did not perceive themselves as subordinate nor passive recipients of services; they recognised that they bring enormous value; demonstrating their steady commitment to expending their own resources. However, parents understood that they cannot ‘go it alone’. Professional agencies bring resources and expertise and can be enablers for stronger plans to support disabled children. Figure 29 provides a summary analysis based on what families reported are the key strengths that they and agencies possess.

Figure 29. What families believe they and professionals bring to partnerships



The remaining third of families within the cohort were more likely to characterise their relationships with professionals as ‘a bit of a dance’. They reported power rests outside of the family group and professionals carry the weight in decision-making. These families often reported feeling ‘done to’ and less actively involved in decision-making about their lives. They also felt unable to sufficiently influence the services they receive.

Parents were generally aware of policy imperatives for co-production; most perceived this as aspirational rhetoric. That professionals tend to take only embryonic steps towards any meaningful adoption of the policy. Theoretically, it should be mutually beneficial for both families and professionals in pooling scant resources and recognising differentiated expertise. Parents recognised the embedded nature of centralised power and were therefore sceptical about a genuine professional shift towards more shared power. Despite this scepticism, they acknowledged that much more active collaboration between themselves and professionals is necessary and this should adopt principles of co-production. These must not be simple partnerships where professionals offer what is available rather than what is needed. Julia’s comments where she argued that agencies often seek to maintain the status quo, not the best outcomes, exemplified this:

> *‘They don’t ever change her plan, they have never reviewed her outcomes; they stay the same, they never review the provision, I mean, co-production with the school, it doesn’t exist.’*

Six families described positive, though not necessarily consistent, experiences of co-production. These included working with different levels of co-production models at the macro, meso and micro levels. Figure 30 highlights some of these experiences.

Parents already working with co-production models at macro and meso levels admitted they are seeking changes at a more structural level, challenging agencies to do better for all. One parent applying herself at a macro level is deeply frustrated by the provisions her child receives and believes that challenging at the top, where services are commissioned, may filter down and create positive change. This mother who deeply distrusts the system finds that her activism for change at a macro level does not threaten professionals at a national strategic level; she feels there is positive working. However, her relationships with professionals at a micro level lack co-production and are very challenging; she constantly fights with local systems to get the right services for her child.

Figure 30. Family examples of co-productive working

Macro

- Working with the NHS as an expert by experience to change national service designs.
- ‘Think Local Act Personal’, a national partnership of people with lived experience, local government, social care providers, the NHS and the voluntary and community sector.

Meso

- Working with health professionals to change locality service models and then training professionals.
- Collaborating with local authorities in a parent forum on SEND strategy.

Micro

- Co-productive planning with local authority social workers to create holistic plans for their children.
- Co-productive planning with the mainstream school SENCO and headteacher, using parental expertise not just to improve their child’s plan but to help the school understand the SEND system better to help other pupils with SEN.

Other parents who described positive experiences of working co-productively at a micro level, pointed to a sense of common purpose, where joint expertise is harnessed for benefit. They agreed though that this is not always easy and described conflict, particularly during times of transition, when resources are being discussed. All families were hyper-aware that the situation can change very quickly when plans need to be modified due to changing needs. Even a mother who was particularly positive about her co-production experiences, commented that she worries about future changes in personnel as her son moves to adult services and potential changes in joint working. Even the most positive parents did not entirely trust entirely how the system works and that changing of personnel can threaten a previously hard-won equilibrium. The system is too reliant on personalities, and co-productive principles are not embedded, despite policy rhetoric.

Parents indicated that they believe that co-production offers opportunities to address systemic issues and challenge dysfunctional relationships that are barriers to support. They concluded however, that professionals seem more comfortable participating in macro and meso-level co-production initiatives that focus on national policy or local service designs. This significantly distances professionals from having to own individuals' outcomes at micro levels of co-production.

7.7. The threats and risks presented by co-production

Parents recognised that co-production models can strongly challenge professional identities. Dunston *et al.* (2009) discuss how professional experts differentiate themselves from laypeople. Co-production can create a sense of threat for professionals, leading them to resist change. A few parents described how them adopting more involved roles in planning, particularly in controlling aspects of budgets, left professionals worrying and resistant, believing that sparse budgets would be uncontrolled. This resulted in little, if any, meaningful involvement in budget decisions for these families. Three families received direct payments on behalf of their children, but these involved very low levels of funding and the parents complained that these payments do not cover what they need to. Angela highlighted this issue:

> *'We said, really, it would be better if you gave us a direct payment. Even if that is agreed, if they don't give the right amount, and they don't give* [funding for] *2:1* [staffing], *then we won't have enough to buy what we need.'*

It is evident that professionals strictly gatekeep statutory resources. All of the families confirmed that when major decisions are being made about funding, they must wait to hear outcomes. They are not allowed to attend funding panels to discuss needs.

There is a sense in talking with parents that the politics of planning, with its inherent pressures on achieving value for money and controlling budgets, makes SEND planning a minefield both for parents and professionals alike. Families referred to instances where they became overtly assertive about their children's rights, and co-productive relationships disappeared. Two mothers highlighted their experiences of this. They were shocked that when insisting on support for their children, previously good relationships degenerated into veiled threats of Section 47 safeguarding assessments by professionals.

Parents highlighted other barriers to effective co-production. For instance, when they are given limited decision-making rights and freedoms to choose, including providing personal budgets to families, professionals can easily remove them when they believe they are no longer helpful or valid. Examples cited by parents of the barriers they have faced all highlighted issues of power and control.

Co-production will not always be harmonious, and in such situations the question is how equally power will be distributed. Parents questioned the reality of so-called values-based reciprocal relationships when the professional default is to exercise power over parents, rather than to give them power, or to share power.

Barriers to co-production do not lie with professionals alone. Some parents expressed worries that they may be given additional responsibilities in the name of co-production that they have neither the capacity nor the appetite to accept. Stephanie described her wish to be a mother first and enjoy her time with her son, unburdened by the complexities of service planning and decision-making. She was deeply appreciative of the team around her who understood this and did not exert undue pressure for her to take on more than she feels able to, she commented:

> *'The head teacher in school said to me, let us concentrate on us educating him, and you just concentrate on being his mum. So, I've got a child who wears a stoma bag and he went into school and he had to have his nappy changed about ten times during the day. The head teacher was adamant that he was going to be in the school and they would support him.'*

Other families argued that professionals insufficiently recognise the pressures on parents as full-time carers. They explained that they have had to resist being given responsibility for tasks that would overwhelm day-to-day family life and affect other children within the family. Barron *et al.* (2013) found that 'informal care systems', i.e., family; account for around 86 hours of weekly care for disabled children with complex support needs. None of the families wanted co-production to be a means for agencies to avoid providing services by over-relying on families' resourcefulness in finding solutions; and then dressing their success up as co-production. Angela, generally a proponent of co-production, expressed concerns about her experiences:

> *'There is no co-production and that adversely and greatly affects those like my son most. It was unfair just to land it all on me, but nobody ever thought that. I*

> *mean, how do you think families can cope with three programmes and try to have any semblance of a life? In fact, I think if I hadn't said that I wouldn't agree, I would have been landed with three programmes on top of everything else.'*

Angela's comments also reflect a point that other parents made about a lack of community-based provision that means co-production with agencies is difficult to achieve. McGill *et al.* (2006) comment that whilst there has been a policy drive to reduce institutional care; there has been insufficient investment in community-based supports to offset the impact of complex support needs being managed within the community. Parents, as the main carers, by default have found that they have little access to, or availability of, flexible community services to meet particularly complex needs. Angela contended that the rhetoric of co-production has become a means to pass additional responsibilities to parents, rather than genuinely providing community supports. Parents discussed their frustrations with the lack of provision but believe that more activist forms of citizenship, such as campaigning for better services or applying their individual rights to appeal through systems of redress, are positively discouraged by professionals. There is certainly evidence within the literature, that SEND parents can be characterised as difficult and litigious (ISOS, 2022).

Parents accepted that recourse to formal actions is indicative of relationships having broken down. All of the parents who had used formal systems stated that they would rather not have had to. They reported that the experience can be stressful and expensive; and puts family life in limbo pending resolution. All of the parents described feeling dispirited at least some of the time with 'the fight' and in being seen as difficult. They want something different, more balanced, more responsive and more collaborative regarding their encounters with professionals.

Parents argued that proper attempts at working together to find alternative solutions must be a better solution. Marcus, Angela, Julia, Chand and Gemma, all parents, pointed to the money spent annually by local authorities to fight, mostly unsuccessfully, legal cases against parents of disabled children; £253 million since 2014 (Special Needs Jungle, 2021). Parents themselves have also expended significant monies on fighting cases; monies saved on legal fees could be invested in community services instead. Parents argued for more collaborative, open dialogue and joint problem-solving in the spirit of co-production believing it is likely to be more effective. Parents argued for systemic transformation and changes to the nature of some professional relationships; involving more reciprocity.

Rather than relationships of reciprocity family narratives indicated that parents and siblings experience some professional cultures as deeply entrenched, adopting sometimes unhelpful positions. Professional interventions can be experienced as transactional rather than relational, which affects families' abilities to exercise choice and control. Chand, the father of an autistic son, commented:

> *'I don't think I have lots of control; they say when you have an EHCP, the parents always have the highest rights in that. I don't even know what choices I have; I don't know if it is me who fails (in not understanding) or if the system fails (in not explaining).'*

This sense of powerlessness is understandable. Fighting as hard as some of the families reported doing, simply for agencies to meet minimum legal standards, can feel very disempowering for parents. Parents recognised problems with the 'meeting of minds.' They described that they are criticised by professionals for being difficult; but also, if they are seen as competent to meet day-to-day needs, they are deemed 'not requiring of services' and left to get on with things. They cannot win; they are either superheroes or warriors. This does not reflect a professional mindset of co-production.

Parents also described a lack of professional sensitivity to the ebb and flow of complex and changing needs; that families sometimes will need more support and sometimes less. Parents accepted that there have been times when they have been able to manage largely on their own, mostly when their children were younger. They also generally prefer to maintain their independence, but as Stephanie remarked:

> *'You can get discharged because they don't like having people just sitting on their files. But it just doesn't consider the fact that patients with long-term health conditions are never going to change and will need some support sometimes. It can then be difficult to get back into the system.'*

This pressure of 'just being left' during a less demanding phase and then struggling to be recognised again as having support needs, is described by some parents as unbearable. Angela commented about her son:

> *'Young people like Jonathan are lost even in systems that do good things for other disabled children. Those who need that long-term planning, it just isn't there; it has seriously affected our confidence. I nearly lost my mind actually... I was feeling stressed greatly, and they* [the local authority] *didn't know what they were doing or offering.'*

7.8. Moving forward with co-production

Critiquing the challenges of co-production and acknowledging the reported experiences of parents in this study, may suggest that a system built on co-productive principles is too utopian to achieve; or riven with conflict and defensiveness, thereby offering little benefit. Whilst it is important to acknowledge its challenges and that human relationships are not always straightforward; genuine co-production offers a chance to shift the relationship dynamics. Boyle and Harris (2009) argue it is an opportunity to transform public services; parents agreed that transformation is needed. Whilst this cohort is small, there are strong indicators that the better the co-working relationships between parents and professionals, the more positive the overall experiences and outcomes are for families; despite the pressures, complexities and challenges they face. Gilbert (2005, p. 456) cites Barnes and Prior (1995) and comments that: '*choice can be empowering especially when no coercion is involved, when services are significant to people and users have meaningful participation'*. This is at least in part true for co-production.

Research on prototype services built on models of co-production has presented some success. Although these outcomes are sometimes intangible, they can include improved self-esteem, more satisfaction with working relationships and people feeling involved in democratic processes. The outcomes may not result in everything individuals had hoped for, but meaningful involvement in the process provides a better understanding of why some things are not possible, which returns some control. Parents in this study certainly confirmed their understanding that professionals have their own pressures. Parents are therefore, prepared to give reciprocal ground where it is helpful. Julia commented:

> *'I always think it helps in that sort of co-production mindset if I understand the challenges that school is going through; then I know what I can push back on*

> *or what I can't push back on. Or I know this is a current agenda, and if I play to that agenda, I might be more likely to get what we need next time.'*

To truly adopt co-production, parents believe that cultural change involving all parties is needed. Government rhetoric is not achieving sufficient traction. The starting point must be understanding the factors that influence the relationships between families and professionals and how they can work together to change and improve the system at all levels. This involves building trust between parties and understanding the professional/family dynamics that influence learning-disabled children's current outcomes. This research has found that bringing professionals and families closer together within a system that both parties experience as dysfunctional, though perhaps for different reasons, will not be straightforward. For some families, building the trust needed for good quality co-productive relationships with professionals will be challenging. However, families indicated that what could make a difference includes:

- creating a clear sense of common purpose in the system that is understood by all parties;
- sharing power in ways that both professionals and families feel comfortable with;
- enabling disabled children and their advocates to have a voice and be attended to;
- investing in training and development to build knowledge and understanding.

Some families cited good experiences with innovative co-productive models that have worked for them. One particular example of this is Person Centred Planning Together™. Julia and her son Luke's description of their experiences of the model is set out in Figure 31, below:

Figure 31: Case Study of Person Centred Planning Together (PCPT)
Julia and Luke (mother and son) each discussed how PCPT worked for their family to successfully plan and achieve a transition from junior to mainstream school. Luke highlighted its success for his sister, who has Down syndrome and for whom mainstream schooling is very important:

> *‘We did this group activity when Elsa was in Year 6. There were people from her current school and old school. I got to miss some lessons for it as well. Her best friend was there too and lots of other people. It was about Elsa’s future and we were talking about…what we want for Elsa, what she wants and what sort of path she is going to have to take to get there. I am glad that so many people were supportive in trying to help my sister to get to where she wants to.’*

Principles of PCPT

- It is about ‘a good life’ and takes a long view, allowing for and building dreams and high aspirations.
- It brings together ‘the team’ involved in the child’s life; their family, including siblings, their friends, community supporters and professionals.
- Attendees are invited not because of their paid or unpaid roles in the child’s life but because they have an investment in the child’s life and future.
- The process focuses on capacity thinking and building and resolving issues from a strength, not a deficit, position.

The model is explained in a handbook; and trained professionals can support agencies that wish to adopt the approach. An independent facilitator with no vested stake in the results enables the process.

Julia highlighted the co-productive nature of the process as:

- The direct and full involvement of her child;
- meaningful participation of family members;
- meaningful participation of friends;
- engagement with relevant community supporters;
- the full attendance of relevant professionals;
- the approach to achieving a common goal of developing the right plan;
- independent facilitation;
- using different types of communication and record-keeping that are more visual and better meet her daughter’s needs; and
- an inclusive and memorable experience.

Regretfully, the application of this successful framework was a once-only opportunity for this family. They attributed this in part to the level of resources involved and the requirement of skilled independent facilitators.

PCPT has not become mainstream within SEND services, although its principles offer much in terms of learning.

The families involved in this study argued, that interventions are needed to disrupt the dynamics of shorter-term transactional interventions with professional imperatives to close cases quickly wherever possible. They seek instead more understanding, relational and fluid partnerships from professionals; where working relationships offer support when needed and then step back when things are more straightforward.

Families described that many good professionals are trying to find solutions to support good outcomes. Professionally speaking, those working in SEND services are in vocational careers. Registered health and social care professionals are mandated by their professional values and ethics to do right by families. These values underpin their professional registrations. The majority of professionals will genuinely want to find the right outcomes for children and families. This is not how many of the families described their experiences of professional relationships; so, the system is not working in this respect. Practitioners seeking to do their best are likely to find families' expressed disappointment in their professional practice as stressful within working relationships as families do. This can polarise positions, with characterisations of difficult parents and insensitive professionals creating defensive responses amongst all parties. Initially constructive relationships can degenerate into negative, destructive interactions for all sides. Marcus reflected on his long-term relationship with his local authority:

> *' Things started quite well but I don't quite know how the relationship goes; we had three adverse ombudsman's reports found against the council. If I were them and I was dealing with somebody like me, they would have known that I would be prepared to go the distance, and I look like trouble; you would think they would make sure they didn't do anything which led into a bad situation again. Yet they seemed to not care…It was a very odd way of going on.'*

Marcus is not alone; eight of nine families in this study have had to seriously consider taking, or have taken, formal action either through complaints, legal processes or their MPs; and this highlights the problems experienced. A dynamic of scepticism and sometimes mistrust is apparent throughout the parental and sibling narratives.

Families affirmed that professional and family relationships sometimes experience negative conflict. This is a cycle that needs to be broken. A recent report on reforming the social care system describes it as a rigid and sometimes unresponsive system (*Independent Review of Children's Social Care*, 2022); and argues for a relentless focus on supporting families. The 2019 SEND review also concluded that families are poorly served. Families would concur with these assessments and argue that they and professionals involved in their children's lives should be united in a joint desire to find different ways to handle their conflicts of position and divergent views. This is in children's best interests and, done well, could even save money for constrained budgets.

It is to all parties' benefits to seek real changes and develop processes that leave everybody feeling better heard and, ideally, more positive about the other parties. Creating a way of working that reduces these frustrations and misunderstandings, which at times cause impasses and lead to expensive and emotionally punishing legal processes, is likely to be welcomed by professionals and families alike.

The positive experiences of one family with the Person Centred Planning Together Model point to opportunities for constructive and useful collaboration in co-productive relationships. Other models in the wider environment could also provide the basis for exploring co-productive relationships, including family group conferencing and transformative mediation (Bush and Folger, 1994).

Both of these frameworks evolved through circumstances where conflicts between parties were recognised for their potential to spark a vicious circle of disempowerment for all; leading to poor outcomes. Notably, these models and PCPT integrate sometimes polarised parties; bringing them more closely together through independent facilitators or mediators. Each model seeks to shift and change the nature of relationships by empowering and developing recognition for each of the parties' points of view, thereby progressing towards finding solutions and resolutions.

7.9. Conclusions

This thesis does not seek to provide the solutions that could make positive changes in the system, but it does seek to reflect what parents believe could help. Families bring their own abilities to analyse their challenges and identify solutions. Professionals bring resources, knowledge, expertise and accountability. Developing collaborations amongst all parties and pooling expertise should be a win/win, but families do not always report this experience. Their relationships operate in both the lifeworld and through the system. Families seek to harness relationships to optimum effect for affiliation, to access support services and address dissatisfactions with the system**.** In this context they can welcome co-production. Policy rhetoric equally promotes family/professional partnerships of co-production though Government policies, but legislation and codes of practice have not yet gained sufficient traction.

In reality, co-production is not without challenges. It confronts multi-disciplinary professional power structures within the system, requiring a dispersal of power away from professionals to be more equally shared with family members. This has proven one of the main obstacles to genuine co-production; professionals have the power to discard true collaboration when the situation becomes challenging. The increasing numbers of disabled children and lack of funding, with its concomitant lack of investment in community-based services, all contribute to a ‘tough’ environment and become barriers that prevent co-production.

Trust amongst all parties must be built, but scepticism about the system and some professional relationships are obstacles for families. They seek for professionals to be knowledgeable, respect family expertise and listen. Families do not want to feel as if they are an irritating drain on resources. They want to be treated with humanity and compassion. This is explored further in the next chapter.

Chapter 8: Findings and Discussion: Disability, and Ableism

8.0. Introduction

In this chapter, parents' and siblings' reflections about how professionals understand disability are explored, including how families have described a lack of professional knowledge and training in this context as problematic; and to families' detriments. Linked to knowledge, awareness of theoretical models of disability and understanding the embodiment of disability is discussed. Professional agencies' tendencies to emphasise the dichotomy of social and medical models of disability of how disability is understood is explored. It is argued that conceptualisations have evolved; developed through the lived experiences of disabled people. These should be better informing professional practice and social policy going forward. The need for disability models to better consider the nature of childhood and the symbiotic basis of relationships with parents and carers is discussed. A child and family disability contextual framework, drawn from the insights gained from family narratives is offered for future development.

Families' views about embedded discriminatory societal attitudes and ableism which stigmatise learning-disabled children and undermine their rights; thereby affecting their QoL, are discussed. Also, the 'deficit' way in which learning-disabled children are viewed and othered which still negatively influences some professional practice and how children are supported.

Highlighted as a case study of continued societal discrimination is an analysis of how Covid-19 led to disproportionately negative outcomes for learning-disabled children and adults. There is an uncomfortable reality reported by parents and siblings alike; that limits are still placed on learning-disabled children which diminishes their human rights.

8.1. Professional knowledge

In the previous chapter, the importance of good quality family/professional relationships to achieve good outcomes for children is discussed. One area highlighted in this discussion is that professionals can bring valuable knowledge, expertise and humanity to their work with families. Quality professional knowledge is multi-faceted; includes system insights; an understanding of legislation and rights; theoretical perspectives; practice models and relationship skills. When these are integrated into working partnerships, families reported positively about the difference professional expertise can make and recognised its benefit. Annaliese highlighted one such positive outcome when her daughter finally learned to walk:

> *'The nursery teacher was the one that got her walking. She had all these amazing ideas. She got my daughter one of those floats that help with swimming so it was, like, really tight around her core and she took her first steps. No physio had ever come up with that. I mean, I have a lot to thank her for.'*

Whilst parents maintained substantial respect for many of the professionals that they have worked with or were currently working with, they also reported particular problems when professionals lack sufficient knowledge or understanding of the details or context of their children's disabilities. They argued that support requirements can differ according to specific conditions and different individuals' needs. No two children are alike.

In this study, there were two broad groups of families:

- those who have a child with Down syndrome;

and

- those who have an autistic child.

In at least one family there is a dual diagnosis of Down syndrome and autism; an assessment was awaited regarding a similar dual diagnosis for another.

Whilst all of the children in this study had been diagnosed; and some might argue labelled, with a 'lead condition' they also all have associated health conditions often linked to that condition (see Figure 5). This makes for very different and complex additional support needs for these children and young people. Professionally understanding each child and the impact of their disabilities, requires those working with them to be trained well and to build specialist expertise. This can be a tall order given the multiplicity of conditions those professionals will potentially work with. Parents described however positive examples of professionals who have recognised their need to learn new skills and so have accessed relevant training. Gemma described her daughter's headteacher investing in Makaton training for teachers and pupils alike to enable better communication with Gemma's daughter, Martha. Angela described how her son's teaching assistant also learned new and specific communication methods.

Families explained that learning-disabled children are often treated as one group and described as 'SEND children' in professional and societal contexts. This labelling is unhelpful and often ableist. The additional support needs of any child, whether they are autistic, have Down syndrome, cerebral palsy, epilepsy, dyspraxia or any other condition can differ markedly, requiring more nuanced and informed professional understanding. Families indicated that applying a generalised approach to disability will not lead to sufficient recognition of the particular skills professionals need to understand the experiences their children have. Parents also expressed frustration with professionals declaring themselves experts when they are clearly not. Chand, father to an autistic son, explained that at his son's school, a teacher who is officially described as an expert in autism had actually attended just a short course:

> *'There was a lady who did the job labelled as specialist in autism and she had no qualification; the school label people so they can tell they have someone, but they don't have a real understanding. They may have some course or something, she was just part of the school and that was a role for her. You can't have people in these kind of roles without any proper education.'*

Angela expressed similar disappointment with so-called specialist expertise:

> *'I did get a referral to a specialist place for my son, and what a total disappointment that was; I was just horrified, there was just a total lack of understanding of autism, of how the sensory issues really mattered for my son; nobody seemed to be able to understand my son's problems as having anything to do with his autism.'*

Parents further highlighted their observations that training in specialist skills linked to disability is often inadequate and professional knowledge is sometimes informed by outdated ideas. Parents of children with Down syndrome reported that outdated knowledge and attitudes towards their children's condition have led to experiences of minimising their child's future capabilities. Gemma described this at its most extreme when she reported being questioned about the wisdom of having continued with a screened pregnancy that confirmed her baby had Down syndrome. This led to the same child's father, Darren, commenting:

> *'It comes back to education, doesn't it? I mean, people are ignorant, so you know the health services lists all of the problems with Downs syndrome, and it is exaggerated through ignorance of the condition; you know, there's a lack of understanding, really.'*

Two parents also described a phenomenon known as diagnostic overshadowing; the process of a person receiving inadequate or delayed treatment because their physical symptoms are misattributed to their disability. In both cases, parents believed their children's medical symptoms were ignored and then incorrectly attributed to common problems linked to their conditions. Distressingly, this led to treatment oversights that caused both children additional discomfort and, for one, over two years' delayed relief of symptoms.

Angela described how her autistic son was not assessed for a common problem linked to a family genetic condition. She believes this was disregarded and her son's expressions of pain were attributed to behaviours linked with autism:

> *'He seemed to be in a lot of pain walking. I found through another parent about Ehlers-Danlos hypermobility. We pieced together how he seemed to be with walking and then crying. Nobody ever thought it important or helped us, so I found out and did it myself, but it was important to him for us to resolve that so he could have not as much pain.'*

Gemma reported that her three year old daughter had oxygen withheld when she had a chest infection. She was told children with Down syndrome naturally have lower oxygen saturations, so she didn't need oxygen. She explained:

> *'I said to the nurse* [my daughter's] *oxygen is saturating at 88. The* [lower] *limit it's* [supposed to be] *is 91, so she'll be having hypoxia. The nurse said that the consultant said 88 is good because she has Down syndrome. The nurse agreed if she didn't have Down syndrome, she would have been given oxygen. I said no, she's got a respiratory infection. That's why she's saturating at 88, not because she's got Down syndrome. Normally, when she doesn't have a*

> *respiratory infection, she's in the high 90s. But they refused oxygen and my daughter was gasping for air.'*

Both parents believe that generalised knowledge of their child's conditions in these instances led to medical professionals exercising insufficient diagnostic curiosity. This meant delayed diagnoses and the withholding of treatment. Parents argued strongly for better condition-specific training coupled with less discrimination towards disability. They also argued for more time to be spent on positive relationship-building so that children's needs are better understood and individualised.

In relation to quality of care, a strong theme of luck and chance also emerged from parental narratives. Interestingly, 12 of 14 parents referred to its significance in achieving some family aims. Heider (1958) argued that when a successful outcome is attributed to luck, environmental conditions rather than a person are considered primarily responsible for the outcome, and these environmental conditions are the product of chance. Chance factors are likely to be attributed to luck.

Chance encounters and conversations can alter life courses, and parents cited numerous examples. Notably, parents seemingly accepted that luck and chance are integral to life and not within personal control. When there are positive encounters leading to better treatment, luck is welcomed as something to be grateful for. However, if one were to transpose 'luck and chance' instead with 'accident', maintaining the idea that something happened serendipitously, rather than by design, parents would likely view 'accidentally' getting the right treatment for their child differently and certainly less positively. Recognition of the need for treatment should not occur through luck. Parents described though numerous chance encounters or conversations which had huge import in some cases. Angela commented:

> *'I just happened to meet this other mother by chance, who happened to explain to me that she had found this great service at Great Ormond Street for chronic pain; I went there and paid privately to see this expert physio, who said, 'Yes, he has hypermobility and would benefit from rehabilitation therapy'. Something that nobody locally identified though they could see he was in pain.'*

Whilst accepting notions of luck and chance as part of life, parents also recognised that getting the right diagnosis or service should involve good professionals with the right training exercising zero discrimination towards disability and positive relationship-building. This leaves less to chance or luck. Diane commented:

> *'I didn't even know that we could get ESA* [Employment Support Allowance]; *it was just a chance meeting with somebody who told us. It shouldn't have to be like that, if some families aren't as pushy as us, they are going to be left by the wayside by professionals.'*

Another pattern of thinking evidenced amongst parents is that whilst access to statutory universal services is a right and should not rely on good luck, some parents reported that when things work well, they do regard it as good fortune rather than a right. Claire remarked:

> *'I never had issues with his transition from nursery to school. I never had problems with it, I count my blessings on that, and I think we have been very lucky.'*

Whilst it is not a generalisable finding, it is evident within this cohort of families that parents with autistic children are generally less satisfied with their professional support than those who have children with Down syndrome. Parents with autistic children commented that despite a huge increase in awareness about autism across society, its complexity across the spectrum is still poorly understood by many professionals. They commented on the frequency with which professionals make trite assumptions about autism, including that autistic people have special talents or are not very sociable or can't hold eye contact. Their worry is that having a limited understanding of the condition leads to ableist assumptions that mean their children do not receive the right services or professional responses.

Parents also expressed concerns about different care regimes that are not fully researched but are commonly used within autism services, where professionals work within particular practice or theoretical models. Social work, education and health professions all develop practice models that can be helpful in informing practice. They may not be universally applied, but they can become sufficiently established to be influential in professional/service user relationships. Some of these models can be controversial, which causes anxiety for some parents. An example Angela cited is Positive Behaviour Support (PBS), a method linked to principles of behaviour modification 'to reduce behaviours that challenge'. She argued that practice models are certainly required, but that those for autistic children need to understand behaviour as a form of communication. They should not be developed simply to contain ‘challenging’ outbursts. Angela illustrated this in her description of PBS in relation to her autistic son:

> *‘His placement is supposed to be stuffed through with therapists and PBS and blah blah blah. Then all these issues came out that Jon wasn’t very happy, that he was distressed. I saw a report that said they were worried about him hurting other kids, that he was hurting the staff, and then Covid happened and they more or less chucked him out. So, we said ‘We’ve lost confidence in the PBS programme’. He has red lines; I think people think, they really don’t matter, or they aren’t really red lines…He has never really got beyond the early stages of them reflecting on the complexity of his communication challenges, I don’t think anybody understood or acknowledged any understanding of that.’*

Although the parents of autistic children understood that practice models can be helpful, they were emphatic that professionals need to be well-trained in working with them; programmes need to focus on supporting children not containing them. All but one of the parents with an autistic child expressed concerns that autism is still very poorly understood, and their children’s progress and their quality of life is put at risk through a lack of professional knowledge.

8.2. Attitudes towards disability

Whilst all parents and some siblings highlighted lack of knowledge and understanding amongst professionals about specific conditions, they were often optimistic that better training and professional development could generate greater understanding and change. There was, however, a less positive dimension within parental narratives; that a lack of professional understanding leads to disabled children being problematised, pathologised, dehumanised; and seen as a drain on costs. In this respect parents believed professionals who work within the system are institutionally ableist.

Many parents described incidents where their disabled children have been treated as if they are invisible. Several parents, particularly those who are more involved in wider activism, highlighted individual cases they were aware in the public domain. These cases were significant to them in confirming their fears not only of a lack of professional knowledge and care but also problematic and ableist attitudes that can lead to the very worst of outcomes. This represented a great source of anxiety for some parents. Two cases cited by a few parents included:

- Oliver McGowan, an autistic young person administered an anti-psychotic drug to which he was known to be allergic whilst in hospital, leading to his death. His denial of consent to administer was allegedly ignored, with catastrophic consequences.
- Connor Sparrowhawk, who was also autistic and had epilepsy. He tragically but avoidably drowned whilst unsupervised in a bath when he had an epileptic seizure whilst being assessed in a residential medical establishment.

Parents pointed to these two tragedies as apparently resulting from poor care by professionals who were responsible for these young people's well-being. They asked how could they trust a system that had allowed this to happen? They reflected on their own experiences of their disabled child being treated in ways that failed to recognise their support needs, with negative impacts. Parents agreed that sufficient and mandatory training is needed which is properly designed and resourced to address discrimination and ableist attitudes as much as knowledge. Gemma commented:

> *'There are some* [professionals] *that you meet who are just amazing and in it for the right reasons. Then some, I think, it's embedded ableism and embedded prejudice; You know, it is unconscious, but it does feed into their daily work. People don't even know they are ableist but it affects the way they behave towards my child.'*

Oliver McGowan's mother, Paula McGowan OBE successfully campaigned after her son's death for mandatory training in learning disabilities and autism for health and social care staff. The UK Government introduced a requirement within the Health and Care Act 2022 for CQC registered service providers to ensure their employees receive learning disability and autism training appropriate to their role. Training has been piloted and evaluated and next steps for implementation were awaited at the time of authoring this thesis.

Whilst not all of the parents were aware of Oliver McGowan or Connor Sparrowhawk, most of them referenced Winterbourne View. This is a well-publicised scandal dating back to 2011, where staff in a residential establishment for learning-disabled adults subjected residents to abuse and humiliation. In 2020, the BBC highlighted similar abuses of learning-disabled patients in residential care at Whorlton Hall. The exposé of this abuse occurred during the period of fieldwork, and parents referred to it with particular concern. However, it barely generated a ripple across the wider media and the public at the time (Ryan, 2021). One mother, Diane, fiercely expressed her conviction that her autistic son must never end up in an institution where staff are poorly trained and do not care about him. She had little faith, a decade after the Winterbourne View scandal, that institutional care has changed; she pointed to the Whorlton Hall case as evidence and commented:

> *'We have recently done a power of attorney and a will because I don't want Fraser to ever be put in a care home. After seeing things like Winterbourne and Whorlton, it is terrifying. I would never put him through that, so if anything happens to me and Tony, the house becomes Fraser's and 24-hour care would be put in. For the rest of his natural life, he will have a home, whether we are here or not; our aim until the day we die is that he will be safe … but he is never ever to go into a care home, never ever.'*

Parents felt that they have many reasons to be sceptical about entrusting their children's futures to professionals. They conveyed their belief that incidents like Winterbourne View and the deaths of young people in health institutions with little public reaction demonstrate that learning-disabled people are seen as lesser within society. This raises questions for them about how the government, and professionals who belong to this society, value disabled people and allow tragedies for learning-disabled people to result in so little change. Many parents and siblings attributed a lack of commitment to real change to stigma, discrimination and ableism.

Some parents argued that historical ideas of eugenics, although they are no longer openly supported, still exist and are linked to this perception of learning-disabled people as lesser. They suggested antenatal screening for Down syndrome as an example; two families reported assumptions that they, as parents, would automatically proceed to termination. They argued that this reflects deeply held ableist views both within professional practice and society and that medical training has not sufficiently challenged them. Some believed professional medical training even encourages termination. In response, two families have sought to change attitudes by offering input into obstetric training and promoting the positive experiences of parenting a child with Down syndrome.

8.3. Disability theories revisited

In Chapter 3, theoretical perspectives on disability were discussed. This is important because how society frames disability, provides insights about attitudes towards it. Theoretical disability models have been particularly influential in informing practice understanding since the 1970s. They have become frameworks in how we define impairment, understand its impact; and provide a basis upon which the government devises strategies to meet disabled people’s needs. They have also become important for the development of operational practice models, introducing concepts such as personalisation, individualisation and challenging the basis of institutional care.

Professionals and families alike probably reference the social versus medical models of disability most often. The use of the word ‘versus’ is deliberate because the two frameworks are not necessarily seen as complementary. That the narrative of the social versus medical model is now well-established and professionals use these as a framework is clear. Basic internet searches during this research using the general term ‘social model of disability’ produced multiple agency results, including from the Social Care Institute for Excellence, the Council for Disabled Children, Scope, the Anti-Bullying Alliance and many local authorities. Four of the seven information sites for local authorities where families in this study live, referenced these models as informing operational practice.

Around half of the parents and three adult siblings referred to social and medical models of disability. Peter, an older sibling with a professional background in the NHS, commented in relation to his own professional training:

> *‘I remember having a seminar in the first year on disability and watching some videos and we discussed the idea of medical versus social models of disability, and what disability actually means.’*

There is a sense from parental discussions that the models themselves, although frequently referred to by agencies, have become definitionally blurred by professionals, and their understanding lacks depth. Parents with insights into these models find that referring to the social model of disability has become a shorthand for professionals to convey theoretical meanings that they do not understand well in practice. This is evidenced by how quickly professionals will adopt medicalised approaches of seeking cures. Parents believed they must resist this. Julia commented about the days just after her baby's birth:

> *'So, we were thrown right into that medicalisation thing. But we made a commitment to her and we basically said we would not let Down syndrome define her and that we would make sure that people saw more than that about her.'*

It was argued in Chapter 3 that since Mike Oliver's original and valuable conceptualisation of the social model of disability in the 1980s, more nuanced understandings of disability have evolved that further emphasise the importance of human rights and social justice. Narratives of ableism (Campbell, 2005) and (dis)humanity (Goodley *et al.*, 2016) have shifted perspectives about the experiences of disability. Shakespeare and Watson (2002) point to the original importance of the social model in challenging structural inequalities but argue that the understanding and experience of disability are now more complex. Families agreed about arguments of complexity and highlighted their reality; that societal barriers related to disability are poorly understood by many professionals; and certainly, in terms of the lived experiences of their learning-disabled children. If these were models were truly understood parents argued, there would be better assessments for services. Parents described many examples of how agencies and professionals inhibit access, including limiting services to manage demand:

- Angela described barriers to accessing services through ineffective or delayed planning or referral:

  > *'The thing I couldn't understand was, if you went and had a meeting with a paediatrician, you wouldn't get a letter for a year, and how does that help with planning?'*

- Julia described a lack of reasonable adjustments in her child's school both during normal times and during Covid-19; her daughter is expected to fit in with the way the school generally operates.

- Gemma described barriers to obtaining health adaptations that enable her daughter to walk and handle stairs, enabling access to school.
- Annaliese described a lack of access to curriculum resources that she and her husband then funded to enable her daughter to attend a mainstream secondary school.
- Chand argued that to save money and cut costs, decisions were delayed about his son's education placement, eliminating compassion and humanity from the system.

Around half of the parents within the group have deeper knowledge about other models of disability, either because of their professional backgrounds or through involvement in activism. The families did not describe any single model of disability as reflective of their experiences, and they described a more integrated approach to their disabled children's needs. Family narratives showed that a generalised professional knowledge of disability framed by the social/medical model duality insufficiently informs practice about the nature of the lived experience of disability. Parents believe that professional education and training should sufficiently explore the complex nature and embodiment of disability and build specific knowledge about the effects of different conditions on a child's life. Their narratives indicated that removing barriers to access as in the social model makes a tangible difference for many families, but this alone fails to recognise the complexity of these families' individualised experiences of disability.

Children's experiences of living with disability emerged as a blended mix of personal, societal, medical, technological, economic and attitudinal factors. How parents and siblings make sense of these to achieve a good QoL draws on the families' understandings of their legal and human rights, their psychological and sociological well-being, their children's access to inclusive education, medical treatment and technological advances and the impact of wider economic and political influences.

This complex mix illustrates why Nussbaum's capabilities framework resonated for the family data in this study. Knowledge of their child's complex needs shapes how parents, in particular, advocate for their children. If professionals approach disability with a restrictive understanding that mostly relies on a social model of addressing societal barriers and ignoring individual experiences, they fail to understand the complex embodiment of disability for each child. These limitations to understanding inhibit the support that is needed to enable children to achieve their best outcomes.

The evolution of understanding of theoretical perspectives in both disability and critical disability studies reflects a new, more integrated understanding of the complexity of the embodiment of disability than the medical versus social dichotomy. Disability models however have been built predominantly from an adult perspective, recognising individual agency, independence, responsibility and freedoms as adult constructs. These aspects of adulthood can apply differently to children, who are deemed immature. Although disabled children experience the same societal barriers and, like adults, experience individual embodiments of disability, they have additional considerations that do not feature or feature differently in adult-focused models.

A primary consideration for children is their natural reliance on their parents/carers to care for and advocate for them. This is a symbiotic relationship. Within adult disability politics however, tensions and contradictions related to ‘caring’ arise as disabled adults attempt to redefine their identities, retaking control from a depersonalised care system and challenging the policies underpinning it. Caring in a childhood context is different as all children rely on adults to care for them. Disabled children will have many additional support needs met by their families. How parents are integrated into the understanding of childhood disability is, therefore, important. It is intersectional.

This research study has identified the very complex nature of family experiences in caring for learning-disabled children with complex support needs. Families believe that the system needs to change to become more responsive and informed by a better and more compassionate understanding of the experiences and embodiment of disability. They also seek a whole-system approach to understanding well-being for all family members, including parents as carers and siblings whose lives are also affected by the experiences of complex disability.

Families’ lifeworlds, providing support and affiliation, combined with their need to interact with the system were previously discussed. All families have unique cultures but will interact with system cultures reflected through policies and legislation. Families develop social networks but must interact with and navigate agency structures and networks. They and the system will broadly have common purpose in seeking a good quality of life for all citizens, although how this is defined is not universal. How family and professional skills and knowledge are combined, and who has power and how they exert it is important. Also important are the systems of partnership aimed at achieving desired outcomes.

8.4. Ableism: Finding humanity

Whilst parents and siblings believe that higher quality and more differentiated training would be beneficial for professionals in better understanding disability, an equally strong theme in family narratives is the negative impact of ableism. Numerous examples are provided of discriminatory professional attitudes and restrictions being placed on disabled children's human rights. Parents and siblings alike contended that professionals belong to a society that perceives learning-disabled children to be less human and of less value, and so they are othered and discriminated against. Gemma reflected on this in describing her experiences of working to get the right services for her daughter:

> *'I think it's embedded ableism. And I think it's embedded prejudice, but it does feed into their daily work. I think the whole SEND team at the Council needs sweeping out and starting again. I think they're so entrenched in this and in the way that they treat parents.'*

Campbell (2017, pp. 287–288) defines ableism as:

> '*a system of causal relations about the order of life that produces processes and systems of entitlement and exclusion.… Ableist systems involve the differentiation, ranking, negation, notification and prioritization of sentient life.*'

Nussbaum describes how, philosophically, social policy has focused on rational inquiry, critical thinking and scientific achievement. Perceptions of a lack of intellectual capacity and notions of sentience somehow render individuals less human. This lack of inclusivity disenfranchises learning-disabled people. Prejudices and negative attitudes may hinder individuals' social inclusion in different arenas, such as school and work, regardless of their specific limitations and disabilities (Marcone *et al*., 2016, 2021).

These ideas resonated with families' experiences of some professional responses that implied in professional practice, ideas of less sentience. Parents reported a system which exists where ableist attitudes involves their children having to 'fit into the mainstream' rather than professionals adapting the mainstream to be more inclusive. Two parents from different families described how their children's places in mainstream schools are predicated upon their children keeping up and assimilating with the education model of the school. They must fit in intellectually and socially rather than the school adapting to them individually.

Annaliese highlighted these challenges:

> *'So, you are always balancing, making sure you don't overstep the mark in* [requesting school supports] *expecting too much and they* [the school] *then want to kick you out* [of school]*; but also wanting your daughter to be included and for her to be a success; it is a difficult negotiating job you have to do.'*

Parents shared examples of reasonable adjustments that were only achieved because parents used their own financial resources to fund teaching materials that the school refused to purchase.

Two other families reported issues when their children were due to start mainstream primary schools and were still struggling with toilet training. School headteachers insisted that they could only manage the children's support needs if parents came in throughout the day to change nappies, completely disregarding the impact of this requirement on other aspects of parents' lives, including their employment, responsibilities to other children, and their children's statutory right to education. Claire described this:

> *'There was one issue about toilet training; he was still wetting himself and occasionally he would do a poo in his pants as well. And they didn't want me to put him in pull-ups for school. The SENCO was very funny about the fact that he might need changing and saying that the school weren't able to do that. And that they would call me down to do it. And I was thinking, well, what happens if I am out? Do I have to stay in the whole day?'*

However, Stephanie described a very different approach, demonstrating what is possible when professionals take an inclusive approach. The headteacher recognised that her son needed personal care during the school day to access his education. He accepted it as the school's responsibility to meet this child's education support needs and identified a reasonable solution from within the school's resources. Staff were organised to ensure that Stephanie’s son was kept clean and comfortable during the school day. Stephanie commented:

> *‘I’ve got a child who wears a stoma bag; he went into school, and he had to have his nappy changed about ten times when in school, and it was difficult and it was messy. The Headteacher was adamant that my son was going to be in the school; we thought they would say they couldn’t meet his needs, but they managed.’*

The majority of parents reported, however, their belief that negative unconscious bias is deeply embedded in ableist cultures within education and, as a result, learning-disabled children are othered within schools. Julia described how, at parents’ evenings, she is persistently told that her daughter needs to try to fit in more and make more effort to build friendships. She contended that the school lacks awareness and acceptance of the support needs of her daughter who, whilst friendly and keen to make friends, does not always understand how to manage this. Sadly, this undermines the self-confidence of a child who was previously less anxious about building friendships.

In this scenario, teachers have not understood that they, too, have parts to play in how they support social development amongst all pupils in school. A different approach would create opportunities for students to build relationships on an equal basis with each other. Instead, families understand that their children can attend mainstream school as long as they adapt to and fit in with the ableist norms of school life.

Challenging ableism is a difficult, sensitive subject that requires able-bodied people to honestly reflect on their responses to disability. Parents themselves reflected that they also find some types of disability easier to understand and respond to than others. Some parents, within their narratives, reflected that whilst they may have a child with a disability, there could be much worse conditions than their child’s. This evinces the fear of the unknowns about different types of disability and its impact even within a community that has direct experiences of complex disabilities. Humans can find that which is not understood difficult to accept and this can become discriminatory.

Another aspect of ableism that parents described is professionals’ minimalist approaches to involving their children in assessment and planning. They attributed this in part to a societal belief that learning-disabled children lack sentience, resulting in them having little voice within the system. In the analysis of EHCPs, the section in which children can directly state their needs demonstrates that very few have been given this opportunity. In only 2 of 6 plans analysed is there any evidence of children's direct involvement in their own plans; otherwise, their views have been mediated by parents or not at all. This study's disabled participants all have complex needs and all have some challenges with communication, including speech and language support needs related to their conditions. For some, these challenges are extremely complex as they have neither expressive nor receptive language skills. Parents with children who have limited language emphasised however that their children can express their views in other ways and believe professionals should take more care to learn from the child about what matters to them. Notably, whilst parents point this out, they have not themselves followed this through and ensured their child's direct participation in their own EHCP.

The minimal evidence of disabled children's direct participation in their own EHCPs highlights how their views are invariably mediated through other family members in most professional relationships. Parents see an important and valid role for themselves as strong advocates for their children; however, this role is also problematic, as others are then mediating children's views. That it is difficult to achieve direct participation is illustrated in this research. Despite an aim to offer real opportunities for disabled children to participate, it proved extremely difficult due to Covid-19. Whilst parents constructively mediated the approach to enable some inclusion (see Chapter 6), these children's voices have become mere 'whispers' in the overall data. This offers insights about how hard it is to involve children with communication challenges and build relationships that genuinely involve them even where there is strong intent.

Opportunities to get to know a child well enough to build trust are limited for most professionals. This is a structural issue due to imperatives for short-term transactional interventions (see Chapters 2 and 8). The exceptions can be school staff, speech and language therapists and other longer-term therapists who work with children. They are likely to have longer-term direct contact with young people, which enables them to build relationships. Julia described how well her daughter's speech and language therapist has come to know her child and how she has been able to support parents in understanding their daughter's views and wishes. This therapist also supports Julia's daughter in communicating her views to others.

This research demonstrates learning-disabled children's dependence on family members to advocate for them. Whilst parents and siblings showed high levels of insight about their disabled family members and what makes them happy, angry, sad, or content amongst other emotions, as well as what aspirations they may have, mediating children's views through others raises problems. Parents and siblings recognised this. The reliance on families as advocates highlights three obvious issues:

1. An individual child is at risk of never being truly heard by professionals. Their views being mediated through others leads to a subjectivity of interpretation representing the interpreter's views rather than the child's. In parental and sibling narratives within the same families, differently nuanced understandings of a disabled child's views arise. E.g., two parents comment that they had not understood something about their disabled children until one of their other children commented on it during research interviews.

2. When the understanding of a person is mediated through others, it is somehow less real than when relationships are built from direct contact. This risks a child with no established relationships with professionals becoming easier to dismiss and treated as a case and not a person. Some parents argued that the professional panels that make decisions about funding for their children's plans can be dispassionate because they do not know or see the children, making it easier to dismiss applications for support. Diane, the mother of an autistic child, described her experiences in trying to get a social worker allocated for her son:

   > *'They all turned up to the meeting and they were fighting amongst each other about who would take him. So, I just took a photo out of my wallet and put it on the table and I went 'Right, don't forget that this is a child that you are fighting over!'*

3. Views that are mediated by somebody else are easier to dismiss. When parents are in conflict with professionals and seen as difficult, or where parent blaming has become a feature of the parent/professional relationship, the child's views can be lost or ignored as they are attributed to the parents' vested interests.

Parents recognised that how they are perceived by professionals matters. They pointed to professional representations of the 'the superhero/human parent' versus 'the warrior parent.' What language conveys in terms of societal discourse is discussed in Chapter 2; warrior and superhero parents are good examples. The warrior parent is a common trope in disability studies. Sousa (2011) comments on the warrior–hero narrative of the parent fighting social and political systems to achieve the healthcare and education their child needs despite the huge cost to the family. Families in this study described this ‘fight’ model and reported its significant and usually negative impact on quality of life, as this dialogue with Diane indicated:

> *‘If we hadn’t fought, we wouldn’t have gotten it* [help]*. What I think the system needs, and I have always said this from the beginning, is when your child is diagnosed with whatever, whether it is a learning disability, or it is autism or epilepsy or anything like that, you should be given a pathway which is a clear – that you can follow, that clearly defines what you are entitled to and what the next steps are; you shouldn’t have to fight so hard.’*

In describing themselves parents also referred to the language of the superhuman parent; to be sympathised with for the burden of care in having a disabled child. Gemma explained another societal trope where parents of disabled children are described as somehow otherworldly. She argued this is a way for professionals and society to sweep away the uncomfortable feelings generated by the barriers to inclusion that are in place for disabled children and their families. By making parents less real, they can distance themselves from a culture that is failing disabled children. Gemma commented on this in a personal blog provided as an artefact in support of this research:

> *While I have never seen a parent of a child with a disability waxing lyrical about how heroic they are, we are often lauded as having ‘superpowers.’ When parents like me talk about various aspects of our role, for example, staying awake most nights to check your daughter or learning a new language to communicate with your child, we are described as ‘amazing’ or similar. This is such a complex issue. Rather than engaging in a conversation with parents about the challenges they face, offering support and discussing possible solutions, it is easier not to address the issues present. Remember, I’m not a superhero. I get tired too.*

Gemma is highlighting issues of social justice and has argued that her child's quality of life and well-being, as well as that of her family, is undermined by unhelpful ideas of superpowers. She stated:

> *If children with disabilities were treated as equals, if prejudice was a thing of the past, then perhaps we could get on with just 'parenting.'*

8.5. Use of language and what it tells us about ableism

Parents and siblings asserted that attitudes towards disability are constantly reflected in ableist language. These are sometimes experienced as microaggressions; indirect, subtle or unintentional markers of discrimination. Families pointed to the use of 'deficit' terminology that minimises their disabled family member. Cohen-Rottenberg (2013) comments that when a culture's language features pejorative metaphors about a group of people, that culture is more likely to view those individuals as less entitled to rights such as housing, employment, medical care, education, access and inclusion. Older siblings, in particular, referenced concerns about discriminatory and ableist language, highlighting two key points:

- How learning-disabled children are described by others;
- How the siblings of disabled children are described.

Every sibling involved in this research cited examples of ableist and discriminatory language in relation to their disabled sibling. It is one of the most consistent themes in sibling discussions. They described the language of discrimination in the use of words such as 'retard,' 'stupid' and 'autistic' used as casual insults. Goodley (2021, p.17) asked, 'How come retard is a commonplace put down of young people in Britain?' He describes how disabled people struggle to be recognised as human in contemporary society. Examples of discriminatory language are provided by every participating sibling and are included in Figure 32.

Figure 32: Use of language in school as evidence of the early development of discrimination
Luke: *'My friends used to say the word retard a lot and I spoke to them about that because my Mum told me that it had mostly been used for those that have Down*

syndrome. I talked to them about that and they said, 'Oh right...sorry but we will try and use it less' and they did! I mean I barely heard it after that.'

Matthew:

'In my school life … like in the typical sort of friends' relationships there tends to be a bit of mocking each other and so, quite often, it would be using sort of strong nasty words, mocking somebody because they might be a bit slow and calling them a retard or a spaz, those sort of words.'

Florence:

'I think hearing terms, particularly retard, or people just using it as slang. Kids and teenagers using slang and looking down on people. I try not to be judgemental but it was quite demeaning.'

Chaten:

'I've had is loads of people calling other people autistic; I feel a bit of pang when anybody says something like that but I get used to dealing with it. I get a bit angry; I think autism is seen as a really bad thing; the prejudices, I don't think they are justified. That's why I get quite annoyed.'

Peter:

'I do remember that there were times when I might be walking upstairs like overhearing human conversations and you would hear certain words like, retard. I do remember that kind of really did hit me.'

Max:

'I mean, the word retard is, I hate to say, relatively common among young people. That's kind of just how it is. It's not something that is obviously good at all but that is definitely something that you know from going to school. I can say that's a relatively common word, and that's mainly from people who often don't really know what it means.'

Rosie:

'People do comment when you are out in public, they say things and use words which aren't good. I mean, my brother may be making a scene, but you have to learn to ignore what people say.'

Donna:

'Yeah, people call my brother names, 'cause he has Downs syndrome. it's wrong… it's sad.'

Some siblings reported that, unlike experiences of racism within school, teachers do not always respond when ableism occurs in class. They also described how opportunities in school to challenge attitudes and to educate in relevant lessons including ethics, biology, IT and PHSE are barely considered. Disability might be referenced but is not explored as an equality or social justice matter. Four siblings reported that aspects of disability were referenced in lessons, with Down syndrome described solely as a genetic anomaly and not a human rights issue. Luke described how a fellow pupil in a sex education class expressed disgust at having sex with a person with Down syndrome that was not challenged by the teacher. Families shared their views, that professionals as members of society, will inevitably reflect the stigma of disability and that this will negatively affect professional practice; therefore, some things remain unchallenged. Siblings described regularly feeling the need to challenge the vocabulary that pervades their social groups at school and many of them gave examples of doing so, sometimes putting themselves at personal risk when challenging. Interestingly, siblings tended not to frame this language as bullying but as disability discrimination and ableism.

8.6. Siblings as ‘young carers’

The roles that siblings adopt within families was an important part of the dialogue in this research. Language and labels matter in this context. Within family contexts, professionals are known to use the terminology of ‘young carers,’ when describing children who help to look after a disabled relative. There is a small body of research on children as young carers, which tends to be centred on caring for disabled adults. Rossiter and Sharpe (2001) conducted a meta-analysis of research studies involving young carers and found only a very small negative effect on siblings’ psychological and social status. Mascha and Boucher (2006) and Petalas *et al*. (2012) equally highlight positive sibling experiences and note that siblings often refer to perceptions of their disabled siblings’ strengths and qualities rather than any difficulties they experience.

The siblings involved in this study generally rejected the professional characterisation of being ‘young carers,’ seeing this as a deficit-based and ableist narrative that devalues the nature of the sibling relationship. They mostly described a strong sibling bond and support as something a good sibling naturally does in families. Luke commented:

> *'I am not her carer, I am her brother. I'll look out for her, that is a brother thing.'*

Parents and siblings recognised, however, that meeting the support needs of a disabled family member can affect other children within the family. That this can sometimes be challenging is understood. It can involve supporting a range of needs, including medical needs, as Peter observed:

> *'I've been exposed to healthcare quite young and you know and doing his stoma care. And I can remember sitting on the top landing helping Mum with suppositories and different things.'*

Siblings also refer to adjusting family activities to meet sensory needs, as Luke described:

> *'There are some limits on what happens; it is more about what she would be OK with…Because if she gets panicked with something, then she really does get panicked and sometimes that would cause an overreaction. So, if something is too noisy then she will cover her ears. And that happens in theatre productions sometimes, like, say, pantomimes.'*

A different sibling, Matthew, described his role in keeping his autistic brother safe in the community when people comment on and criticise his behaviours:

> *'My brother has his limits, so I think carefully when taking him out and where. He does draw a lot of public attention, and a lot of people tend to gawk 'cause he does a lot of flapping and screeching and things that people, you know, are scared of, or maybe unfamiliar with...'*

Whilst recognising that there are challenges, siblings and parents described how the terminology of 'young carers' implies that supporting a disabled sibling is a burden. Families do not deny that there are pressures, but they argued the pejorative nature of burden and pity implied in language like 'young carer' is discriminatory and ableist. Services set up to 'support' young carers felt, to many families, like a representation of the ‘pity model.’ Julia described a conversation with her son where he had talked about what being a young carer is:

> *‘My son did come home once from school saying they had had an assembly about young carers. He asked if he is one. We have always made it really clear to him that that is not what we have expected…we have always expected him just to be her brother.’*

8.7. Technology

A further area that some families have highlighted in relation to ableism is the discriminatory impact of technology on disabled people’s experiences. This requires more research to enable a deeper analysis. In contemporary times, technology is mostly perceived as a positive in supporting disabled children. Electronic tablet technologies, software packages adapted to different learning styles and technological advances in supporting physical impairments can aid communication and enhance quality of life. However, some family members perceived other aspects of technology as more dangerous and they believe these can reinforce ableist ideas and discrimination.

Goodley *et al.* (2021) comment that recent technological advancements may permit individuals designated as disabled to be supported enough to become ‘nearly’ able. The notion of becoming ‘more able’ resembles the arguments made in the context of the medical model of disability where treatment seeks a cure and using technologies as enhancements can become a form of ableism. Goodley *et al.* (2021)) describe there being something violent in seeking to change the disabled person through technology to become “normal.”

The implications of technology in the context of ableism were discussed in this research by Max, who has a sibling with Down syndrome. He discussed that whilst technology has hugely advanced human thinking and development about what is possible and can be used for good, it also widens the gap between conceptions of able-bodiedness and disability. Max’s argument is that technology permits ‘super humanity’, which begs the question of where a learning-disabled person with a genetic condition fits in a society that is focused on excellence and super-development. He commented:

> *‘A lot of people have the mindset where everything is built to be the most efficient. All technology nowadays has one fundamental aim, essentially to make our lives easier. If someone is shown the list of things that can happen; if your child has learning difficulties, and then say, do you want this? With technology,* [they say] *we can now do this* [terminate]*. I think naturally, humans have an innate desire to just be the best as possible. And naturally learning difficulty doesn't stand out to be the best thing unless you have had positive experience like my family; people don't really understand the lessons that it teaches you. So, where does that leave my sister?’*

i. Antenatal screening

Several families focused on the violence of technological advances in the context of antenatal screening. Non-invasive screening during pregnancy is now medically possible with less likelihood of miscarriage. Whilst this has not been previously available in the UK, parents pointed to the ‘violent’ effect screening has had in Iceland, where non-invasive antenatal tests have been in place for some years and have led to 99% of pregnancies where Down syndrome has been identified in the unborn child being terminated.

Families commented with some consternation that technological advances will lead almost inevitably to the ‘eradication’ of Down syndrome. They argued that these interventions have developed ahead of full ethical and human rights debates. Ableist attitudes have not yet been sufficiently confronted to protect Down syndrome pregnancies; one mother shared her belief that sadly societal understanding of disability lags behind technology, and this reinforces ableist constructs of humanity in seeking the perfect being as the ideal. For some parents and siblings technological advances are seen as an existentialist threat for those screened with genetic conditions early in pregnancies. Five parents and siblings particularly commented on their concerns about new technologies. They argued that something becoming medically possible is not necessarily right, but there is an assumption that individuals will adopt a medical course. If they do not, and there are adverse effects, they are blamed or judged.

Some parents in this research described their experiences of feeling pressured by medical staff to have abortions when screening indicated that their baby had Down syndrome. There was an assumption that it was the right thing for the parent to do. Gemma commented:

> *‘If the woman has a high chance or confirmed diagnosis of having a baby with Down syndrome, you don't get the choice not to consider an abortion. They make you consider it as soon as you get that diagnosis. And you don't have the right to just have your pregnancy and not have anyone talk about killing your baby. It's very similar to what the Nazis did. And for me it's just, it's another form of eugenics, women like me who are seen to be carrying a baby that isn't desirable, they will do anything they can to make you feel like that.’*

After having her child, Gemma described experiences of what she feels is parent blaming. Her daughter with Down syndrome suffers persistent bronchitis linked to her condition. Gemma explained how a medical practitioner commented that as the effects of Down syndrome would have been explained to her during antenatal screening, what had she expected regarding her daughter’s health, having chosen to continue with the pregnancy? Gemma feels she is being held responsible for her daughter’s suffering. This is understandably deeply hurtful to her. Goodley *et al.* (2021) comment that it is a strange paradox of humankind that our species is enhanced by science and augmented by technology and yet it can be so destructive.

Not to minimise Gemma’s experiences, it is important to emphasise that not all parents of children with Down syndrome have had these ableist experiences with professionals. Some parents report extremely supportive, warm and caring professional responses where practitioners have gone out of their way to support children and families.

8.8. Covid-19, ableism and social impact

‘How a society treats its most vulnerable is always the measure of its humanity.’ (Rycroft, 2015)

During the Covid-19 pandemic, every citizen had to face the possibility of their mortality through the virus. In the early stages of the pandemic, the UK Prime Minister commented that Covid-19 was no respecter of position or status; all are at risk. Families now challenge this assessment in light of subsequent knowledge arguing that some parts of the population were disproportionately affected by the virus and that this is evidence of ableism. The virus does affect the able-bodied norm, and for many otherwise healthy people during 2020 and 2021 it was the first time they had faced a real and imminent threat to their well-being and longevity. The future was very uncertain. It is significant that all of the data for this study were collected during the most intense parts of the Covid-19 pandemic before mass vaccinations had really started as it is provides a case study of sorts as to societal responses.

Whilst disability is a protected characteristic under the UK Equalities Act 2010, disabled people and, particularly, learning-disabled people, even in pre-pandemic times, experience disproportionately poor health outcomes, struggle to gain employment, experience pay gaps and struggle to access inclusive education (See Chapters 2 and 3). They also have a significantly lower life expectancy. Disabled children are more at risk of abuse and are often more socially isolated, struggling to engage in recreation and leisure due to access issues and lower family incomes.

Covid-19 further highlighted these inequalities. The quality of life for families of disabled children was not affected only as it was for all citizens, but also by their children’s additional clinical vulnerabilities to the virus. The pandemic brought into sharp relief the ableist nature of UK society. Parents referred to many examples of this. After the first lockdown in 2020, as previously discussed the government focused on medical priorities as they contemplated the NHS being overwhelmed with patients who had contracted the virus. Inevitably, this led to discussions about the prioritisation of medical treatment. There appeared to be value judgements being made based on ideas of an individuals’ value and who was worth saving. Evidence as to the truth of this were contained in the initial guidelines of the National Institute for Clinical and Care Excellence (NICE) for the prioritisation of treatment; based on the notion of frailty scores (see Chapter 2). If the system became overwhelmed those with the highest scores would receive only palliative care at home. Initially learning-disabled people were a particularly low priority for specialist lifesaving treatment, no matter their health or age profile. Chand, the father of an autistic child, recognised this and commented:

> *‘Maybe what the question would be, if there were three patients and only one could be treated, would* [my son] *beside the other two get the treatment, because they are normal, and he is not. If you go to hospital, then he will not get treatment.’*

Braidotti (2013) describes how the concept of humanity has been monopolised by a kind of political ideology which recognises the status of some more than others. Whilst all citizens are human, some are more mortal than others and some are more disposable. Parents' fear during Covid was that their children were viewed as less important and, therefore, more disposable.

The NICE guidelines raised serious questions about ableist discrimination and were later successfully challenged in court by disabled communities. The guidance was modified to say that learning disability in itself is not a reason to withhold treatment if there is a crisis in demand. Families also complained however that during this time, do not resuscitate (DNR) notices were being placed on learning-disabled people's medical records without proper consultation. Gemma furiously remarked:

> *'When will I be able to stop being angry? When people with learning disabilities aren't earmarked for do not resuscitate orders by our NHS. When my daughter is treated like a human being by our council…When schools don't tell me that they don't want my daughter there because she is disabled.'*

In addition to medical prioritisation and recognising the anticipated pressures of Covid-19 on health and care agencies, the government agreed to easements of rights under the Care Act 2014 and the Children and Family Act 2014. Both key legislative frameworks for accessing assessments for disability services. Parents reported that these easements contributed to disproportionate and negative effects for their learning-disabled children in many ways, including:

- that even with their EHCPs, some children experienced the withdrawal of their education support. Whilst government guidelines on school attendance during the national lockdown stated that children of keyworkers and children with SEND could attend, parents reported that their children's schools would not accept their children attending;
- the education resources provided for home schooling were undifferentiated for disabled children's needs;
- one particularly complex young person was sent home from a full-time residential placement, with no supports and little professional recognition of the impact on the family;

- home care services and some therapies were halted with little thought for the impact on the family's ability to manage.

Parents were sympathetic to the challenges professionals faced in managing Covid-19 but reported that their children were invariably a low priority in the planning and consideration of their needs. They also indicated that learning-disabled children who already struggle with education milestones would be even more affected by not being in school. Claire, the mother of a child with Down syndrome, commented:

> *'I mean, I've got my son; he's, you know, he is not academic at all. The school didn't send home the right sort of work. I have got to write it and he has got to copy it. So, I got a lot of workbooks and we did reception-age workbooks with him, and we did less English and ignored it, and I did maths, technology and different things, just to get some brain activity going.'*

Claire finally insisted that her son needed to go back to school as his mental health was being impacted and he was showing signs of anxiety. He was allowed to return part-time. Notably, however, his mother argued his return on the basis of his father's keyworker status rather than her son's SEND status. She had more confidence in this creating leverage than her son's EHCP, she explained:

> *'I contacted the school and played the fact that my husband was a key worker. Because he works at the council and he was bracketed there. I said you need to have my son back. But... two days a week, they gave me.'*

Five of seven families with school-age children reported that whilst their child's mainstream schools clearly understand their child is learning-disabled, they failed to provide differentiated learning materials, making continued education from home difficult. One parent reported that once her daughter's school had settled into a new routine, all children in that school were offered, positively, in her view, individual Zoom sessions each week with a teacher. Through this it became clear that in more normal times, her child had actually had very little direct teaching from a qualified teacher; her lessons being given to her by a teaching assistant. This was not what the mother had understood to be specified in the EHCP. During the pandemic, her child, albeit with a very limited number of online lessons with a teacher, markedly improved her attainment – so much so that the school subsequently organised some differential learning approaches to better meet her needs. Whilst this is a positive outcome, it highlights the different and probably detrimental treatment she had experienced at school in more usual times.

Families also highlighted the additional problems of social isolation for their children during lockdown; an issue for disabled children even in non-pandemic times. During the pandemic, many children maintained their social lives via social media, but this is not always a feasible option for learning-disabled children. Florence, a sibling, expressed her concern about her younger sister's isolation from her friendship groups as they continued to communicate via social media during Covid-19 lockdowns; something her sister struggles with:

> *'My sister has a lot of FaceTime with just her close friends and they* [school groups] *probably did have* [social media] *groups that she wasn't on. Maybe there are separate group chats where she is not included on, that, yes, it is very likely, and the thought of my sister to not be included is awful.'*

Isolation is further highlighted by parents in describing barriers to accessing information about keeping safe in a pandemic. Care support was removed and it was a struggle to leave the house for basic provisions if their child was being shielded due to medical vulnerabilities. Diane highlighted this:

> *'There is sort of general* [uncertainty]*, they are not quite sure what they are doing for him that is related to Covid-19...well, the other issue, that is worse, is that a lot of things our son likes, they have cancelled…I can't get out and there is no respite because of the regulations.'*

Angela commented:

> *'And with social care an absolute disgrace, carers like us are working 24/7 without any respite. The pandemic has highlighted this for many.'*

A national study by the Family Fund during the pandemic found that 75% of families reported that support services for their children, such as speech and language therapy, psychiatric provision, physiotherapy and access to carers funded through direct payments were significantly reduced. The experiences of the families in this study reflected similar findings.

Towards the end of the fieldwork, data about the impact of the pandemic were beginning to emerge (discussed in Chapter 2). Public Health England reported that the death rate for learning-disabled people aged 18 to 34 was 30 times higher than that of the same age group without disabilities (Public Health England, 2020). Covid caused anxiety for the whole population, but the families in this research recognised their children's particular vulnerabilities. Many of the children have physical and medical conditions that required them to be shielded. Some families reported their experience that whilst agencies were under pressure, their children were often treated as a low priority. Those families that had previously had supports in place to manage complex situations and behaviours found services removed. Angela, six weeks into the first national lockdown, commented:

> *'The legislation has been eased in relation to SEND, so anything in his EHCP, he doesn't have a right to now anyway. I think there really needs to be personal individualised planning for these young people…you know, the college* [he goes to] *have got all the money, the £200k! You think, what have we got? We haven't got any resources; we haven't got any communication aids; they haven't given us those. I think there will need to be individual scrutiny and oversight nationally for our children, for the families, because, you know, we are all struggling in one way or another…'*

Three other families reported the pandemic's detrimental impacts on the mental health and well-being of their disabled children and on mothers. Julia reflected:

> *'We fit in nowhere, and it feels like a really forgotten group of people, and however able the parents are, it's a real struggle to actually get anything to work for you. It is something we are finding difficult. Covid-19 somewhat took over.'*

If the humanity of society is indeed judged by the way it treats its most vulnerable, then Covid-19 has highlighted through these families' experiences, a lack of social justice; society's humanity in relation to learning disability is found wanting. Families' narratives have demonstrated how the pandemic has emphasised the ableist nature of the society their children inhabit in the UK, and the discriminatory way that professionals and agencies allocate services.

8.9. Conclusion

Families argue the need for, and the importance of, good quality, differentiated professional training to improve knowledge and understanding of disability. Society and professionals still behave in ways which are institutionally ableist. Ableism is reflected in negative language and the promotion of ableist norms; with the Covid-19 pandemic becoming something of a disturbing case study of how learning-disabled people still suffer some of the worst outcomes in all aspects of their lives. This is a social justice issue. Parents believe that professionals need to better understand the complexity of learning disabilities; and how these impact in individual ways for their children. Whilst welcoming training parents report that they do not want professionals who have undertaken training to over-claim specialisms or expertise where that training has been insufficient to reasonably make such claims.

Discussed in the context of professional practice, the social and medical models of disability are recognised as a predominant narrative. Whilst these models are valuable in understanding the need to differentiate impairment and disability; nevertheless, it is argued that evolving knowledge relating to the embodiment of disability and grounded in human rights, relational practice and critical disability studies now needs to better inform contemporary professional practice. Disability theories however have been developed mostly in the context of adult perspectives; whilst these are mostly applicable for children; they do not sufficiently take account of the nature of child and parent symbiotic caring relationships. To begin to address this a child and families disability contextual framework is outlined for further development; built in part from the insights reported by parents and children in this study.

Chapter 9: Conclusion

9.0. Introduction

This chapter directly addresses the questions that underpin this thesis, summarising the key findings from the empirical data that were generated from oral histories, narrative interviews and play sessions as well as the analysis of EHCPs. Conclusions are drawn from these data.

Recommendations are made about systemic changes that could be made to support learning-disabled children and their families. These recommendations are based on the appraisals of the participating families in this study about what would improve their quality of life (QoL).

The contribution to knowledge that this research offers, as well as the study's main strengths and limitations and suggested future research areas, are discussed.

Finally, some personal reflections are offered on the process of undertaking the research and preparing the thesis.

9.1. Addressing the research questions

The main question addressed is:

> **How do parents and learning-disabled children and young people exert choice and control in decisions about the support they receive to achieve a good quality of life?**

Several additional sub-questions tease out the themes underpinning the primary question; these are discussed as well. It is useful to divide the main question into its component parts to first understand what quality of life means to families and then how families exercise choice and control.

i. Q1a: How do families define quality of life?

Whilst the data indicate that parents and children do not recognise a universal definition of QoL, they nevertheless have very clear views about what it involves. Families discussed many factors. Many family members recognised Maslow's (1943) hierarchy of needs, spanning basic physiological needs through to full self-actualisation, as a framework. Empirical data from family narratives highlight the range and depth of families' considerations. Parents and siblings presented some nuanced differences that reflect their different life stages and priorities. In Chapter 6, the data were cross-referenced with two QoL frameworks, the UK government well-being framework and Nussbaum's capabilities framework. Considering the analysis through these frameworks highlights the breadth of what matters to families.

Ultimately, families' wants in terms of their QoL are unsurprising within their cultural contexts; they seek overall well-being with good health, a good home, friendships, family, love and affiliations, the means to pay their way, feeling safe and secure and having purpose in their lives. They also want their necessary relationships with professionals who provide access to supports to be constructive, compassionate and enabling.

Importantly whilst families recognise the extra challenges their disabled children face, they do not believe that their children's QoL should be any the lesser because they are disabled. As Nussbaum also argues, they feel that more should be done to make things more equitable and ensure that their children's lives are good; this is their human right. To reiterate Marcus's comments cited in Chapter 7:

> *When you look at Maslow's bit of self-actualisation, that bit that is meaningful at the top, it is almost like the system thinks that so long as you get the bottom layers of Maslow's needs fulfilled, the top layers don't matter.*

Whilst not all families referred to models of disability in their narratives, they all described and recognised the barriers that society presents to their children and the family more generally. This affects all families' overall QoL. Family descriptions of QoL are very grounded in embodied experiences of disability for the child and other family members' experiences as carers.

ii. Question 1b: How do families exert choice and control?

In considering the second part of the main question, about how families exert choice and control to achieve a good QoL, reference to Habermas's characterisation of the lifeworld and the system is helpful. The data evince that these families all seek to be independent, not dependent on agencies and want 'the system' to be an enabler and not to assert patronage. All of the families recognised the necessity of professional support; that will sometimes need to be more intensive than at other times, depending on their children's situation. They want the system to work with the ebb and flow of family life and the needs of all of its members. This brings into play how the families' lifeworlds interact with the system.

The family lifeworld is characterised as the everyday world of family life, culture and informal social interactions that occur within their personal and community-based lives. These families can and do exert significant choice and control in this domain, which is manifest in many ways. Common strategies include:

- developing a team within the family unit where each person has a place. Kinship is paramount and strong family cultures and values are apparent;
- focusing on the well-being of the whole family; if any family member struggles, then it is recognised that the whole family is likely to struggle;
- parents using financial resources to support what they need and drawing on wider family and the community to fund private provisions. They apply this where they believe it will provide leverage for necessary services or where it will enhance family well-being;
- parents and children alike building allegiances and networks within their own social domains. These can include wider family, friends and disability communities, faith groups and specialist charities;
- parents building system knowledge and information to become experts in their children's conditions and the services designed to support them. Siblings, as they age, also develop expertise that informs how they, too, support disabled family members and advocate for them.

Where there are more complex support needs, parents recognised that they will seek help from external agencies, and this is where they meet 'the system'; defined in this context as organised or institution-driven provision and the policies, legislation and agencies with which families have to interact. Habermas (1987) argues that, ultimately, the system grows and colonises the lifeworld. Families in this study agreed that the system can be overwhelming and can sometimes remove their power and autonomy.

The data affirm that the predominant system with which all of the families interact is the SEND system. This mostly occurs within an education context, preparing children for employability in adult life. Other systems that can be accessed include children and adult services provided through local authorities, but their eligibility criteria can feel opaque to families. They can also access universal and specialist, or acute health care systems.

Despite families' choice and control being key principles built into legislation, access to and eligibility assessment for services are controlled by professional systems that families must navigate. Agencies' responses involve the professionals' interpretations of policy legislation and service responsibilities to meet needs, and these can differ from area to area and as well as in relation to families' interpretations of eligibility. Parents reported that they are often unable to exert true choice in the services that are available to them. There are issues of power, control and dominance. Parents often reported that professional relationships 'do to' families rather than 'work with'.

Families described how they exert choice and control in this context:

- They build networks with other parents, sometimes creating representative bodies to challenge agencies.
- They build relationships with professionals in a wider context to create more influence (e.g., sitting on governing bodies, being involved in policy work as experts by experience and getting involved in co-production projects).
- They use social media to learn what has worked for other families and then challenge the system.
- They develop comprehensive knowledge of the system, including the law and codes of practice, to understand and assert their rights. Parents can become more expert than most professionals (e.g., one parent advising the school before Ofsted did).
- They fund private assessments and provisions to use as leverage to prove the need for publicly funded provision.
- They use informal and formal complaints systems.
- They use democratic processes involving councillors and MPs.
- They use legal processes of tribunals and the ombudsmen.

How children exert choices and control is different.

- They tend to work through parents advocating and mediating for them.
- They are given little voice in formal systems, as the lack of their participation in their EHCPs demonstrates.

iii. Q2: What are parents and children within families’ aspirations for the learning-disabled child?

Aspirations in life are important for everybody; they offer a glimpse into the type of life a person might hope for. Having a vision with goals for the future can inspire purpose. Although some aspirations can seem like daydreams, they are nevertheless important for motivation. In this study, each family member has individual aspirations, as well as aspirations for each other.

Parental aspirations for disabled children fundamentally start with their children’s human rights being fully met. The families in this study assert that their disabled family members have the same rights as any citizen and these must be promoted and protected. They recognise that these are at risk due to disability discrimination. In particular, they do not want their family members’ conditions to define them or society to create barriers because of ableist notions of disability. Parents want all of their children to have good lives with meaningful and fulfilling relationships, to be safe and have purpose.

Parents and siblings alike recognised roles for themselves as advocates, enablers and supporters of disabled children’s aspirations. They want their family members to believe that it is possible to have dreams. Parents and siblings believe that professionals tend to underestimate their disabled family members’ capabilities, consequently minimising what is possible. In this respect, they feel that professional behaviours are driven by ableist notions of possibility, diagnostic overshadowing and an over-reliance on beliefs in developmentalism. This also translates into budgetary constraints driven by notions of worth. Parents challenge and seek higher ambitions during assessments and reviews in response; and adopt the responsibility to meet some support needs themselves using the family’s resources. Reported examples included home physio to teach their children to walk; buying equipment to enable inclusion in activities; or developing employment opportunities.

Parents and siblings also see roles for themselves in developing opportunities within family life to deliver on disabled children's ambitions. Families make reasonable adjustments to enable participation in wider leisure activities. These include the development of friendships; travel, including abroad; benefiting from culture, and the creation of meaningful opportunities to achieve purpose.

iv. Question 3: How are decisions made for and with the child, and by whom?

There is little evidence within this research of the concept of the agentic child (Sorin and Galloway, 2006) being applied to learning-disabled children who have complex support needs. They experience double challenges of constructs of childhood immaturity and ableist attitudes regarding sentience. Their involvement in formal decision-making systems is minimal, as their lack of involvement in their EHCPs indicates. The age of the child does appear to have a small influence, with older children having marginally more involvement, particularly in transition to adulthood plans. However, the complexity of the children's conditions and minimising of their cognitive abilities tend to reduce their personal power in deciding consequential things for themselves or about their lives.

In most families' experiences, professionals fail to build the necessary relationships or trust to meaningfully involve disabled children in decision-making about their lives. Even formally mandated systems of review are not properly followed; including at key points of transition in children's lives. Most families see little evidence of professionals paying sufficient attention to understanding disabled children's views and involving them in future planning decisions about adulthood.

In parent/child/professional dynamics, adults have dominant positions. Parents likely assume this position at first because of their parenting roles, ascribed through societal constructs; they are expected to nurture and care for their children and make decisions on their behalf until they can assume agency for themselves. Professionals also assert dominance over disabled children, and their parents. This study found minimal evidence of professionals engaging directly with any of the disabled children about future life plans. These are mostly mediated by parents in their advocacy roles, and sometimes, professionals dismiss parents. Whilst some direct child/professional relationships are evidenced, particularly in the school context; these appear to be more day-to-day and do not feature seeking the child's views about substantial decisions regarding their future lives. Professionals who are responsible for drafting EHCPs possibly accept the lack of direct involvement of most children in their plans because they revert to parents speaking for their children. This is true even with older children and young adults. This lack of direct involvement points to ableist assumptions that learning-disabled young people lack sufficient sentience to contribute meaningfully in direct discussions about their future life plans. This leads to professional over-reliance on parents as advocates and parents accepting this role.

The challenge for learning-disabled children is that even when others act as advocates for them with the best of intentions, when adults speak for them, they are rarely able to directly speak for themselves. In this respect, they have little power. Parents as advocates can also be minimised through professionals' negative applications of particular parenting constructs. They are either seen as warrior parents who are combative, or superhero parents who are managing and do not need help. All of these factors in combination mean that a disabled child's 'voice' becomes little more than 'a whisper'.

Parents who feel that decisions are being made that insufficiently incorporate their or their children's views are more likely to resort to formal processes of complaint or democratic or legal means of redress to promote what they perceive as the right decisions for their children.

v. Question 4: What are the key tensions within the decision-making process?

Tensions in the context of decision-making are very evident in this study. These tensions occur within families; and from the nature of relationships with professionals. A critical aspect of where tensions lie is in who is perceived as holding power. Different power dynamics arise in different situations, and it is not always obvious who believes themselves to be dominant or subordinate in a relationship. Families reported that they feel that their service relationships are often very transactional rather than relational. Professionals approach their work with families as problems to be solved and completed. Families believe however, that an investment in building long-term good-quality relationships where trust and knowledge can be established is needed when working with long-term disabilities. Their perception that this is lacking in the system is a point of tension.

Parents tend to believe that agencies acting as the gatekeepers of service provisions and budgets hold power over families seeking support. They see budgets as key drivers in decision-making. Whilst families did not refer directly to neoliberal policies, which continue to dominate economic, political and social life in the UK, they conveyed their frustration with a system that they perceive as often unresponsive, overly cost-focused, ignorant of needs, lacking in compassion and understanding, and poorly accountable. This system does not achieve family well-being.

Both the literature and parental narratives affirm that professionals believe that parents can assert sometimes-excessive power by exercising their rights to legitimate systems like complaints, tribunals and the ombudsman. This creates tensions in relationships and decision-making. Local Authorities through the LGA have been openly critical of parents' high success rates in the decisions made at SEND tribunals and by the ombudsmen. This is referred to as an issue in the government's 2019 review of the SEND system and subsequent green paper (2022). Professional critiques notably blame parents for litigious behaviour. Few indicators show that agencies reflect on their own accountabilities where fault has been found and learn from them. This causes mistrust within families.

A further source of tension for families lies in understanding the various systems of access to service provision. These include EHCPs, Child in Need Assessments, and Continued Health Care Assessments. All of these technically involve multi-agency collaborations but families highlighted that reaching the right group of professionals and engaging them in working together with their families often proves challenging. The lack of social care support is a notable point of tension for many parents, two-thirds of whom believe that social work practitioners are overly concerned with bureaucratic systems of assessment eligibility and an excessive professional imperative to assess and manage risk. This is combined with a drive to limit resource allocation and proves a poor basis for collaborative or co-productive work.

Tensions further arise from parents' and siblings' beliefs that there is a fault line in the system; due to the shallowness of professional knowledge about certain types of disability and how children can be best supported. Families believe that their knowledge as experts by experience is insufficiently recognised. Frustrations with discriminatory and ableist approaches to disabled children's needs also cause stress and put pressure on families. Siblings particularly commented on professionals' failure to sufficiently challenge ableist language or behaviours in the context of school. They expressed their frustrations that teaching staff could challenge disability discrimination as they rightly challenge racism, but often do not. Siblings see this as perpetuating ableism in the next generation of adults as they are educated in schools.

Tensions between family members are often most evident in planning for the future. Parents fear what will happen to their disabled offspring when they are no longer present to advocate for them. In this, they seek the co-operation of their other children to support their disabled siblings in the future. Whilst all of the siblings in this study who were old enough to comment rejected the notion of the burden of being young carers, they did recognise aspects of the sibling relationship that place responsibilities upon them in the present and future. Some siblings admitted that despite recognising that it cannot be easily changed, they do feel they have missed some opportunities for a family life that enables a wider range of leisure and cultural activities, travel and extended family relationships. They largely accept that all family members are equally important and sincerely believe the need for reasonable adjustments to family life.

Many of the parents have made, or plan to make, provisions in their wills for their disabled children, setting up legal trusts and guardianship arrangements in advance. In some cases, siblings are named as trustees. Siblings reported varying degrees of willingness to become the lead responsible adults when their parents die. They expressed a degree of concern about the effect this role could have on their own lives and future plans. It is a difficult area for parents and siblings to discuss, and siblings, in particular, are torn between their love for their parents and disabled siblings and their rights to have the lives they choose, including responsibilities to their own children in due course. Many of the older siblings recognise that they wish to pursue careers that may entail geographic distance from their families.

The freedom to live the lives they choose is a point of tension for some, but not all, siblings. It is not consistently and openly discussed within all families. An additional aspect of future arrangements is that in writing their wills, some parents are leaving a greater proportion of their estates to their disabled children to pay for care and to protect their interests. This may create some resentment in the future for siblings who are also trying to build their lives. Again, these discussions do not always occur and siblings and parents acknowledged awkwardness about the subject.

vi. Question 5: How has Part III of the Children and Families Act 2014 affected families' choices?

A key principle of Part III of the CFA 2014 is that children and parents or carers should be able to exercise choice and control. Parents were very aware of this principle and wished to see it better exercised to improve their children's quality of life. Most of the parents in this study have prioritised knowing about and understanding the provisions within the CFA 2014. All of the families contended that the CFA 2014 has not been entirely successful in its aims to give children and their parents more choices or influence in how their needs are assessed and services are delivered.

The CFA 2014 appears to have further strengthened the SEND system as the dominant system for assessing disabled children's needs and offering services to them. It is unclear whether this is truly by design or by default, as priorities in the role of children's social care have shifted after the child abuse scandals of the late 20th century and into the 21st century. There appears to be a weakening of the application of the 'child in need' system in relation to disability under the Children Act 1989. There is also evidence that focussing on short-term interventions to move children out of social care systems, combined with a strong emphasis on the assessment and management of risk within Local Authority Children's Services, has changed how these agencies understand and plan for services for disabled children. The CA 1989 specifically identifies disabled children as eligible for assessment as children in need, but many families struggle to convince social workers to engage. In many cases, they are referred to the SEND system. Families that are persistent in seeking social care support can encounter social work agencies that threaten to apply Section 47 safeguarding procedures. At least two families in this study have experienced this and perceive it as a punitive and unhelpful response to seeking to do right by their children.

This emphasis on SEND provisions is problematic for families that need social and health support. Family narratives show that this shift in focus is particularly disadvantageous to the children with the most complex support needs. When families access SEND provisions, they struggle to attain other statutory services as some agencies no longer see their children as their responsibility, even when legislation mandates it. In this respect, the Children and Families Act 2014 has not had the positive impact on choice that the government intended when the legislation was enacted.

vii. Question 6: What are the families' professional power relationships and how do they navigate them?

Parents' and children's reliance on professionals for support and to access services highlights possible power dynamics. Legislation mandates that families have levels of choice and control and that professionals must properly account for their views. These relationships must be negotiated within a set of power-based dynamics, which parents reported as constantly shifting and changing. Many families reported occasionally feeling 'done to' rather than 'worked with', highlighting their belief that professionals tend to hold more power than family members do.

Parents seek to develop knowledge of the system because they believe that knowledge of systems and processes enables them to assert power and regain some control. In this respect, Avelino's (2021) power framework is helpful. Using knowledge as power and, often, knowing their rights better than many professionals, can redress the power imbalance to a degree. Families also seek consensus through models including co-production and can use conflict as a disruptor when necessary. Examples of this include applying accountability systems such as formal complaints, contacting regulators and applications to tribunals.

Some families reported that good professional experiences can improve quality of life. Practitioners who genuinely invest in good outcomes for learning-disabled children and recognise their worth are valued. Parents with good relationships with professionals tended to describe feeling more empowered within the system. The length of professional experience or particular roles do not appear to be the main factors influencing good family experiences. Instead, professionals' understanding of and investment in a child or in recognising their particular challenges makes a positive difference. When parents described good professionals, they used words like humanity, compassion and empathy.

Parents recognised power imbalances and reported that to navigate them, they adopt strategies to manage and sometimes circumvent systems to achieve better outcomes for their children. They can be very effective at this. They plan for long-, medium- and short-term goals, anticipating the challenges ahead and addressing them to maintain more power over their family's circumstances. As previously described, they use personal and financial resources for leverage to achieve goals that enable the best quality of life for their families.

When parents find systemic power constraining, they will assert their personal power to create leverage that forces the system to be more enabling, for example, by using private assessments to prove the case for a publicly funded service. Parents also decide which battles to fight and seek quality over quantity, using power to achieve what really matters and giving ground on less critical elements. They also use strategies to build trust by becoming part of the system themselves, for instance becoming school governors or members of strategic parent forums to change the system from within and build credibility as fellow 'professionals'; shaping how the system works at a strategic level. In these roles, they work alongside paid professionals to address service provider dilemmas and solve problems. These strategies create a sense of empowerment rather than disempowerment.

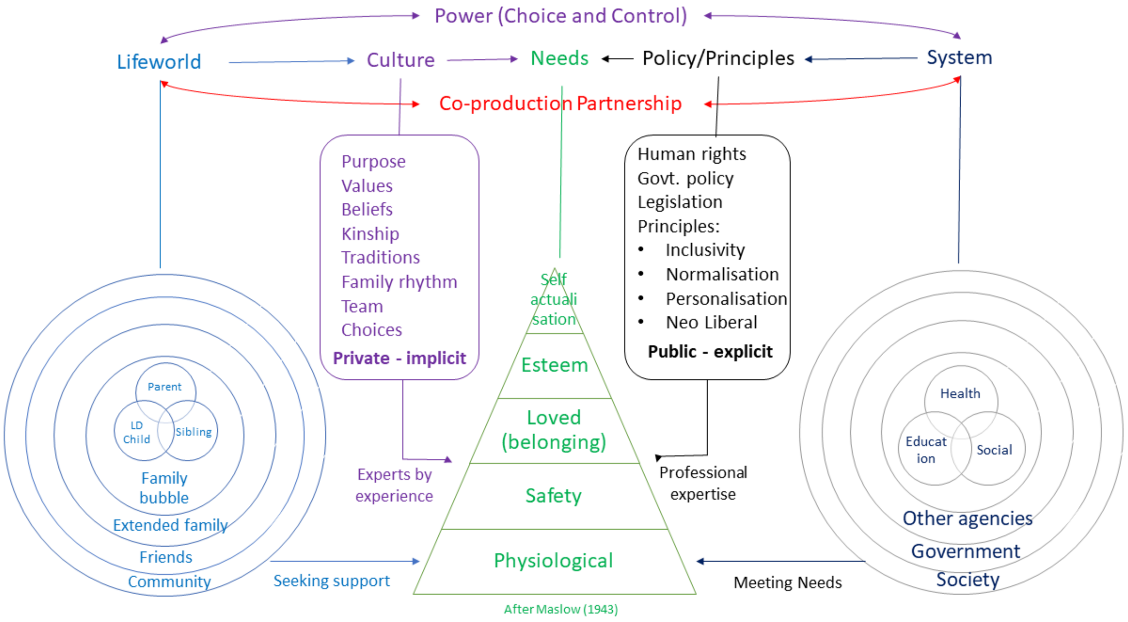
9.2. Conclusions and potential ways forward: a contextual framework

Whilst it is recognised that nine families is a small sample size from which to draw conclusions and make recommendations that could impact for hundreds of thousands of disabled children; what is learned from these particular families resonates strongly with findings in other academic and grey literature. Clement and Aiello's (2021) study on parent blaming, Adam's *et al*. (2018) evaluation of EHCPs, and the SEND Review (2019) are all examples of recent studies that echo these families' frustrations with the system and what isn't working for them.

Macdonald and Deacon (2019) argue that theoretical and qualitative explorations, using disabled people's experiences need to progress representative evidence-based research in order to facilitate professional practice. This qualitative research has focused on what disability means for children and their families, what matters to them and the changes they would want to see in the system and to professional practice to achieve better outcomes. In this thesis there is a critique of current policy and legislative systems. Families have shared their views about how their lifeworlds interact with this system and where power lies. Drawing from this it has been possible to develop what I have termed a Child And Family Disability Contextual Framework. (see Figure 33). This seeks to build contextual understanding about the interactions between families, policies, professionals and society and that influence quality of life.

This does not claim to be a new model for childhood disability, but instead a starting point for further work to develop better systems and improved professional understanding of how children and their families experience disability. Knowledge of these experiences can facilitate improved professional practice, and better support policy development. This framework provides a basis for future research and discussion to develop into a working model. This may be the starting point for a post-doctoral study on how to make the system more responsive to families of learning-disabled children.

Figure 33 Child and Family Disability Contextual Framework.



Family Lifeworld is represented in the framework diagram as the ‘family bubble’ supported by extended family, friends and community. This bubble has its own culture underpinned by its values and belief systems; where it gains its sense of purpose and offers kinship to its members. It is implicitly a private system which becomes expert in understanding how needs for all family members can be fulfilled. Those in the family bubble will recognise that in support of some individual and familial needs, it will require interactions with the system to achieve desired outcomes.

The system itself is represented in the framework diagram through the key agencies (education, health and care) and that these link with other professional agencies; the voluntary sector and government. How this system operates is underpinned by policy principles at a macro level (e.g., human rights), meso level (e.g., governmental policy and legislation) and micro level (e.g., local arrangements and practice principles). It is explicitly a public system which develops professional expertise that is then applied to address needs. The two elements of the family bubble and the system integrate in a system of common purpose to achieve quality of life outcomes, though not always successfully. Maslow's hierarchy has been used because it represents a well cited study of human needs though other models could be developed.

In the framework it is recognised that power exercised through choice and control is integral to how things will operate. In this respect Avelino's (2021) meta-analysis of power models becomes helpful (Chapter 3). Avelino highlights how fierce power struggles and inequalities can arise through governmental policies and interventions. This cannot be ignored in the context of this framework. Power is therefore highlighted within the framework recognising how it is shared backwards and forwards between families and the system. Also represented and built into the framework is the learning gained from families about the importance of co-production and models of practice. In Chapter 7 the value of recognised co-productive models is highlighted (e.g., Person Centred Planning Together, family group conferencing and transformative mediation) Recognition of co-productive systems of working are built into the framework.

In addition to recommending the further development of this framework, below are some other specific points regarding possible changes within the system that could be considered. Some of these it might be argued are overly bold being drawn from a small qualitative study, but they are intended to really challenge thinking about the ways to progress practice to improve the experiences of families and warrant debate.

i. The system

- Analysis within this research of both academic and grey literature, and the data generated within the study indicate that in its entirety, current children and family legislation, codes of practice and human rights legislation should provide the right basis for family support. Problems arise in its application. There are sufficient legislative powers to meet disabled children's support needs, but these are not properly applied (see Ombudsman conclusions; SEND review 2019; Clements and Aiello, 2021)

- The complexity of the legislative system is challenging for families to navigate and the lack of good-quality information does not help them. Children and family-based legislation can be applied in contradictory ways and case law will influence this application, e.g., education legislation tends to be needs-led and funded, whilst social care legislation can consider cost and affordability during application (Booth *et al.*, 2014). This creates inconsistent responses for families.

- Legally challenging the system is expensive and not all families can afford to, or have the capacity to enter into legal challenges, thereby restricting some families from asserting their legal rights. Families believe that if the system worked with them rather than against them, investing the public money used to fight them in legal processes to enhance services instead, all would benefit.

- The SEND system's neoliberal focus on an education for employability model is problematic when children have such complex support needs that paid employment is unlikely for them. Evidence from this study indicates a requirement for better integration of health, social and education provision to deliver purpose for a good quality of life. Over reliance on SEND provisions leaves the wider family system poorly supported.

- The analysis of EHCPs reveals how little other relevant legislation is considered within the SEND system. How multi-agency professionals work with SEND in conjunction with other children and family legislation and provision warrants further review. In this context professional organisations sometimes require challenge regarding territorial disputes where agencies argue other's responsibilities rather than recognise their own.

- Neoliberal systems within social care can lead to the creation of a marketplace that has overly aggressive focus on value for taxpayers; these tend not to treat people with long-term needs well. This is apparent in the level of stress and distress experienced by families in this research.

- The Children Act 1989, despite its partnership ethos, has translated into social workers becoming investigators and commissioners of services; moving away from welfare and professional therapeutic interventions. Since the enactment of The Children and Families Act 2014, The Children Act 1989 appears to be less frequently applied to complex support needs for disabled children in favour of more EHCPs. Social work has adopted a narrower, more restricted role. This has led to short-term interventions, gatekeeping resources and managing risk. This is to the detriment of the long-term social care support needs of disabled children. A lack of early intervention can lead to more complex social needs and higher spending on disability support in the longer term, particularly given the lack of investment in community services.

ii. Professionals

- Professionals and society must better understand the heterogenic support needs of children with complex conditions and services need to be differentiated. Better training and professional development across all relevant professions with a recognition of the heterogeneity of disability built into professional education and training would be welcomed by families.
- Additionally, professionals need to understand when and where condition-specific expertise at the right level is required. They and their managers require the sensitivity to recognise when specific children’s individual needs require more specialist knowledge. Professionals cannot be reasonably expected to know about every condition; but can be expected to recognise that they may need to learn or take advice about specific ones as they work with individual children.
- Professional agencies should not over rely on basic understandings of the medical and social models. There are indications these have become buzzwords. This is an equality issue as psychological models of development maintain their dominance. Outdated ideas that lead to discrimination and maintain ableist frames of reference need to be challenged with a stronger

focus on the agentic child. The lack of theoretical knowledge of disability is an example of professional practice falling behind good quality academic enquiry, thinking and review.

iii. Family Support

- The parent/child relationship is symbiotic; if one part of the family is in distress, the whole family is affected. Children need their parents to be healthy and supported. The family's other children's rights to have good childhoods should also be respected. The lack of holistic support services within professional systems for the families of learning-disabled children leaves parents and other children within the family to assume a disproportionate level of care with little consideration of the impact on family well-being.
- Mature approaches to models of co-production that recognise families' expertise and the invaluable resources they bring to support children's plans need to be better developed. This will require some renegotiating of power relationships but is likely to mutually benefit families and professionals.
- The national review of children's social care published in 2022 that occurred during the course of this research did not address disability. It identified, however, the need for a multi-agency transformation in family help, which offers support to families before stress escalates situations to the detriment of the child, and family life. It argues for a system that is relentlessly focused on children and families. That disability strategies are not included in this report is regrettable. A relentless focus on family is equally needed to achieve better outcomes for disabled children.

9.3. Unique contribution to knowledge

Through the analysis of parents' and children's narratives, I have been able to contribute to the field of knowledge in disability studies in several ways. Working with family units wherever possible has provided opportunities to learn how professional responses to disability affect different family members. This study highlights the importance of whole-family well-being. The amount of learning-disability research in childhood that directly involves whole nuclear families is limited. In the context of disabled childhood experiences, this study highlights the importance of understanding family culture. It garners insights about how families navigate life, negotiating amongst themselves to meet all family members' needs. My research has contributed the contemporary voices of a group of families to build on previous knowledge.

The design of this research has permitted further learning about how embodied disability is experienced by learning-disabled children but also how it affects other family members. It highlights areas of challenge and expectations within the context of family roles, exploring the characterisations of different professional tropes, including warrior and superhero parents; non-disabled siblings as young carers; and notions of pity and burden regarding disabled children. This research highlights that family life is highly nuanced and that some ableist roles ascribed to family members within professional systems are neither recognised as real nor welcomed by families. This further builds on existing knowledge about disability providing insights into continuing ableist societal attitudes that apply during childhood.

By inviting all family members to participate, differential insights about the impacts and experiences of different individuals within the family at different life stages have been gained. This can inform professional practice not only in relation to disabled children but also regarding their siblings and parents. That all family members discuss struggles at times and need support highlights the importance of professionals understanding that more holistic approaches to family life are needed.

This study also provides additional intersectional insights regarding societal constructs of childhood, parenthood and disability. Understanding family dynamics provides new knowledge about how these constructs converge. Aspects of what the system apparently values and expects, typically in relation to separate constructs, become more confused, contradictory and sometimes negative in the context of disability. For instance, parenting in the UK societal context is about caring for children, protecting them and nurturing them (Ladd-Taylor and Umansky, 1998; Burman, 2008). Caring in the context of disability becomes linked with pejorative notions of patronising the disabled individual (Oliver, 1996; McLaughlin, 2006). Parents can find themselves criticised for caring too much and described as barriers to their children's progression, or experience forms of ableism without being disabled themselves (Ryan and Runswick-Cole, 2007).

A further example of an intersectional contradiction relates to contemporary notions of the importance of the agentic child (Sorin and Galloway, 2006). Despite provisions within the CFA 2014 that learning-disabled children should be given their voices, there is evidence that they are denied agency even more so than non-disabled children. A strong emphasis on developmentalism in childhood studies is unhelpful for learning-disabled children because it supports medicalised models of disability. Ableist frames of reference for a child's capabilities that focus on 'improvements' or even 'cure' alongside underlying, though not always acknowledged, conceptions about their lack of sentience are problematic. Evidenced in this study is that professionals rarely engage in opportunities to directly engage learning-disabled children. Failure to recognise children's agency means professional systems resort to over-reliance on parents to represent their child's views. Parents and their disabled children are thereby placed in a double bind; parents are expected to advocate for their children, but if they do so in ways that agencies dislike, they can be dismissed as difficult or as barriers to children's agency.

The evidence in this study suggests that there are contradictions in how children's agency, and acceptance of children taking responsibility in aspects of their own lives, is differently understood by professionals. There is evidence of non-disabled siblings' taking on responsibilities with accompanying assumptions of agency that may be inappropriate to their ages. There was minimal evidence of statutory agencies assessing the impact on non-disabled siblings of the responsibilities they may carry, or understanding of those children's support needs, although this is set out in legislation. The system accepts non-disabled siblings taking on highly responsible tasks, including intimate medical and personal care.

These responsibilities can extend into siblings' adult lives when their parents age or die, so parents assume and the system accepts, that siblings will adopt roles that parents can no longer fulfil. Young adult siblings in this study reported preparedness to support their disabled siblings long into the future and to maintain advocacy and caring roles for them; the effect of this choice on their future lives and any choices they might make is significant. While the changes that have occurred in disability policy and practice are well documented, to date, research has done little to increase the understanding of the impact of these changes across childhood and into adulthood for non-disabled siblings. The evidence in this study highlights the weight of these responsibilities and their impacts on mental health and well-being. This further highlights the need for greater understanding of the family context; siblings are as entitled to a good childhood as any child, so society should consider their support needs as well.

Whilst evolving disability theoretical perspectives consider the personal embodiment of disability, these tend to be focused on ideas of autonomous adults being deprived of agency by societal barriers. The exploration of disability within this thesis has highlighted the need for more work to understand the family context as disabled children grow up. In common with the findings of other studies on disability and childhood (Finlay and Lyons, 1998; Priestley *et al*., 1999; Shakespeare and Watson, 2015), learning-disabled children participating in this study want to be seen as ‘normal’, and they look to their parents, siblings and sometimes professionals to support them in achieving a life typical of their peers. They are in symbiotic relationships with their parents and to a lesser but important degree, their siblings. Disability models require further development in understanding the nature of the relationships between children and their carers, upon whom they are dependent. This involves rethinking aspects of adult-oriented models. Dependency on others for care is typical of childhood, but the additional support needs involved with complex disabilities to achieve a good life highlight the need for a deeper understanding of family.

Finally, in arguing that family context is significant, this study highlights the need for a framework that policymakers and practitioners can apply to understand the integrated nature of family life and how this supports disabled children. The system insufficiently recognises the need to support family well-being. Mothers, in particular, are at risk of mental ill health when caring for disabled children and marital relationships are strained, demonstrating how poor support contributes to poor outcomes not only for disabled children but also for other family members. The system’s reliance on families as the main supports for disabled children highlights the importance of supporting the well-being of the whole family unit.

9.4. Strengths and limitations of this research

The strengths and limitations of this research were discussed in greater detail in the methodology chapter, but they are worth further reflection. A key strength of this research is its focus on families and, in this context, the experiences of different family members at different ages and life stages. The cohort includes families from different socio-economic backgrounds, all have benefited from higher levels of education which in some respects makes them less representative of the general population. Different cultural backgrounds as well as gender is reasonably well-balanced within all participating groups. However more mothers (100%) directly participated than fathers (55%). This reflects aspects of gender differences that are apparent in the literature regarding who tends to lead in navigating systems on behalf of their children.

A limitation of the research is that a cohort of 28 individuals across nine families inevitably represents a very small sample in the context of a whole population. However, the narratives are rich in data and all participants contributed substantial detail about their experiences across many facets of family life. In this respect, the data are very strong.

Another limitation is that it was not possible to analyse EHCPs for all nine disabled children involved in this study. There were good reasons why some families could not share their plans, however, six is a small sample and can skew the overall impression of the quality of EHCPs. How professionals approached the three plans that were not evaluated cannot be determined. However, the analysis in this study highlights some very similar issues of quality found in larger national research studies assessing EHCPs in 2018 and 2022.

Within the cohort, some family members excluded themselves from participation for reasons including their unhappiness with their family's situation, lack of interest in the study, or lack of availability due to other commitments. All of the brothers and sisters who elected to participate are positive about family life and spoke warmly of the kinship of family. They recognised difficulties in their family's situations but they saw participation as an opportunity to positively challenge stigma and discrimination on behalf of their learning-disabled family members; by sharing what they have learned. Those siblings who chose not to participate articulated different feelings about their circumstances and referred to the pain of some experiences and anger with the system. Their views may not have presented such overall positive feelings about family life, had they been included. The views of the siblings involved could, therefore, skew the analysis as they are coming from a positive position about their families.

Siblings with very different starting points might have provided some very different insights about their experiences and what they believe needs to change. This is the nature of phenomenological study however, and this research does not seek to generalise.

Covid-19 posed challenges for this study. Opportunities to meet participants in person were reduced due to lockdown restrictions and university guidelines for safe research practice during the pandemic. All meetings were online, and although this meant that participants were able to be in safe spaces of their own choosing, without the researcher encroaching on their territories, online meetings have some disadvantages. It is harder to build rapport and somewhat harder to notice body language online. However, all but one participant gave permission for the sessions to be video recorded, which supported later review. Online sessions with an unknown researcher and non-verbal children seemed unethical and were not pursued. This exacerbates the problem of research about children often not involving them. Had the pandemic not restricted travel, I had planned to visit families, build some rapport with disabled children and young adults and involve them more directly in this study. It is disappointing that despite my sincere aims to involve the young people who are the focus of the research, this was not fully possible.

9.5. Reflections

I came to this research with a long professional background as a qualified and registered social worker; this professional background makes me an insider in professional systems. In this respect, I recognised from the outset that this research would be something of a heuristic journey (Moustakas, 1990, 1994; Sultan, 2019). Throughout my professional life, parents have at times challenged me and my colleagues about not truly understanding service users' experiences and not involving families properly in exercising choice and control. My own experiences of having a disabled child has highlighted how the system can be unresponsive and insensitive as well as how a good-quality professional relationship can be transformational.

Meeting and working with families in this research has been a privilege, and I recognised my responsibilities to them as a researcher to represent their views faithfully, constructively and beneficially. My understanding has grown and I have changed during this research process. I have learned much from young people's and parents' narratives about how professional systems could be different and this has made me reflect, sometimes uncomfortably, on my past practice.

In a professional role before taking up this research, a parent trustee regularly challenged our organisation to listen more, and understand better what families said to us about our services. This parent clearly felt that we were sometimes paying lip service when we assured him that we understood. Metaphorically speaking, this trustee seemed to feel that he was speaking to us through glass; we could see him talking, but we did not hear him. In concluding this study, I understand the frustration of this parent trustee much better. I see that professionals do not always listen or hear service users, becoming preoccupied sometimes with their own agencies' challenges.

Families that interact with the system are not seeking dependency but, as the disability academic Ryan (2021), a mother of a learning-disabled son contends, listening and reflection, communication, information, love and 'pockets of brilliance' are required. I would add to this, humanity, compassion and a sense of professional responsibility in understanding family challenges properly. Families expect professionals to not adopt a one-size-fits-all approach because they are a population of individuals.

As professionals, we owe it to families and our own professional credibility to take responsibility for our training and learn to be the best practitioners we can be. We should constantly evaluate the nature of the power we hold and work in meaningful ways. I often reflected that as practitioners, at the end of the day, we return to our own lives and families continue to live theirs. Our work with families and how we support them through our professional relationships can make the difference between working positively and not falling prey to subtle and overt forms of dismissal emanating from a low-expectation culture (Runswick-Cole, Tweet @K-Runswick Cole, cited in Ryan, 2021).

I have strong and abiding recollections of this process of research. I was constantly surprised by people's generosity in sharing their stories and what they were willing to talk to me about; trusting me to honour what they shared and treat it with respect. I hope I have done justice to this trust. Parents and siblings shared many stories that touched me deeply, and I carried those stories with me for days and weeks afterwards. The young people with Down syndrome who shared their hopes and aspirations for the future were particularly impactful. I also carry a huge sense of optimism for the future from talking to siblings; they carry the baton for continued change and will be champions in this cause.

I have maintained links with old colleagues throughout this research, as is common during a working life, and I increasingly became a louder advocate for the families of learning-disabled children. I sometimes felt the need to challenge professional biases and lack of knowledge and understanding. This could be deeply uncomfortable because my observations and challenges have not always been welcomed. However, I also had good, open conversations with professional colleagues, and many of them welcomed the sharing of what I was learning from this academic process, something that few practitioners will experience once they qualify.

Interestingly, at times I felt, as a previous insider, like the parent trustee who was on the other side of the glass; mouthing important messages but not being heard. This, I concluded, is a problem. Often we only hear people if we think they are like us. Much evidence suggests that the professional system, sadly, does not recognise learning-disabled people as sufficiently ‘like us’ to be heard.

9.6. Possible areas of future research

This section highlights possible areas for further development:

i. Family models

- A better understanding of childhood and family context should be integrated into disability theory and disability models. Developing research that recognises the symbiotic nature of parent/child relationships in the context of the embodiment of disability would be valuable. Whole-family children’s disability models are needed to recognise the integrated nature of parent/child relationships.

- Developing a professional working model to aid policymakers and practitioners that recognises the complexity of the system that disabled children and their carers must navigate. Other parts of children’s services have succeeded in developing contextual practice frameworks for professionals. A strong framework can provide structures for describing, guiding, analysing and evaluating professional practice; developing one for disabled children and their families would be beneficial. A preliminary contextual family disability framework is offered in Chapter 9. It seeks to take an integrated approach to the factors that affect families, recognising how the whole system interrelates. This is a starting point for discussion; further work to develop this would be a useful area for future research.

ii. Economics

- Linked to developing family support models and in the context of current reviews of how the SEND system operates, a sincere appraisal of how much supporting a good-quality system would cost is required. Legislation sets out expectations about how disabled children's rights are to be supported, and open and honest evaluation of costs and how provisions will be funded is needed. This study shows how disputes about funding can lead to unhelpful, polarised characterisations of 'difficult parents demanding resources' that 'unsympathetic professionals deny to protect budgets'. No party benefits, least of all disabled children. A mature approach to developing an economic model for disability support is needed.
- The economics of community and residential care are particularly poorly researched, with a small number of studies, few of which are contemporary. Evidence from family narratives and in the literature indicate that economic considerations are a source of great tension within disability services. These can negatively affect professional decision-making. Families expend large amounts of their own resources and statutory agencies complain that provision is financially unsustainable. Any review of the disability system must research the economics and develop a fair and affordable model.

iii Professional knowledge

- The findings of this research point to the need for professional training and more universal education about the nature of disability. More specialist learning also needs to be made available to some practitioners and managers. What a comprehensive professional training and development programme should include requires further investigation.
- Condition-specific disability-focused training should be of sufficient depth to make a positive difference whilst challenging institutionalised ableism. The

need for better training and professional development is not difficult to argue; what this should look like and what would best meet current needs requires further exploration. This should include types and levels of training and education, as well as what is appropriate for which practitioners. Collaborative enquiry with the participation of disabled people and their families in a process of participatory action research is essential.

- How technology impacts on understanding of and attitudes towards the embodiment of disability is an important area for future research. Whilst technology can be a force for good in improving quality of life outcomes it can equally be a cause for concern if ethical debates are not run concurrently with developing knowledge.

9.7. The Final Words

In this research, the narratives of siblings expressed, in the most straightforward ways, what life could and should be like for learning-disabled children. It, therefore, seems appropriate to give one of these siblings the final words; his narrative encapsulates the essence of what for all the families matters most:

> *'I'd like her just to be living her own life really, to be able to work for herself because that is what she wants to be able to do. She wants to live with her friend at some point. I am not sure… just how…crazy…that house may be…but it will be good fun and no more crazy than a student house at least. And if she wanted to go on some holiday, I don't know… to Hawaii or something, then yeah! She should be able to do that if she wants to. I have to stand behind what she is doing and sometimes will help fight for her because she can't always do it herself. But I know I would want her to live life as much as I can live it, and she will!'*

Appendices 1-8

Appendix 1: Research Flyer

Research Study

Carol Long
Researcher
Durham University

Hello, my name is Carol, I am a researcher from Durham University exploring the experiences of families with children with severe learning disabilities, and of the services open to them to achieve a good quality of life.

- My research seeks to gain better understandings of the lives, the hopes and dreams but also the challenges for children and young people with learning disabilities and their families.

- It is a space where children and young people aged 8-25 with a severe learning disability, (and who have, or have been assessed for an education, health and care plan) can with their parents and siblings tell their stories, share their hopes in life, and how these are supported by the services they receive.

If this is your family, I would be really interested to hear what you think. You can contact me for more information at Carol.m.long@durham.ac.uk

What's involved?

- Visiting to collect stories, known as oral histories from you as parents about family life since the birth of your child with a disability, and to talk about the support you receive.

- Using art sessions to understand from your son or daughter with learning disabilities what they enjoy about life, and what is more difficult.

- Asking brothers & sisters too about their experiences of what life is like for them.

- Looking at how your child's Education Health and Care Plan if they have one meets their needs.

Thank you for reading this information

Appendix 2: Information Booklet for parents and consent form

Research Study: Information Booklet for parents/carers

Having choice and control in decisions to help achieve a good quality of life.

My name is Carol Long, I am a self-funded PhD research student. I am based in the Department of Sociology within Durham University.

You are being invited to participate in a research project about families and their choices and the control they have in decision making for their child with a learning disability. Before you decide if you wish to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Feel free to ask me if there is anything that you do not understand, or if you would like more information.

Thank you for taking the time to read this Participant Information Booklet.

My research will consider how social policy, the law, and professionals support or create barriers in enabling families to achieve what they believe to be the right plans in life for their child with learning disabilities. Whilst considering the wider context, I will focus on;

How do parents and young people with learning disabilities exercise choice and control in decisions about the support they receive to achieve a good quality of life?

What is the research purpose?

This research seeks to develop new understandings of the lives, hopes, aspirations and contributions of children and young people with learning disabilities and their families. It seeks to understand how much choice and control families are able to exercise in decision making for their child to achieve a good quality of life. I will assess how this is then reflected in the formal Education Health and Care Plan(EHCP) for the child.

Our culture has some problematic ideas about disability and disabled people's lives, particularly the lives of children with learning disabilities and this can place limits on those children and young people in what society believes it is possible for them to achieve.

I will work with you with your agreement to gather oral histories of family life and how your child with special needs is supported within the family but also by external services. In working with children and young people with learning disabilities and their families, the research will be a space where disabled children and young people and parents can tell new stories of learning disability and describe their aspirations; narrating their own stories.

Through engagement with families, this research aims to offer opportunities for disabled children and young people and their families to speak about their lives just like anyone else and recognising they are also creative, fun, challenging, just like any family. It will also draw out what families would like to be different in the way they receive support as well as what they value. This is important because knowledge about life with a learning disability rarely comes from disabled children and young people or their families themselves.

The research will have four parts;

1. Talking to parent/s to gather their stories of their experiences of caring for a child with a learning disability within their family. What their hopes and aspirations are for the child and how they access support to enable these to be fulfilled.
2. With parental permission to talk to your son or daughter with learning disabilities about what they enjoy about life, and what is challenging and what choices they feel they have control over. Whilst I will seek consent from you as a parent to do this I will also ask for the young person's assent too. I will use arts materials and communication methods in our session/s that take into account your child's age and development.
3. With parental agreement and the consent/assent of your child's siblings I will ask brother/s and sister/s too about their knowledge of how their sibling with a learning disability is supported and what life is like for them as their siblings. (N.B. A sibling under 18 requires parental consent to participate. Over 18's can give consent for themselves)
4. I will seek with your agreement to analyse your child's Education Health and Care Plan to consider how their needs are assessed by professionals and what identified outcomes are included.

Why have I been chosen?

I want to invite parents of children and young people with learning disabilities who have an education health and care plan(EHCP), to participate either in their home or other safe space by describing their experiences of having a child with special needs within their family and the supports they receive and how they are involved by agencies in decision making for their child.

I am asking you to participate because you are a parent of a child with a learning disability who also has an EHCP.

Do I have to take part?

No, it is completely up to you whether you take part or not. Your participation in this research is entirely voluntary.

You will be asked to sign a consent form to say that you are happy to participate in the research. However, you can still change your mind and stop participating (also known as 'withdrawing'). You can with withdraw at any time, and you do not have to give a reason.

What do I have to do?

You will participate in between one and three one-on-one interviews known as biographical oral histories where you talk about your experiences of parenting a child with a learning disability, what supports have or have not been available to you and how much choice and control you feel you have in decision making to achieve a good quality of life for them.

You will be interviewed in your home or a place where you feel comfortable.

I would also like to talk to your son or daughter with a learning disability about their experiences and also with their siblings with their agreement. These sessions for younger siblings will be play based rather than oral history taking and for adult siblings interview based.

My sessions with your disabled son/daughter will be play based and age appropriate. I can answer any questions you have about this.

It will be me who will interview all members of the family who participate in the research. I have a professional background of working with children with a learning disability and their families although I am now a full time PhD researcher.

Will I be recorded, and how will the recorded media be used?

Our sessions will be filmed and recorded if you agree. The audio recordings made during this research will be used only for analysis and possibly for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the research will be allowed access to the original recordings.

Any data collected, in both written and digital formats, will be securely stored in either a locked cabinet or in Durham University cloud and password protected. This will be destroyed no later than 10 years after the conclusion of the project.

According to data protection legislation, and the General Data Protection Regulations (GDPR) I am required to inform you that the legal basis I am applying in order to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’ (Article 6(1)(e)).

For further information about the University's data protection and retention policy please see:

www.dur.ac.uk/research.innovation/governance/ethics/considerations/people/consent/privacynotice/

What are the possible disadvantages and risks of taking part?

I don’t foresee any significant disadvantages or risks in participating in this research. However, sometimes reflecting on our lives can be upsetting or distressing. You can take time out whenever you wish. You do not have to answer every question in our discussions; you have the right to say no to questions if you do not wish to answer them.

What will I gain from taking part?

Participating in oral history telling is a chance to tell your story and contribute to an important research project that aims to improve understanding of how the lives of young people with learning disabilities and their families can be better supported.

When we meet, I will discuss with you if you are happy for your comments to be attributed to you and I will also answer any questions you may have before we begin the interview. *As stated above you are free to withdraw from this process at any time and are free to refuse to answer any of the questions.*

If you decide to withdraw from the research, we will discuss what, if any, information attributed to yourself will be included in the research. Also, if you do participate in the research and there are particular things that you do not wish to be included, you can let me know and I will not refer to these when I write up the research.

What if something goes wrong?

If you feel something has gone wrong or would like to raise an issue/complaint, you can contact my supervisors Professor Simon Hackett or Dr Josie Phillips at Durham University.

Will my taking part in this project be kept confidential?

Your participation in this research will be kept strictly confidential. You will not be identified in any reports or publications when I write up the findings of the research. I will give you with your agreement a pseudonym(i.e., a fake name) in any write up about the research and in my PhD thesis. However, if you tell me something that worries me where your child is in danger or at serious risk, I might have to share it with someone else; such as a professional or someone you trust. I will let you know if I plan to do this.

Your data (your interview story) will only be shared with me as your interviewer, and my supervisory team as necessary to complete the requirements of my PhD and write up my thesis.

What will happen to the results/findings of the research project?

In the third year of my research (2020/21)I will be writing up my research in a report known as thesis which will then be reviewed by an exam board of the University of Durham. If my thesis is accepted it will be published in Durham's University e-library. I will be working in a variety of ways to make sure that my findings have impact – that they matter and are meaningful and relevant to the lives of children and young people with learning disabilities and their families. This could include attending conferences, training, and inputting into Government Consultations or Select Committees and publishing in journals amongst other things.

Who has ethically reviewed this research? This research has been ethically approved via the Department for Sociology at Durham University's ethics review procedure. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University. If you agree to participating in this research, please fill in the consent form provided and return it to me, Carol Long.

Research Consent Form for Parents .

I would be grateful if you would complete this consent form prior to being interviewed, thank you.

- I have read and understood the information sheet. YES/NO
- I agree to being interviewed and it being audio recorded. YES/NO
- I agree to my child being involved in the research providing they give assent where this is possible YES/NO
- I agree to my child's siblings being involved in the research providing they are willing to be part of it and give assent. YES/NO
- I understand that any recording will be stored securely and will not be used for any other purposes without my consent. YES/NO
- I am willing for interviews to be transcribed and extracts used in this research and in other materials such as reports and teaching. YES/NO
- I am willing for my child's Education and Health Plan to be analysed. Yes/No
- I wish to remain anonymous (that is, no views or comments will be attributed directly to me by name) YES/NO.
- If 'NO' to the above, I am happy for views or comments to be attributed directly to me by name YES/NO,
- I would like my name to be listed as a contributor to this research in the acknowledgments section of the PhD thesis or any other publications. YES/NO

Name……………………………………………………………………………………………..

Signature……………………………………………………………………………………...

Date……………………………………………………………………………………………...

Appendix 3: Schedule of questions in support of oral history sessions with parents

Guide for interviewer: Biographical interview/oral history. Prompts/potential follow up question Guide

(drawn from Wengraf's BNIM technique)

First session. Encourage free narrative. Starting script. Reiterate purpose of study and info in leaflet previously provided. Check still comfortable to proceed.

I'm collecting life histories for a research study about choices and control that families have in decision making for their child with a learning disability.

You have agreed to share your experiences and I want to hear these from your own individual perspective.

Please could you tell me your life history of being a parent to xxxx

Please take your time. We've got as much time as you need for this and start wherever you like it does not have to be in chronological order simply what you want to draw out.

I'll listen first, I won't interrupt you and I may take a few notes that I'll ask you questions about later. We have agreed I can also record the session so that I can transcribe it later and it will help me prepare for our next session to build on the themes that are important to you.

So can you tell me your life history of being xxxxs parent, the events and experiences that have been important to you up till now.

In subsequent second/third sessions pick up on main narrative points from first interview so any questions asked will be framed by this.

In addition, may draw out by using possible prompts framed around *who, what, when where and why/how questions.*

what is important to your family?

what for you is unique about your family?

Impact over time, what has changed?

Supports, what has made the difference?

How have people reacted to your family circumstances?

Hopes for the future/Concerns for future

Optimism/pessimism

Who makes the difference and why?

What would you change/keep?

Prompts (not all of these will necessarily be used)

Diagnosis

How/when did you know there were issues for your child?

When/how did you get a diagnosis?

What was the impact for the family?

What support was available

What did you understand as the future prognosis?

What reactions did you get from those around you, family and friends?

Impact

What has been the effect on the family over time?

What do you see as a good quality of life?

What new skills/expertise have you had to develop?

What do good times look like? what are the more challenging times? What do you enjoy, what frustrates you?

What are the attitudes you experience?

What would you change, what would you keep?

The future

What are your hopes and fears?

What would be the ideal scenario for your child, and for your family

How close to that do you believe is achievable?

What services were available to you, how did you find out about them and then how easy were these to access?

What information was available to you about future prognosis or issues.

Acclimatising

What would/does a good quality of life look like for your child (and for the family)

How close to your definition of a good quality life are your current circumstances

What has been the effect for the family day to day, and over time?/What has it meant for different members of the family?

What new skills/expertise have you had to develop?

Where do you get support from?

What have proved to be the main support networks available to you?

Which services/supports are most and least effective?

What do good times look like? what are the more challenging times? What do you enjoy, what frustrates you?

What are other people's attitudes towards your child? (professionals, other children, families, the public)

What are people’s attitudes towards you as parents?(professionals, friends and wider family, the public)

What would you change, what would you keep?

The future

How do you see the future?

What are your hopes for your child?(in 3-5 years? 8-10 years? Beyond 25 years of age)

What would you like to see happen for your child?

What would be the ideal scenario for your child, and for your family

How close to that do you believe is achievable?

What would need to be in place to meet your aspirations for your child?

How well does your child’s EHCP reflect your hopes?

Appendix 4 : Information leaflet for older/adult siblings and consent form

Research Study.

Title: Exercising choice and control in decisions to achieve a good quality of life

My name is Carol Long, I am a self-funded PhD research student at Durham University. I am based in the Department of Sociology within Durham University.

You are being invited as the sibling of a brother or sister with learning disabilities to participate in a research project about families and how support is provided to your sibling and the rest of the family. Before you decide, it is important for you to understand why the research is being done and what it will involve.

This leaflet summarises the aims of the research and seeks your agreement to participate.

Please take time to read the information carefully and discuss it with others if you wish. Feel free to ask me if there is anything that you do not understand, or if you would like more information. Thank you for taking the time to read this Participant Information Sheet.

My research will consider how social policy, the law, and professionals support or create barriers in enabling families to achieve what they believe to be the right plans in life for their child with learning disabilities. Whilst considering the wider context, I will focus on;

How do parents and young people with learning disabilities exercise choice and control in decisions about the support they receive to achieve a good quality of life for their child?

Why am I being asked to be involved?

As the brother or sister of a child with a learning disability who also has an education health and care plan, I am interested in your views of how your brother or sister is supported and about the services provided to your family. I am also interested in how this has affected you as a brother or sister of a child with a disability.

What is the research purpose?

This research seeks to develop new understandings of the lives, hopes, aspirations and contributions of children and young people with learning disabilities and their families and how much choice and control families are able to exercise in decision making for their child to achieve a good quality of life. I will assess how this is then reflected in the formal education health and care plan for your brother/sister.

The research will be in four parts:

- Collecting oral histories from parents about family life since the birth of their child with a disability.
- Talking to your brother/sister with learning disabilities through art-based sessions about what they enjoy about life, and what is challenging and where possible asking what choices they feel they have control over
- Asking brothers and sisters of the child with a disability too about their knowledge of how their sibling with a learning disability is supported and what life is like for them as their brother/sister .
- Analyse your brother's/sister's Education Health and Care Plan to consider how their needs are assessed by professionals and what identified outcomes are included.

The research will be a space where disabled children and young people and their parents and brothers and sisters can tell their stories of learning disability and describe their aspirations and how these are supported;

I will be taking notes and/or digitally recording the sessions. These records will be kept securely in a locked cabinet or digitally in the Durham University cloud which is password protected. Both the written and recorded, will be destroyed no later than 10 years after the conclusion of the project information

Further information regarding the data protection and retention policy of Durham University can be found at:
www.dur.ac.uk/research.innovation/governance/ethics/considerations/people/consent/privacynotice/

The information I collect will be used to inform my PhD research, write reports, and may be used for teaching and research training. My written PhD work may also include quotations from our meetings, but everyone will be anonymous throughout, that is, I will not attribute any views or comments to any name.

I am writing to ask if you are willing to be included in the research, and whether you as a sibling of a child with a learning disability agree to this.

If you change your mind part way through, and wish to withdraw from the research, this is OK and any notes which have already been taken we will discuss and agree what, if anything, is included in the research.

I have attached a consent form for you to fill in yourself and sign (if you agree) and return to me. If you would like further information, please contact me.

Thank you for considering being part of this research.

Carol Long

PhD Researcher, Durham University

Research Consent Form for Brother/Sister of Child with Disabilities .

I would be grateful if you would complete this consent form prior to being interviewed, thank you.

- I have read and understood the information sheet. YES/NO
- I agree to being interviewed and it being audio recorded as part of the research. YES/NO
- I understand that any recording will be stored securely and will not be used for any other purposes without my consent. YES/NO
- I am willing for interviews to be transcribed and extracts used in this research and in other materials such as reports and teaching. YES/NO
- I wish to remain anonymous (that is, no views or comments will be attributed directly to me by name) YES/NO.
- If 'NO' to the above, I am happy for views or comments to be attributed directly to me by name YES/NO,
- I would like my name to be listed as a contributor to this research in the acknowledgments section of the PhD thesis or any other publications. YES/NO

Name…………………………………………………………………………………………..

Signature………………………………………………………………………………………...

Date………………………………………………………………………………………….....

Appendix 5:format for semi-structured interviews with adult siblings

Indicative questions for adult sibling interviews

Information booklet sent in advance. Consent form to be received in advance.

Mode of meeting explained: On line, Zoom technology. Check this is available to interviewee

Agree in advance cameras on or off.

Email confirmation of meeting date and time in addition to Zoom invitation

Any particular considerations need to be aware of (disabilities, things to avoid, length of time available etc)

Introductory script.

Brief recap of key info. Introduce self again. This is a PhD study focused on quality of life for families who have a learning disabled family member (son or daughter). What has been the impact for family.

Participation is entirely voluntary. Can stop session at any time, can ask for breaks. Have some pre-set questions but these are to provide some structure to discussion, participant can develop the conversation to cover things that matter to them.

Meeting will be recorded and later transcribed. All information will be safely stored and will be anonymous. What is discussed will not be shared with other family members.

Check levels of comfort and confirm happy to proceed. Check any time limits or other constraints from the outset.

Questions for semi structured format.

To be used as a guide, not all questions may apply or be appropriate to the actual discussion.

The present

Can you tell me a bit about yourself, your interests etc. (encourage introductory remarks about themselves to provide context)?

Can you tell me about your brother/sister and your family?

This study is about quality of life what does the term quality of life mean to you/your family?

What have been the things over the years that you have enjoyed doing together as a family?

What are the things that you haven't been able to do?

How close to your definition of a good quality life are your current circumstances?

What has been the effect for the family day to day, and over time?/What has it meant for different members of the family?

What new skills/expertise do you think you have had to develop?

Where do you get your support from?

The future

How do you see things in the future for your sibling?

How do you see things in the future for yourself?

How do you see things in the future for the rest of your family; parents other siblings?

What are your hopes and aspirations for yourself, for your sibling/s? for your parents?

Impact

What have you learned in growing up in a family with a disabled sibling?

Prompts: professionals, in the community, friends and wider family

What supports do you think have been available to your family/sibling/you when things have been challenging?.

What supports do make a difference?

What supports could make a difference?

Are there barriers that get in the way for your sibling, also the family?

(If appropriate) how does it make you feel experiencing what you have described?

How has Covid affected your family? You? Your sibling? Your parent/s?

Attitudes

How do you find others respond to your sibling/ you/your family?

(*Prompts: explore re people they know, family, friends, community, professionals, as well as strangers responses when out and about)*

What can be learned from your experiences of how others respond to Disability?

(*Prompts Explore behaviours as well as language, media coverage, written, social media)*

Concluding remarks

Anything else you would like to say?

What do you think is important for others to understand about disability?

End of interview

Check interviewee is Ok?

Check if another meeting would be helpful.

Thank them and reiterate what happens next particularly with their info.

Appendix 6: Information leaflet for learning disabled child and consent form.

Information for young people about being part of a research study. Your Mum, Dad or carer will go through this with you.

If you need help to read this, you could ask:

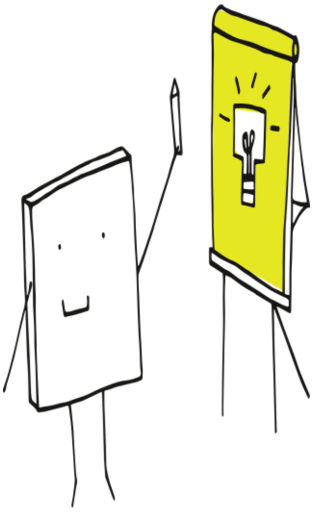
- Your Mum or Dad
- Someone in your family.
- A friend or carer.

This easy read summary will:

- Tell you who I am
- Tell you about a research project I am doing which looks at how families and children with a learning disability get help and support and how much choice they have.

(Research is a careful study to find out answers to important questions)

- It explains how the research will work
- It explains how you can take part, but only if you want to.
- It explains what happens to the information I collect



How will the research work?

My name is Carol Long, I am a PhD research student at Durham University.

I am studying what choices families and children with learning disabilities have about the support and help they get so that they can enjoy life.

As part of my study families will be able to tell their stories and be able to talk about their hopes and wishes for the future.

This will be done by

- Collecting stories from your Mum and Dad about family life.
- Talking to you about what you enjoy about life, and what is difficult and what choices you feel you have
- Asking your brothers and sisters too about what life is like for them.
- Reading your Education Health and Care plan to understand what help you and your family are given.

What happens next?

If you and your mum and dad agree I will visit you at your home or in a place you would prefer, or we will meet online, and I will talk to you, about;

- your world
- what you do,
- what you think is going well
- what you think is not going well

We will use play and art materials and make pictures to help you share your views.

We will meet once or twice and you can have somebody with you too if you want, like your mum, or dad or brother or sister.

After we have finished you can keep a photo of your picture

Why do you want to write up my story and my family's stories?

By collecting stories about lives of families with children who have a disability we can learn what their hopes and dreams are,

This can help others like teachers and doctors and social workers to think about the best ways to help the families to achieve these.

What happens to the information from our stories ?

The information I collect will be used in my research, sharing the stories I hope will mean we can learn more about what help families need sometimes

- I will write up my research into something called a thesis
- I may use the stories I collect for teaching others
- I may include things you tell me in my writing, but your name will not be given, so nobody will know it was you who said it.

How will you keep our stories safe?

If you agree I will record or film our sessions and that will help me to write them up later so that I can include them in my research.

The notes and films that I make will be kept locked safely in a cabinet at Durham University

	If I keep anything digital, it will be password protected and stored safely and securely Any written, recorded, or filmed information, will be destroyed no later than 10 years after my research is finished.
Yes NO	**What if I don't want to be involved?** You don't have to be! It is fine. Just tell me or your Mum or Dad Even if you agree now you can still change your mind later.
✓ ✓	**What do I do if I want to be part of the study?** I have attached a form for you to sign (if you agree) and your mum or dad or carer can return it to me. I also need your Mum, Dad or carer to agree too and sign a form giving their agreement, which we call consent. If you would like further information, you or your mum or dad or carer can contact me by email or telephone. Carol.m.long@durham.ac.uk
😉	**Thank You for reading this guide**

Assent Form

I would be grateful if you would complete this agreement form with your Mum , Dad or carer prior to us meeting, Thank you!

- I have had the information sheet read to me by my parent/carer and agree to be part of the research study Yes/No
- I understand I can stop being part of the study at any time Yes/NO
- I agree to written notes being taken and/or audio recorded. YES/NO
- I understand that the recording will be stored safely and will not be used for any other reason without my agreement. YES/NO
- I am willing for the meeting to be written up and extracts used in this study. YES/NO

- I understand that I will not be named when the research is written up, and no views or comments will identify me. YES/NO
- I would like my name to be listed in the acknowledgements(thank you) section of any publications as a contributor to this study YES/NO

Name………………………………………………………………………………………….

Signature…………………………………………………………………………………….

Date…………………………………………………………………………………………….

Name of person taking consent   Signature   Date

Address………
………

Parental Consent

I would be grateful if you would complete this consent form prior to me meeting your son/daughter to talk about their views about the support that they get. Thank you.

- I have read and understood the information sheet provided for my child. YES/NO
- I agree to written notes being taken of sessions with my child and/or audio recorded. YES/NO
- I understand that recordings will be stored securely and will not be used for any other purposes without my consent. YES/NO
- I am willing for the meeting/session to be transcribed and extracts used in this research and in other materials such as reports and teaching. YES/NO
- I understand that neither I nor my child will be named when the research is written up, and no views or comments will be directly attributed to me or my child. YES/NO
- I would like my name and my child’s name to be listed in the acknowledgements section of any publications as a contributor to this research. YES/NO

Name………………………………………………………………………………………….

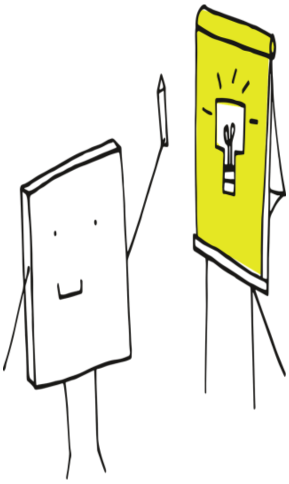
Signature…………………………………………………………………………………….

Date…………………………………………………………………………………………….

Address………
………

Appendix 7:

***Information for brothers and sisters about being part of a research study.* (Your mum, dad or carer will go through this with you).**

	**If you need help to read this, you could ask:** • Your Mum or Dad • Someone in your family. • A friend or carer.
	**This easy read summary will:** • Tell you who I am • Tell you about a research project I am doing which looks at how families and children with a learning disability get help and support and how much choice they have. (Research is a careful study to find out answers to important questions) • It explains how the research will work • It explains how you can take part, but only if you want to. • It explains what happens to the information I collect
	**How will the research work?** My name is Carol Long, I am a PhD research student at Durham University. I am studying what choices families and children with learning disabilities have about the support and help they get so that they can enjoy life. As part of my study families will be able to tell their stories and be able to talk about their hopes and wishes for the future. This will be done by • Collecting stories from your Mum and Dad about family life. • Asking you as a brother or sister about what life is like for you and what you think it is like for your disabled sister or brother . • Reading your brother or sister's education health and care plan to understand what help they and your family are given.

I am asking you if you would be part of this research as the brother or sister of a child with a learning disability and talk to me about your life and the choices you can make.

What happens next?

If you and your mum and dad agree I will visit you at your home or in a place you would prefer, or we will meet online, and I will talk to you, about;

- your world
- your disabled brother or sister's world
- what you think is going well
- what you think is not going well

We will use play and art materials and make pictures to help you share your views

I will visit you once or twice if you agree

After we have finished you can keep a photo of your picture

Why do you want to write up my story and my family's stories?

By collecting stories about lives of families with children who have a disability, including the stories of their brothers and sisters we can learn what their hopes and dreams are,

This can help others like teachers, doctors and social workers to think about the best ways to help the families to achieve these.

What happens to the information from our stories ?

The information I collect will be used in my PhD research, sharing the stories I hope will mean we can learn more about what help families need sometimes.

- I will write up my research into something called a thesis
- I may use the stories I collect for teaching others
- I may include things you have told me in meetings in my writing, but your name will not be given, so nobody will know it was you who said it.

How will you keep our stories safe?

If you agree I will record or film our sessions and that will help me to write them up later so that I can include them in my research.

	The notes and films that I make will be kept locked safely in a cabinet at Durham University If I keep anything digital, it will be password protected and stored safely and securely Any written, recorded, or filmed information, will be destroyed no later than 10 years after my research is finished.
Yes NO	What if I don’t want to be involved? You don’t have to be! It is fine. Just tell me or your Mum or Dad or carer Even if you agree now you can still change your mind later.
✓ ✓	What do I do if I want to be part of the study? I have attached an agreement form for you to sign (if you agree) and return to me. I also need your Mum, Dad or carer to agree too and sign a form giving their consent. If you would like further information, please contact me. Carol.m.long@durham.ac.uk
😉	**Thank You for reading this guide!**

Assent Form

I would be grateful if you would complete this agreement form with your Mum , Dad or carer prior to us meeting, Thank you!

- I have had the information sheet read to me by my parent/carer and agree to be part of the research study Yes/No
- I understand I can stop being part of the study at any time Yes/NO
- I agree to written notes being taken and/or audio recorded. YES/NO
- I understand that the recording will be stored safely and will not be used for any other reason without my agreement. YES/NO
- I am willing for the meeting to be written up and extracts used in this study. YES/NO
- I understand that I will not be named when the research is written up, and no views or comments will identify me. YES/NO
- I would like my name to be listed in the acknowledgements(thank you) section of any publications as a contributor to this study YES/NO

Name………………………………………………………………………………………

Signature…………………………………………………………………………………..

Date…………………………………………………………………………………………..

Name of person taking consent	Signature	Date

Address………
……

Parental Consent Form

I would be grateful if you would complete this consent form prior to me meeting your son/daughter to talk about their views about the support that they get. Thank you.

- I have read and understood the information sheet provided for my child. YES/NO
- I agree to written notes being taken of sessions with my child and/or audio recorded. YES/NO
- I understand that recordings will be stored securely and will not be used for any other purposes without my consent. YES/NO
- I am willing for the meeting/session to be transcribed and extracts used in this research and in other materials such as reports and teaching. YES/NO
- I understand that neither I nor my child will be named when the research is written up, and no views or comments will be directly attributed to me or my child. YES/NO
- I would like my name and my child's name to be listed in the acknowledgements section of any publications as a contributor to this research. YES/NO

Name…………………………………………………………………………………………….

Signature……………………………………………………………………………………….

Date……………………………………………………………………………………………..

Address………
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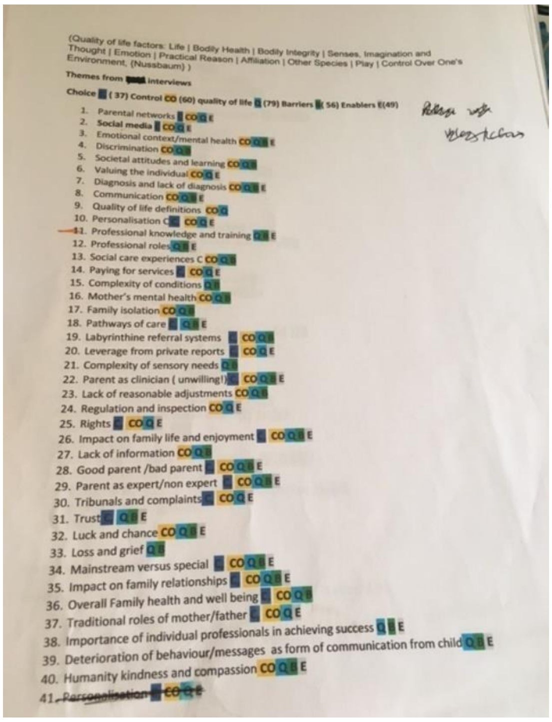
Appendix 8: Photographs evidencing approach to data analysis and coding

Examples below of data Coding: There were 1600 codes in total across all parental and sibling interviews.

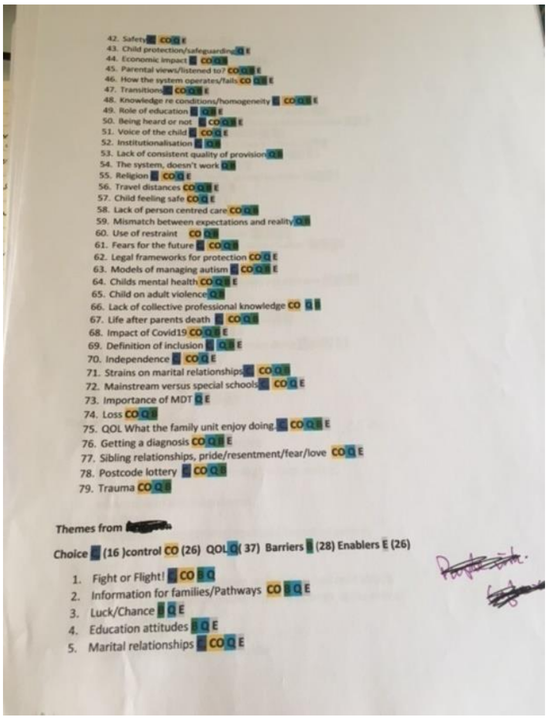


(Quality of life factors: Life | Bodily Health | Bodily Integrity | Senses, Imagination and Thought | Emotion | Practical Reason | Affiliation | Other Species | Play | Control Over One's Environment, (Nussbaum))

Themes from [redacted] interviews

Choice C (37) Control CO (60) quality of life Q (79) Barriers B(56) Enablers E(49)

1. Parental networks C CO Q E
2. Social media C CO Q E
3. Emotional context/mental health CO Q B E
4. Discrimination CO Q B
5. Societal attitudes and learning CO Q B
6. Valuing the individual CO Q E
7. Diagnosis and lack of diagnosis CO Q B E
8. Communication CO Q B E
9. Quality of life definitions CO Q
10. Personalisation C C CO Q E
11. Professional knowledge and training Q B E
12. Professional roles Q B E
13. Social care experiences C CO Q B
14. Paying for services C CO Q E
15. Complexity of conditions Q B
16. Mother's mental health CO Q B
17. Family isolation CO Q B
18. Pathways of care C Q B E
19. Labyrinthine referral systems C CO Q B
20. Leverage from private reports C CO Q E
21. Complexity of sensory needs Q B
22. Parent as clinician (unwilling!) C CO Q B E
23. Lack of reasonable adjustments CO Q B
24. Regulation and inspection CO Q E
25. Rights C CO Q E
26. Impact on family life and enjoyment C CO Q B E
27. Lack of information CO Q B
28. Good parent /bad parent C CO Q B E
29. Parent as expert/non expert C CO Q B E
30. Tribunals and complaints C CO Q E
31. Trust C Q B E
32. Luck and chance CO Q B E
33. Loss and grief Q B
34. Mainstream versus special C CO Q B E
35. Impact on family relationships C CO Q B E
36. Overall Family health and well being C CO Q B
37. Traditional roles of mother/father C CO Q E
38. Importance of individual professionals in achieving success Q B E
39. Deterioration of behaviour/messages as form of communication from child Q B E
40. Humanity kindness and compassion CO Q B E
41. ~~Personalisation C CO Q E~~



42. Safety C CO Q E
43. Child protection/safeguarding Q E
44. Economic impact C CO Q B
45. Parental views/listened to? CO Q B E
46. How the system operates/fails CO Q B E
47. Transitions C CO Q B E
48. Knowledge re conditions/homogeneity C CO Q B E
49. Role of education C Q B E
50. Being heard or not C CO Q B E
51. Voice of the child C CO Q E
52. Institutionalisation C Q B
53. Lack of consistent quality of provision Q B
54. The system, doesn't work Q B
55. Religion C CO Q E
56. Travel distances CO Q B E
57. Child feeling safe CO Q E
58. Lack of person centred care CO Q B
59. Mismatch between expectations and reality Q B
60. Use of restraint CO Q B
61. Fears for the future C CO Q B
62. Legal frameworks for protection CO Q E
63. Models of managing autism C CO Q B E
64. Childs mental health CO Q B E
65. Child on adult violence Q B
66. Lack of collective professional knowledge CO Q B
67. Life after parents death C CO Q B
68. Impact of Covid19 CO Q B E
69. Definition of inclusion C Q B E
70. Independence C CO Q E
71. Strains on marital relationships C CO Q B
72. Mainstream versus special schools C CO Q E
73. Importance of MDT Q E
74. Loss CO Q B
75. QOL What the family unit enjoy doing C CO Q B E
76. Getting a diagnosis CO Q B E
77. Sibling relationships, pride/resentment/fear/love CO Q E
78. Postcode lottery C CO Q B
79. Trauma CO Q B

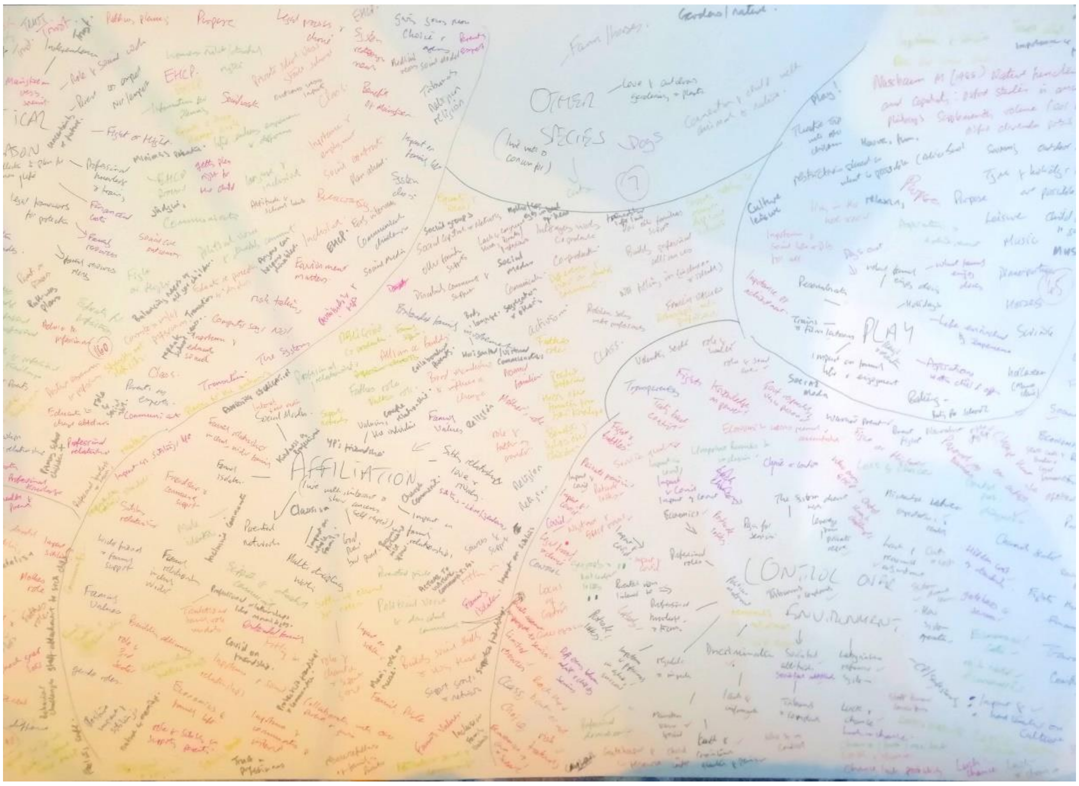
Themes from [redacted]

Choice C (16)control CO (26) QOL Q(37) Barriers B (28) Enablers E (26)

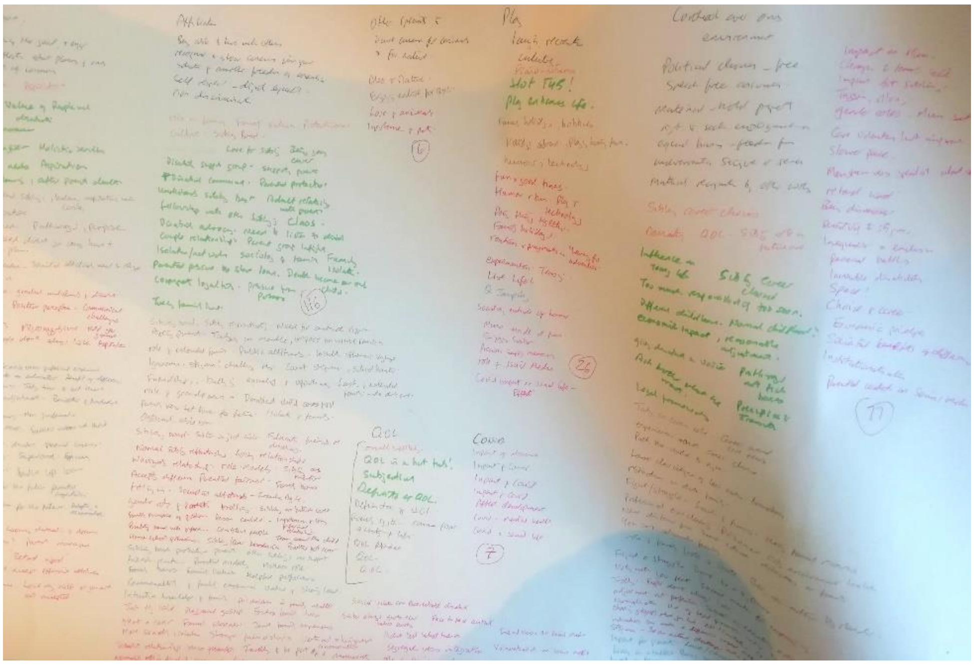
1. Fight or Flight! C CO B Q
2. Information for families/Pathways CO B Q E
3. Luck/Chance B Q E
4. Education attitudes B Q E
5. Marital relationships C CO Q E

1. **Photographic examples (below) matching data codes to quality of life frameworks. These were done manually using colour coding for different families.**

a) **Example of matching parent codes to capabilities framework.**

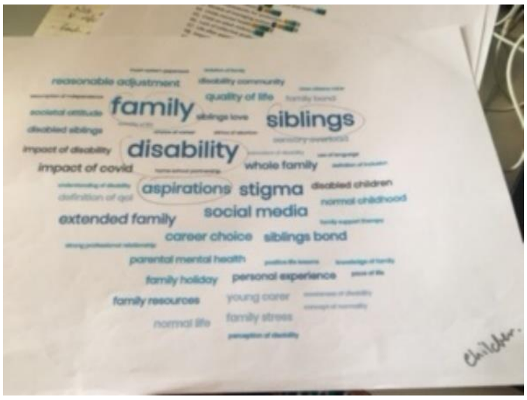


a) Example of matching sibling codes to capabilities framework



2. Word cloud (below) indicating emphasis within identified themes from parental codes.

3. Word cloud (below) indicating emphasis within identified themes from parental codes.



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