Siblings' Experience of Intellectual Disabilities:

An Interpretative Phenomenological Study

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ABSTRACT

Children and young people (C&YP) with intellectual disabilities (ID), and their families, are likely to require support to a lesser or greater degree, across their life course, therefore, it is important for families and those supporting them, to have an optimised understanding of the experience of ID, for all family members. The potential lifelong nature of sibling relationships amplifies the importance of awareness and understanding of siblings' unique experience (Cicirelli, 1995; McHale et al., 2012; Seligman & Darling, 2007; Stoneman, 2005). Previous research tended to rely on reports from others, such as parents and teachers (Mandleco & Webb, 2015). More recent research sought to engage siblings' views directly; however, this remains an underrepresented body of work, particularly for children, adolescents and young people. Different methodological approaches have produced a diversity of results, leaving gaps in the broader understanding of siblings' lived experiences of ID. By privileging the authenticity of sibling participants' accounts, it was hoped that an enhanced understanding of siblings' experience of intellectual disabilities would emerge, adding to the existing body of knowledge. Siblings' experience of ID was explored within their familial and wider context, thereby informing more individualised, appropriate and timely support for siblings who have a brother or sister with intellectual disabilities, and their families.

A literature review was conducted and the research adopted a qualitative approach, two theoretical frameworks underpinned the study, siblings' experience and context were explored through the paradigms of family systems theory (Priest, 2023) and Bronfenbrenner's bioecological theory (Bronfenbrenner & Morris, 2006; Greene & Hogan, 2005; Hayes et al., 2017, 2022). Interpretative phenomenological analysis (IPA) was the chosen methodological approach, (Smith et al., 2022). IPA was considered appropriate in addressing the research question and attending to siblings' experience as the primary source of data recognising their

direct experience is not easily accessed, acknowledging context and providing a means to support sense making of the data. Potential researcher bias and personal influences as a parent, a nurse, lecturer and researcher were integral considerations with a reflexive approach adopted throughout.

Nine children and young people between the ages of 11 and 16 years with a sibling with ID domiciled in the UK participated. Semi-structured interviews were conducted as a participatory approach, gaining insight into the siblings' experiences. A step by step analysis of the interview data was conducted, and individual themes identified from each transcript. Patterns of convergent (shared) and divergent (unique) experiences for all participants' was explored, (Smith et al., 2022). Nine master themes emerged: (1) *Knowledge, understanding and support; (2) valuing sibling relationships; (3) context outside the family; (4) becoming aware of intellectual disabilities, age, birth order and growing maturity; (5) sense of agency, compromise, power and loss; (6) family impact and coping strategies; (7) insight, vulnerability, loss of childhood, changed family relationships; (8) the future; (9) culture, and having a faith.* Emergent themes were discussed, supported by transcript quotations, providing authenticity of the results, connected directly with the data. A synthesis of the C&YP's experiences, themes from the literature review, and further interpretation was offered in the discussion.

The conclusions highlighted the individual, reciprocal and interconnectivity of siblings' experience of ID, with and within their families. This study offers valuable insight for siblings, their families and those supporting them, informed by siblings' self-accounts. There are clear indictors for those supporting C&YP to be attentive to siblings' need for individualised assessment and support, mindful of multiple variables for them, and their families, recognising

therein, siblings' unique capabilities, resilience and insight, with agency to inform their own and the wider needs of their families.

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CHAPTER ONE: INTRODUCTION

1.0 Overview

This thesis is based on a qualitative study exploring children and young people's (C&YP), experience of having a brother or sister with intellectual disabilities (ID). The participants are C&YP ranging in age from 11-16 years, (three boys and six girls).

Chapter one introduces the motivation and drivers that have inspired my interest in conducting this research, while undertaking a degree of Doctor of Philosophy (PhD) study at the University of Hertfordshire. The research aims are identified, definitions of the term intellectual disabilities and family are offered, with socio-political influences and contextual factors related to the study introduced. A context of interconnected experience within families, and theoretical frameworks underpinning this research are presented. Factors informing the development of the research question, epistemological positioning, choice of research design, methodological approach and method of data analysis are proffered. Finally, a brief outline is presented of the subsequent six chapters, introducing the reader to the content of the thesis.

1.1 Aims of the study

This research aims to explore siblings' experience of ID in the context of their familial relationships, in a family who have a child or young person with ID. The study aspires to gain knowledge elicited through siblings' shared insights of their day-to-day life, interpretating their sense making, towards greater understanding of their experience and the impact on them, their siblings with intellectual disabilities and their families, (Smith et al., 2022). This study ultimately aspires to contribute to the body of knowledge available to non-familial services, informing future policy and practice and enhancing professionals' insights towards positively

impacting support offered to siblings who have a brother or sister with ID, and their families, (Finlay, 2011; Greene & Hogan, 2005; Smith, 2015).

The following section provides a brief introduction to my professional and personal interest and wider contextual and motivational factors influencing my engagement with, and the focus of this research.

1.2 Personal and professional context

My personal and professional background is inextricably linked to my motivation and drive to extend my understanding of ID, and more specifically explore siblings' experience of ID. Chapter two provides a more comprehensive reflexive account of my personal context. However, in summary, my interest comes from a lifetime of engagement with people with ID and their families, including from the personal stories within my own family. Multiple identities as a mother of a young person with intellectual disabilities, as a relative, my evolving career as a nurse working with people diagnosed with ID, systemic psychotherapy practitioner, academic lecturer and researcher all play a part in the evolution of my interest, contributing to my knowledge and heightening my curiosity to learn more.

Over time, I have developed an acute awareness of the reality and potential for discrimination, misunderstanding and mis, or lack of representation experienced by people with ID, and their families. These experiences have in part influenced my career choices and driven me to champion equity and inclusivity in my work and personal life. I recognise that many people with ID and their families do not have the opportunity, ability or access to the appropriate support or advocacy to represent themselves. Families continue to share stories of challenges in navigating support services and systems as they endeavour to gain appropriate support for

their child with ID, themselves and the wider family, (Hastings et al., 2020). In my work, and as an advocate, I endeavour to use my agency to enable their 'voices' to be heard. While engaging with people with ID and their families in both personal and professional relationships, particularly when supporting transitional points in their lives, sibling relationships have come to the fore as being important to consider. This is particularly relevant for their life stage connection as brothers and sisters, the potential longevity of their relationships with shared experiences and mutual influence over their lifetime, (Cicirelli, 1995; Hayden et al., 2023; McHale et al., 2012; Seligman & Darling, 2007). From my previous experience and supported by the literature review conducted for this study, (see chapter 3) there is an apparent lack of siblings' direct accounts of their experience of ID, with findings suggesting that their perceived experience as siblings may differ significantly to the perceived views of their parents and other adults around them, (Benderix & Sivberg, 2007; Giallo & Gavidia-Payne, 2006). This highlights the importance of undertaking studies such as this, that bring siblings' perspectives to the fore as a further dimension to inform the whole family's experience of ID.

Therefore, a core principle of this study was to access siblings' lived experience of ID from their self-represented accounts. By foregrounding the voices of siblings' themselves, valuing their unique perspectives, challenging my own assumptions and potential biases, it was hoped greater insight and understanding would emerge. The aim is in growing not only understanding, but also further enhancing my knowledge and that of others to better advocate for and represent the 'voices' of siblings and their families who have C&YP with ID.

1.2.1 Wider context of the study

This study was undertaken in England related to practical considerations given the geographical location of my home and work, and in undertaking this research as part of a part-

time Doctor of Philosophy programme of study at a University in the East of England, (this is further discussed in chapter 3). It is important to acknowledge this context from the outset as while efforts were made to consider broader socio-cultural factors in conducting the study and the literature review, much of the available research has historically been undertaken in the developed western world or the global north (Hayden & Hastings, 2022:35). This has an impact on the breadth and diversity of the literature available, as well as the scope and application of the research. Western constructs therefore had an influence on the definitions, theories and approaches explored in this study. As the participants were a purposive cohort of C&YP domiciled in the United Kingdom (UK), this does relate to their context and aligns to the philosophical underpinnings of this research i.e., to preference the voice and lived experience of ID for a purposive cohort of siblings in England.

The following section provides a definition of the term intellectual disabilities as applied to this research. The significance of the population of C&YP with ID in the UK is introduced, developing the rationale for the importance of exploring siblings' experience of ID as the focus of this study.

1.3 Population and rationale for the study

There is broad debate regarding the population encompassed in the definitions used to describe intellectual disabilities, (ID). This is further discussed in chapter 3. In the UK the term intellectual disabilities and learning disabilities (LD) are often used interchangeably and by different groups. It is recognised that intellectual disabilities is becoming the more widely accepted term internationally (NICE, 2015). For the purposes of this study the term intellectual disabilities will be used throughout referring to ID and LD, defined as:

> *"The presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development,* (DH, 2001).

It is difficult to ascertain the exact population of people with ID in the UK. Drawing on data from the Office for National Statistics (2024) and Public Health England (2015), Mencap estimated approximately 2.16%, 1.2 million of the population of adults, and 2.5%, 349,000 of the population of children in the UK, have ID. Of this population, 297,000 are children in England aged between 0 to17 years (Mencap UK, 2024). Estimates are drawn from several sources, including the number of children in receipt of a special educational needs assessment (SEN), or an education health and care plan (EHCP), and children with a primary special educational needs who do not have a SEN assessment or EHCP. The EHCP population is also estimated given that the population of children who are not in education, those who are educated at home, or those in other educational support are outside the scope of this data collection. The data also focused on school age children so does not constitute the whole population, e.g., pre-school children or those in mainstream education without a diagnosis, those potentially misdiagnosed in other services are also omitted. Therefore, while the exact population of C&YP with ID is hard to define, the data nonetheless points to a significant population of C&YP with ID in the UK indicating this may well be significantly underrepresented.

1.3.1 Siblings with a brother or sister with intellectual disabilities

Given the challenge of identifying the population of C&YP with ID, it follows that data available to identify those who have typically developing siblings is equally hard to define and

likely underestimated. The organisation Sibs UK, a charity offering support and advice to C&YP, families, carers and professionals involved in supporting people with ID, estimated that there were over half a million siblings of children with disabilities in the UK, 5.1% of whom were under the age of 16 years (Sibs UK, 2014). Previous authors have estimated that 80% of children with disabilities have non-disabled siblings (Burke, 2004). While this is more historical data, with better health care interventions for associated health conditions it is likely the population of C&YP with ID will remain significant and their relationships within their families, including with their typically developing siblings will be even more important to understand given the longevity of siblings' relationships. Authors have noted the potential interdependence of the sibling relationship related to future care and support needs and this further highlighted the importance of understanding and learning more about siblings' experience of ID (Hayden et al., 2023).

Research exploring typically developing siblings' experience of ID has often relied on parents or teachers accounts and interpreted perspectives and not informed through the voice and perception of the siblings' themselves (Mandleco & Webb, 2015; Moyson & Roeyers, 2012). More recent studies have engaged siblings direct accounts; however, results vary with studies reporting both positive and less favourable effects and experience for typically developing siblings (Aksoy & Bercin Yildirim, 2008; Cuskelly & Gunn, 2006; Giallo & Gavidia-Payne, 2006; Kaminsky & Dewey, 2002). Authors consistently suggest a need and value in conducting further research drawing from siblings' self-accounted experience, given findings often differed significantly to the interpretation and expressed views of their experience elicited from their parents and other adults' reports (Mandleco & Webb, 2015). This is more comprehensively discussed in chapter three (Literature review). C&YP are the experts of their own lives and should be given the opportunity to participate in and inform research (Burke,

2008; Christensen & James, 2008; James & James, 2004; James & Prout, 2003, 2015). Adopting this perspective validated the importance of conducting the current research study, that is to better understand siblings' experience of ID through a mechanism of research that enables access to their direct individual accounts.

The following section outlines policy supporting the rights of C&YP to express their views and agency, relating this to the epistemological position informing the approach chosen in undertaking this research.

1.4 Epistemology, rights, and agency, of children and young people

The United Nations (UN) Convention on the Rights of the Child Article 12, articulates a child's right to participate in the decisions made about them (UNICEF, 1989). The principles recognise C&YP's rights to self-representation and acknowledge their capabilities, capacity and agency. The UN embeds C&YP's rights to have their experience acknowledged, their perceptions and opinions heard and for these to be considered in the decisions made that affect their lives and that of their families. The approach adopted in undertaking this research was fundamentally influenced by an epistemological position of valuing C&YP, championing their rights and agency, with a foundational interest for this study of exploring typically developing siblings' experience of ID by specifically engaging their direct accounts. This is further expanded and discussed in Chapter four (Method).

The following section further frames the context of this research exploring siblings' experience of ID within the family unit and introduces core theoretical frameworks underpinning the study.

1.5 The family context and core theoretical frameworks

When we are born the family is our primary unit of association. It is reasonable to consider that our identity, beliefs and development are embedded in our experiences within this primary group, with a shared past, present and future, (Carter & McGoldrick, 2005; Cicirelli, 1995; Seligman & Darling, 2007). While recognising that not every person is supported or remains in their primary family of origin, nonetheless for most of us the family unit or the absence of it, has a lifelong influence in shaping who we are, establishing our beliefs, how we engage with one another, influencing us into adulthood, and in our interactions with wider society. Different cultures, beliefs, ideologies and discourses of the society and the time in which we live also impact our experiences, further defining us as individuals within the constructs of our families (Dallos & Draper, 2010).

While it is acknowledged that family structures differ, the foundations of our early experiences embedded in family life, whether positive or averse are important to attend to, given the impact on our development (Cicirelli, 1995; Seligman & Darling, 2007). Seligman and Darling (2007) described the family as being made up of sub-systems one of which is the sibling sub-system. They highlighted the sibling relationship as the first peer group noting the fundamental nature of siblings' early experiences coupled with the potential longevity of their relationships (Hayden et al., 2023; Seligman & Darling, 2007). Primary understanding of siblings' experience in this sub-system rests with the C&YP themselves, emphasising the rationale for conducting this research to explore siblings' experience towards a greater understanding of their individual lived experiences.

The participants in this study all resided in their parental homes with one or more of their parents. Their family was their primary unit of support within which they were part of a sub-

system, i.e., having a sibling with intellectual disabilities. While the aim of this study was to explore siblings' experience of ID and to preference the sibling voice, this was inevitably influenced and embedded within the multiple sub-systems and experiences within their family and could not be viewed in isolation. It was this consideration that influenced the paradigms and theoretical frameworks chosen to underpin this study. These are outlined in the following sub-sections of this chapter and explored in more depth in chapter three the literature review, informing the discussion in chapter six the discussion, and throughout.

1.5.1 The paradigm of family systems

Within the family system the concept of family life cycle refers to the integral and evolving nature of experience for families as they navigate their individual and shared lives, respond to change, adapt to transitions and the cycle of family life (Carter & McGoldrick, 2005; Cridland et al., 2014). The need for adaptation is integral to all families, and not exclusive to those with children with ID. However, having a child with ID is not a planned circumstance adding an unexpected dimension to the introduction of a new member of the family, someone who may require additional support, this may bring different considerations for everyone in the family (Carter & McGoldrick, 2005; Seligman & Darling, 2007). It follows that ID will inevitably influence how the family and individuals therein collectively navigate their life course together (Carter & McGoldrick, 2005; Dallos & Draper, 2010; Priest, 2023).

It is through these interactions and negotiations with one another and the world around them that family relationships are formed, interconnections evolve, with potentially more complexity over time e.g., as children grow and as more members of the family arrive, or changes to the family structure occur. Family negotiation through their life cycle establishes personal beliefs and influences familial interactions, establishing their internal rules and how they negotiate,

with all this being framed within their social, cultural and spiritual contexts. Family beliefs, rules, tasks, roles and responsibilities are identified, issues of power and intimacy are navigated, boundaries are established, and shared understandings emerge ultimately giving the family its identity (Dallos & Draper, 2010:8). A family systems approach acknowledges this cycle of experience over time.

For this study, siblings' experience of ID is interconnected, embedded in the C&YP's relationships with their brothers and sisters with ID, with their parents and in the context of their interactions with their wider systems (Hayden et al., 2023; Priest, 2023). Considering the siblings' shared navigation of life experience, the paradigm of family systems theory was therefore identified as a valuable theoretical framework to inform and support this study.

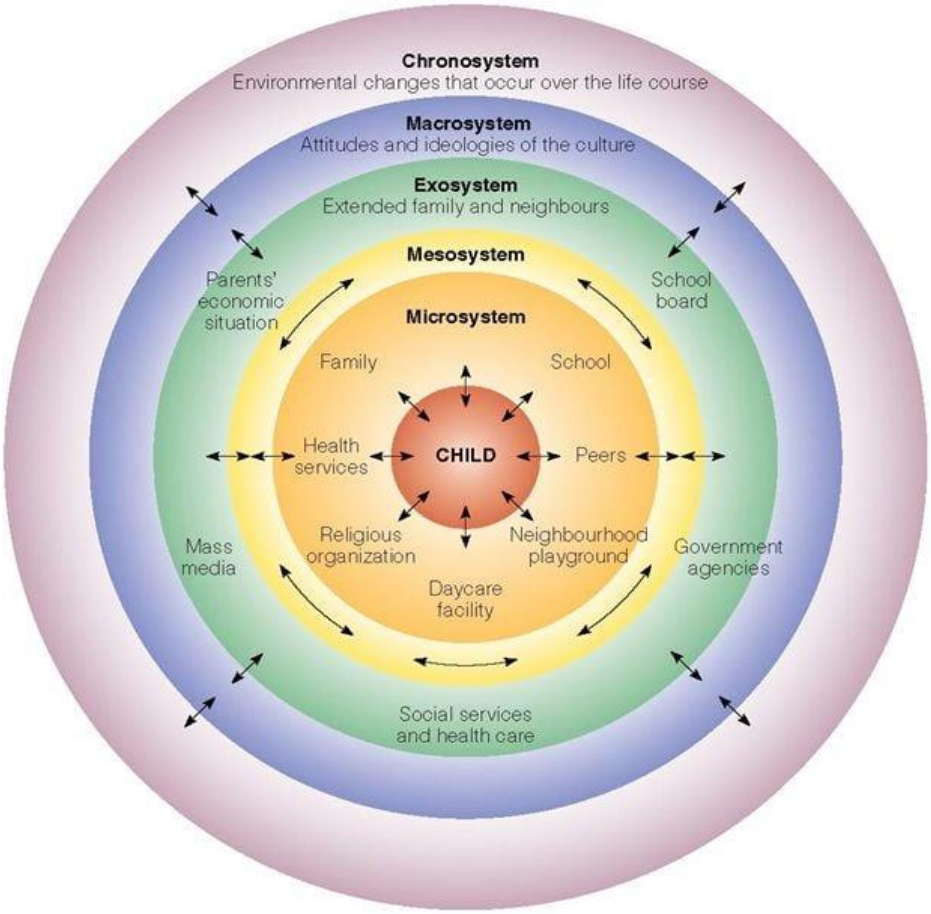
1.5.2 The paradigm of Bronfenbrenner's bioecological model of human development

In further considering the interconnectedness of siblings' experience within their family, Bronfenbrenner's bioecological model of human development (Bronfenbrenner & Morris, 2006; Hayes et al., 2017, 2022) offered an additional and valuable theoretical lens to frame the approach to the study, exploring siblings' experience of ID, (see figure 1.1). Bronfenbrenner's bioecological model described several systems within which the C&YP are as he termed it, nested as they develop. The model identified five systems. Firstly, the microsystem, related to this study in considering siblings relationships within their primary unit of the family. The mesosystem considers the interconnection between microsystems e.g., the family and their wider support systems, schools, support groups and considering the influence and impact of their interactions therein. The macrosystem, related to the socio-cultural context for the family is relevant here, in the consideration of the socio-political factors and societal constructs impacting the experience of people with ID and their families. The exosystem, acknowledged

that the family and individuals therein do not exist in a vacuum, other factors directly and indirectly impact their experience, e.g., parental experience, wellbeing and socio-economic circumstances. Finally the chronosystem, in this Bronfenbrenner described human development changing over time, in this the concept of person (siblings), context (having a sibling with ID), system (within their family and wider networks), time (recognised the study captured their experience at a point in time). This acknowledged that things were not static in families or for siblings and changed over time.

Central to the bioecological model is understanding the dynamic nature of development for C&YP. This connected with the epistemological positioning of this study and with the concept and importance of prompting C&YP's agency. Resonating with the current study, this recognises siblings as not just recipients of their experiences but acknowledges them as active agents with an ability to make a unique contribution and influence their life experiences. In their interactions with those around them C&YP as siblings can and do impact their own development, as well as the environment and systems around them (Hayes et al., 2017, 2022). This core principle connected with the underpinning philosophy and approach to this study in preferencing siblings' direct accounts. It was from this frame of reference that Bronfenbrenner's bioecological model of human development brought underpinning value to the study.

Figure 1.1. Bronfenbrenner's bioecological model of human development



(Rhodes, 2013, as cited in Guy-Evans, 2020)

1.6 The research question

My epistemological position of valuing siblings' individual experiences and insights, alongside a desire to champion C&YP's rights, enable their agency through accessing their 'voice', coupled with the theoretical frameworks of family systems theory and Bronfenbrenner's bioecological model of human development that underpinned this research, all informed the development of the research question as:

"What are siblings' experiences of having a brother or sister with intellectual disabilities (ID)?"

Given the study was concerned with exploring the phenomena of siblings' experience of ID, a qualitative approach was indicated. The research question positioned this as an exploratory study, towards greater understanding of sibling experience of ID through accessing their direct accounts. A method of interpretative phenomenological analysis (IPA) was identified as a valuable approach and was subsequently adopted for this study (Smith et al., 2009, 2022). Considerations of choice of method and methodology is discussed in more depth in chapter four.

The following section provides a summary of chapter one, as well as an outline of the subsequent chapters in this thesis to guide the reader.

1.7 Conclusion

Chapter one introduced the subject area and aims of the study and provided background related to the personal motivation and wider contextual influences of conducing this study. Definitions of family and rationale for the focus on siblings' experience of ID in their familial relationships was introduced. Influences in the design and approach adopted in conducting this research were presented including core theoretical frameworks underpinning this study. The research question was identified as: What are siblings' experiences of having a brother or sister with intellectual disabilities?

In conclusion, an outline follows of the subsequent six chapters presented in this work. In addition to these chapters, appendices and a comprehensive reference list are provided.

Chapter two: Provides a reflective overview of my professional and personal journey, relating this to my curiosity and interest in learning more about familial experiences of people with

intellectual disabilities and their families, with particular interest in exploring siblings' experience of typically developing children and young people who have a brother or sister with ID.

Chapter three: Presents the literature review search strategies, illustrated with a 'preferred reporting items for systematic reviews and meta-analyses' diagram (PRISMA) (Aveyard et al., 2021). Further insight and links to the theoretical frameworks underpinning this research study are considered, namely family systems theory and Bronfenbrenner's bioecological theory of human development (Bronfenbrenner & Morris, 2006; Hayes et al., 2017, 2022; Priest, 2023). A subsequent in depth review of the literature was conducted, relating to siblings' experience of ID. Themes from the literature are discussed with connections made to the research aims and research question. Gaps in the literature are identified connecting this study as a further contribution to the existing body of knowledge.

Chapter four: Explores the context of the study providing detailed discussion of the considerations influencing the epistemological positioning, offering a rationale for the resulting approach, design, choice of method and methodology. Factors considered when recruiting and conducting research with children and young people are explored, including ethical issues and the position of power for C&YP. Further measures for assessing the validity and quality of the research are presented.

Chapter five: Presents an interpretative phenomenological analysis (IPA) of the data identifying nine master or group experiential themes that emerged. An explanation of the transparent process guiding the analysis is provided, following the recommendations of (Smith et al., 2009, 2022). Direct quotations from the siblings' interviews are provided, connecting the

resulting themes in the narratives of the transcripts, embedding the interpretation in the voices and words of the siblings themselves.

Chapter six: Discusses the main findings of this study. New knowledge and tools emerging from the study are presented. The discussion connects the emerging insights with existing literature identifying where the findings confirm or refute previous work. Potential impact of the findings is offered in enhancing the lived experience of siblings who have a brother or sister with ID and their families. Testing of the findings is presented. Methodological issues arising from conducting the study are considered, highlighting strengths and limitations. Indicators for future research are offered.

Chapter seven: Summarises the main findings and emerging knowledge, suggesting their application to inform professional practice and policy. Final concluding remarks are proffered.

CHAPTER TWO: PERSONAL CONTEXT

2.0 Overview

This chapter describes my personal relationship with the research, expanding on the introduction in chapter one (section 1.1) and providing a more comprehensive overview as relevant to this study. This is presented as an independent chapter offering transparency for the reader, considering my multiple contexts, roles, and connections with people with intellectual disabilities (ID) acknowledging potential influences on the choice of topic and the approach taken. The concept of 'reflexivity' is introduced as a means of reflection and ongoing sense checking of my positioning and interpretations in conducting the research (Finlay, 2011; Smith et al., 2009). My professional and personal background is summarised outlining experiences and circumstance that developed my interest in exploring the phenomenon of siblings' experience of ID. The importance of self-awareness of pre and ongoing connections with the research topic is considered. The use of first person in this chapter is essential to enable me to be present and open about what I bring to the research. Using active voice and the first person where appropriate in writing the thesis is consistent with the philosophy of, and guidance offered in conducting interpretative phenomenological analysis (IPA) research, being attentive to personal influences, potential bias and the inter-relational nature of undertaking the study (Mitchell, 2017; Smith et al., 2022).

2.1 Researcher reflexivity

McIntosh (2023) offers a distinction between 'reflection' being how we make sense of experience, and 'reflexivity' that enables us to account for personal perspectives and their potential impact and influence on the research. The latter being a process of continual reflection of our interpretation of our own experience while engaging with the participants' experience and their sense making of the phenomena, being mindful of this influencing the choices and

decisions taken in the research process, and the researcher's interpretations throughout the study (Finlay, 2011). Multiple authors describe the importance of reflexivity when undertaking qualitative research (Finlay, 2011; Flick, 2023; McIntosh, 2023; Patton, 2002; Smith et al., 2009, 2022). Given my personal relationship with the phenomena being studied and the potential influence this might bring (Smith et al., 2022), reflexivity was an essential and integral part of undertaking the research. I adopted the use of a 'reflexive diary' throughout noting down observations, thoughts and reflections as I engaged with the data from the siblings' accounts of their experience of ID, their interpretations and sense making. This allowed me to explore and question assumptions and connections with my own world experience as the work unfolded. Adopting reflexivity from the outset brings an authenticity to the work. This ownership of self-perspectives is identified as an asset in qualitative enquiry (Patton, 2002:64). In doing so, this ensured that I remained alert to potential bias and the impact that this may have had on the development of the research question, choice of approach, method, and outcomes, as well as how I engaged in an interpretation of the experience and sense making of the C&YP participating in this study (Smith, 2004). This is revisited and discussed further in chapter four, relating this to IPA.

My professional relationship with ID is described in the section that follows.

2.1.1 Professional experience

In my late teens I had the opportunity to work in a special needs school on a work experience placement. I recall how much I enjoyed interacting with the students and engaging with their families. I valued being able to help the C&YP and learned a great deal from the educators and from the health and care professionals working to support them. Soon after, I embarked on studies towards a formal nursing registration qualifying as a nurse working in the field of

supporting people with intellectual disabilities in the early 1990s. As a registered nurse my career and professional interest quickly moved from in-patient services to working as a community-based ID nurse in a multi-professional team. Advancing my role necessitated the undertaking of further formal post-graduate education and practice to qualify as a community ID nurse. At that time, the context of my clinical work was supporting people with ID most of whom lived at home with their parents and wider family. Referrals to the community intellectual disabilities service, and the construct of my role, was to assess needs, provide therapeutic interventions, and support the health and wellbeing of the person with ID. In this capacity it was soon very evident that collaboration with parents and the wider networks connected to the person with whom I was working was critical, in optimising clinical therapeutic input, and outcomes for the individual. Concurrently, my community nursing studies honed my interest in professional education and I recognised the reciprocal impact of education, research and evidence based clinical practice. In 1997, I opted to combine my clinical role as a community ID nurse with a part time lecturing role in a university.

My curiosity to understand more about family experience of ID was heightened as I recognised deficits in my own knowledge and skill set in how I supported people with ID and their families, and also considered what I was bringing to my lectures as I supported the education of others in a university setting. Subsequently in 2002, I enrolled on a Master of Arts (MA) course in applied systemic theory at the Tavistock and Portman clinic. Part of the MA course required undertaking a placement outside of my usual clinical practice environment allowing me to work with C&YP and their families as a trainee systemic practitioner. I secured an opportunity to undertake supervised practice in a community children and families team. In this endeavour, one family who presented to the service had a significant impact on me and my future working practice. For me they connected the importance of inter-relationships within the family and the

impact this might have on the optimised outcomes of interventions for people with ID referred to the service. In this environment, as a children and families service, I had the opportunity to meet and work with the whole family. The family in question were a mother and father with three children, two typically developing teenagers, a brother and sister who both were actively engaged in providing support for their teenage brother with ID. The siblings supported their parents in providing care for their brother's physiological needs as well as managing his expressed behaviour which included hitting out, biting and screaming when distressed or when he was seemingly unable to cope with certain stimuli, e.g., noisy environments.

Exploring strategies for managing the behaviours was the focus of the referral to the service, which was challenging for their brother with ID, their parents, and all the family. Despite these difficulties, the siblings were notable in their desire to emphasise to me that they did not view their brother as a problem. In conversation while they did not shy away from the difficulties they experienced and openly shared their worries and concerns, unprompted and often insistently they also highlighted many positive aspects of their sibling relationships and family life.

During our interactions they expressed that as siblings they never seemed to be the focus of discussions or intervention from services or professionals like me, who they experienced as engaging almost exclusively with a primary focus on the needs of their brother and their parents. This challenged me to reflect on my approach and consider how I might better engage with and understand siblings' experience of ID. This also connected with the MA course content, my reading and research that identified siblings' experience of ID as an underrepresented focus of previous research. Alongside this, from my emerging understanding of systemic approaches, I became acutely aware of the emphasis in our services on the

presenting needs for the individual with ID, sometimes viewed in isolation, seeing the person with ID potentially as the problem rather than considering their experience in relation to their wider context and relationships. I began to consider how I might better surface siblings' relationships and brothers' and sisters' experiences of ID, when working with families. This became a strong feature of my supervisory discussions at the time.

Working with this family profoundly impacted my work from this point onwards towards an enhanced consideration of the whole family experience of ID, not isolating this to one person nor solely to the presenting referred problem or needs. Subsequently as part of the MA I conducted a small empirical study of the retrospective experience of ID for sisters, now adults, who had grown up with a sister with ID. The participants being all sisters was not planned, but consequential of the participants who presented at the time. The findings resonated with the literature reviewed for the study suggesting siblings' experience of ID was often a subjective, individualised experience. This also identified that often there are many variables impacting experience that are not considered in existing research literature related to the scope, specific focus or approach taken in conducting the research. I was curious to learn more about siblings' experience of ID to test my own findings.

I resigned to explore the experience of C&YP directly in their day to day lives, rather than through the retrospective lens of recollection for adult siblings, as in the earlier study. It was my belief that an enhanced understanding of the lived experience of ID for typically developing siblings would lead to improved and more insightful support and practice. This would potentially lead to better outcomes for all members of the family, including the C&YP with ID and their siblings. From this experience, through my reading and curiosity an evolving interest developed, all being part of my journey towards conducting the current study.

Having presented my professional journey and motivation for undertaking this study, the following section outlines my personal context and relationship with ID.

2.1.2 Personal context

When I was growing up there were members of my family with intellectual disabilities, the closest relationships being cousins. I do not recall ever being told explicitly that they had ID, I accepted and understood they needed different support. We engaged in typical children's activities, we played together when we were younger and as we grew older, looking back, relationships changed with a divergence in our life experience and expectations subsequently leading to a change and a distance in our relationships. In recent years I have wondered how these early experiences may have impacted me, my values, shaped my career choices and positioning either consciously or subconsciously. As reflected in chapter one, I developed a desire to support and advocate for those who do not have the agency or voice to represent themselves. This has been and remains a feature in both my working and personal life.

While I do not have personal experience of having a sibling with ID, in 2005 we welcomed our fourth child, also our fourth son into our family. Very early on we recognised that our son was not progressing through developmental milestones in the same way as his siblings. Soon after, and with significant perseverance by my husband and I to engage professional services and to secure appropriate assessments and support, our son was diagnosed with ID described as global developmental delay. Over the years further diagnoses and health implications have followed, our son is now a young adult. While we have never set limitations on what any of our children might achieve, for our fourth son his ID and associated health and support needs limit his scope of independence. As parents we recognise that he will require support throughout his lifetime. This research study therefore inevitably resonated with my familial context, and my role as a

mother. Being conscious of this context and connection to the phenomena and adopting a reflexive approach to this study was fundamental from the outset. This has supported sense checking of my interpretation cyclically throughout the study, to ensure the interpretation of the data was embedded in the voice and experience of the participants.

Such transparency and awareness of inter-subjectivity was essential given my personal context; however it is important to note that my interest in the whole family and more specifically siblings' experience of ID pre-dated both becoming a mother and having a child with ID in our own family. In the time frame and the journey travelled in undertaking this research our children have grown. Inevitably the context of my own family's experience has resonated with my engagement with the literature, as well as with the process of undertaking the research, in exploring the data and conducting an IPA.

As a researcher I was not disconnected, but rather consciously open to the connections therein. These layers of connection have been very much at the forefront of my mind, with many entries in my reflexive diary asking questions of what I was hearing, reading, and interpreting from the siblings' accounts, (see appendix 15). Finlay (2011) suggested reflexivity is an attempt to focus on intentional conscious lived experience, in a self-aware way. This has informed my approach to the reflexive diary and supervision discussions, i.e., being alert to my preconceptions of the phenomenon, aware of the connections that resonated for me, recognising also that through conducting the research new understanding of self and my own context may emerge. Yet importantly the work must remain grounded in the 'idiographic' attention to the individual lived experience of the siblings and as the focus of the research (Smith et al., 2022:119). IPA as a research methodology has enabled me to engage with the C&YP's accounts, to make sense of their sense making, with my interpretation of the data

emanating from and remaining embedded in the siblings' experience of ID as interpreted by them and shared from their perspectives (Smith et al., 2022).

2.3 Summary

This chapter has provided a transparent account of my personal and professional context. Key experiences that have motivated me to undertake this work were highlighted. The value of a reflexive approach and use of a reflexive diary was introduced as a means of continual reflection on my own experience as I engaged with the data, and the interpretations emerging from the lived experience and sense making of the participants. The importance of self-awareness and understanding of my pre-connections with the phenomenon of siblings' experience of ID was outlined. From this open positioning, being alert to potential bias and potential influences on the research, greater authenticity was brought to the work.

The following chapter explores the literature review that has informed the research throughout.

CHAPTER THREE: LITERATURE REVIEW

3.0 Overview

This research was concerned with siblings' experience of intellectual disabilities (ID), as a sub-group of their family. Fundamentally the study adopted a systemic perspective with an epistemological position that by design, privileged the voice of children and young people (C&YP) as authentic and unique sources of knowledge (Finlay, 2011; Willig, 2013). This chapter provides an overview of the two core theoretical frameworks, as introduced in chapter one. Bronfenbrenner's bioecological theory of human development, and family systems theory that underpinned the approach to the research, influenced the literature review, and offered contextualised paradigms through which siblings experience of ID was explored (Greene & Hogan, 2005; Hayes et al., 2017, 2022; Priest, 2023). Key legislation, policies, socio-political influences, and consideration of agency of C&YP are presented as related to the context of this study being undertaken in England, United Kingdom (UK). The inclusion and exclusion criteria and method applied to undertaking the literature review are provided in Table 3.1, with a 'preferred reporting items for systematic reviews and meta-analyses' diagram (PRISMA) presented to illustrate the process, Table 3.2 (Aveyard et al., 2021). An interpreted narrative synthesis analysis of the themes from the literature was discussed (Aveyard et al., 2021; Popay, et al., 2006). Finally, a summary of gaps in the literature are outlined and related to the research question and approach for this study.

3.1 Theoretical frameworks underpinning the study

The following section outlines the theoretical frameworks of Bronfenbrenner's bioecological theory of human development and family systems theory applied to support this study. This builds on the introduction of these paradigms that underpinned the research, from their introduction in chapter one.

3.1.1 Bronfenbrenner's bioecological theory of human development

Bronfenbrenner's bioecological theory of human development evolved from his early work in the 1960s and 1970s (Bronfenbrenner & Morris, 1998, 2006). In this he described childhood development with multiple layers of context and interconnections within, referred to as being like the 'Matryoshka/Russian doll' (Hayes et al., 2017, 2022), therefore complex and multilayered.

In his earlier ecological theory Bronfenbrenner outlined four systems influencing the individual and their development. He described the (1) 'microsystem', or early influence environments. In the context of this study this referred to the family itself being a primary influence potentially from birth, in the early years and often over their life course. Bronfenbrenner's (2) 'mesosystem' as applied to this study, considered the connections for siblings and the family with their wider influences i.e., outside the immediate family and their relationships with others. For families of children with ID this might include interactions with schools, early family support services, communication and interaction with health and other care services. Bronfenbrenner's (3) 'exosystem' referred to broader influences outside the family, e.g., services and approaches to support for families of children with ID, parental employment essentially environments that may have a more indirect yet related influence on siblings' lives, environment and subsequently their experience. Bronfenbrenner's (4) 'macrosystem', might be related to cultural factors for the siblings and their families, and acknowledges the influences of their socio-political environment. Additionally, this might also be related to the value-base and beliefs of the family, others around them and their wider societal cultures, constructs and ideologies, e.g., those impacting care and support approaches for people with ID and their families. Bronfenbrenner expanded his theory, later termed the 'bioecological' theory of human development, to include a fifth system the 'chronosystem'. This recognised systems'

interconnectedness for the individual, acknowledged the influence of four interrelated aspects of development, i.e., 'process-person-context-time' (PPCT) (Hayes et al., 2017; Greene & Hogan, 2005).

In PPCT, Bronfenbrenner valued the person, their differing characteristics and acknowledged their active ability to influence their systems. He noted that while their context remained important, time and the quality of their experience was identified as being significantly influential. Time, in this context, was constructed as three elements, 'microtime', 'mesotime' and 'macrotime', i.e., this referred to (1) the duration, consistency and quality of relationships, (2) when and where experiences occur in a child's life, e.g., early childhood or in adolescence, and (3) what was happening or what might be special in their immediate or temporal environments. The extended model considered that the quality of relationships, and the interdependency of their experiences was potentially more influential for children's development than the contextual systems in which they occur (Greene & Hogan, 2005; Hayes et al., 2017). Bronfenbrenner's expanded bioecological theory of human development was therefore helpful for this study.

This research study aligned to the model in adopting an approach of drawing knowledge and gaining insights from siblings' direct accounts of their experience. There is significance in acknowledging their context, while recognising and valuing the agency of C&YP, i.e., understanding that the siblings are not simply passive recipients of their contextual existence, but active co-producers, influenced by close and more distant factors, by the quality of their relationships and interactions with others, experienced over time, and from their wider environmental context. This indicated the value of a systemic approach to explore siblings' experience of ID to enhance understanding of the siblings' world, by accessing their voice,

thereby contributing valuable knowledge to inform current and future support for C&YP with a brother or sister with ID and their families.

3.1.2 Family systems theory

In a slightly earlier timeframe than Bronfenbrenner, Bowen first described family systems theory when working in America in the 1950s (Bowen, 1978; Corey, 2005). Family systems theory offered a further 'contextualist paradigm' that supported this study, a central concept being that individuals exist not in isolation, but within their family unit and are continually influenced by their interrelationships therein (Priest, 2023). Bowen acknowledged that dynamics of relationships change over time, that individuals influence each other, their experience within their families and situations in their broader life. He noted that familial relationships are not linear and identified that multiple and triangulated relationships exist within families, such as sibling sub-systems. Differentiation of self, family dynamics, marital relationships, parents' coping capacities and sibling position were recognised by Bowen as important factors to consider in seeking to understand individuals and their wider families. He also introduced 'societal emotional process' as a concept, i.e., the influence of society and how this in turn influences relationships and responses within and in their interaction with the environment external to the family (Corey, 2005; Priest, 2023).

Priest (2023) stated that family systems theory is difficult to define. He suggested that the concepts of theory, diagnoses and interventions are often 'muddled' and emphasised the importance of knowing the purposes, interactions, and contexts that shape the structure and boundaries of a system. Priest (2023) described family systems theory as follows: 'Family systems theory predicts and explains how people within the family interact, and how these interactions are different from outside the family. The family system is created by genetic,

individual, attachment and triangulation systems and is shaped by the sociocultural system in which the family is embedded.' (Priest 2023:77).

Family systems theory was a supportive underpinning framework for this study, as it described a concept of interconnectedness for families. The family system was recognised as a dynamic entity consisting of groups and sub-systems of interdependent individuals, communicating, responding to and influencing one another through their internal interactive relationships, with one such sub-system being the sibling relationship (Dallos & Draper, 2010:32; Seligman & Darling, 2007). The family also exists as part of broader socio-cultural systems e.g., the extended family and a wide variety of societal systems and sub-systems with whom they interact outside the family. Priest (2023) described the family system as being interconnected with other systems, i.e., '…shaped by the sociocultural system in which the family is embedded' (Priest, 2023:79). In other words, the family system does not function in isolation. Siblings could therefore be said to be influenced by their genetics, attachments, connections and interrelationships within their families, and by assumptions, expectations, socio-cultural context, policies and the values of the societies and systems within which, and with whom they and their families interact. Family systems theory enabled this research to acknowledge the complex and interactive nature of the family as a system and recognised that all members, while being individuals, have an interrelationship with and impact upon one another.

The next section will discuss the siblings as a sub-system of the family in more detail outlining the value and importance of exploring and understanding their experience of ID.

3.1.3 Siblings as a sub-system

As introduced in chapter one, C&YP will have individual, connected and unique relationships with all members of their family as part of varied sub-systems therein. Each relationship offers unique experiences and may require different interpretations and adjustments to be navigated in families. The importance of a study that focused on the sibling relationship recognised this as potentially the longest and most enduring relationship in the family, with siblings growing up together being a primary source of reference, shared experience and support across their life course (Hayden et al., 2023; Seligman & Darling, 2007). Given the longitudinal context of sibling relationships, for C&YP with a sibling with ID the likelihood of an enduring interdependence for siblings' relationships is enhanced. Understanding siblings' early experience of ID offered an opportunity to gain unique and valuable insights, contributing to knowledge and understanding not only to support C&YP as they grow up together but building shared understanding from their unique insights, to inform considerations for their shared future (Seligman & Darling, 2007; Carter & McGoldrick, 2005).

Families of children with ID also become part of a sub-system of society, potentially requiring significant practical, psychological, emotional and spiritual adjustment (Seligman & Darling, 2007). Their experiences and subsequent needs may set them apart from other families or create different challenges in their socio-cultural context, as they may be required to navigate potentially more complex and unexpected circumstances (Kao et al., 2012). Therefore, acknowledging broader family experience and the likely influence on siblings' experience of ID was indicated as an important principle in conducting this study, considering family constructs, socio-cultural and wider context for the whole family (Seligman & Darling, 2007; Burke, 2008). The contextualised paradigm evident in the literature review was applied in the analysis that follows. It explores siblings' unique experience of ID within their familial and

broader context, and interrelationships therein, supported by the theoretical concepts of Bronfenbrenner's bioecological model and family systems theory.

The following section outlines key UK and global policy relevant to this study conducted in England UK. Key societal developments, particularly those related to the rights and the role of C&YP in so called western societies are identified, considering their impact on siblings' and families experiences related to ID. In addition, the role of C&YP as social agents was explored (James & James, 2004).

3.2 Key policies; rights, and role of children and young people as social agents

The United Nations Convention on the Rights of the Child (UNICEF, 1989) is a framework guiding legislation and policy development globally. It sets out the rights of every child in the world to 'survive, grow, participate and fulfil their potential'. The UNICEF convention has been adopted and has thereby influenced UK legislation, policy and practice regarding the rights, protections and opportunities for C&YP. UNICEF Articles 12 and 13 related to this study, with Article 12 referring to C&YP's rights to independent views, and for their views and perspectives to be acknowledged and valued. UNICEF Article 13 refers to C&YP's right to freedom of expression, to share their ideas and be enabled to express this in a manner and means appropriate to their capabilities, age and maturity (UNICEF, 1989; Christensen & Prout, 2002). UNICEF Article 8 refers to C&YP's rights to their own identity, their name, and protection and promotion of their family relationships. The UNICEF Articles do not refer specifically to safeguarding familial relationships of siblings in the context of a family with C&YP with ID, nor reference directly siblings' rights to be heard in these circumstances.

Valuing People, a New Strategy for Learning Disabilities in the 21st Century (DH, 2001) and Every Child Matters (DfES, 2003), were key to advancing protections in the care and support

of C&YP with ID and their families in the UK and were influential in my own professional practice. While the emphasis therein was more directed to addressing the support needs for C&YP with ID, their parents and primary carers, the need for a holistic approach to family assessment, intervention and support, including considering their sibling relationships was referenced in the context of whole family perspectives. While the value of sibling involvement was recognised, it was not emphasised as a consideration in the context of the potential lifelong nature of sibling relationships for typically developing siblings and their brothers and sisters with ID. Neither was the focus specific in considering safeguards and strategies to optimise siblings' potential interdependence for the future. These policies and apparent lack of recognition of the importance of siblings' relational context were influential in developing my early interest in undertaking this study, informed the development of the research question, and guided the approach taken in conducting the work.

As well as adopting the protections outlined by UNICEF, in the UK, the Children's Act (DfES, 2004), Children and Families Act (DfE, 2014), the National Service Framework for Children Young People and Maternity Services (DH, 2004) supported a changed perspective towards protecting and promoting the rights and individual contributions of C&YP, to make informed decisions about their own lives. While legislation and policy have focused on assessment, interventions and care needs, including more specifically for children in circumstances where they are taken into some form of state supported care, there is increased recognition of the rights and considerations of siblings' views and preferences to be taken into account, whatever their life circumstances. Section 8 of the Children and Young Person's Act (DfCSF, 2008), advocated for siblings to be kept together if they required statutory care support, recognising that this would more likely enable positive adjustments, and support their future wellbeing and life outcomes. This further underscored the recognition, importance and value of increased

understanding to support sibling relationships. This statutory, cultural and values led emphasis on enabling siblings' rights and agency is welcomed, however, more focus is still needed specifically on understanding siblings' experience of their relationships directly, and more explicitly when one or more C&YP have ID. This emphasis of C&YP's rights indicates the value of seeking more holistic perspectives of their lives. The importance of direct access to their views is indicated, rather than through the observations of others. C&YP are not bystanders in their lives, nor their experiences merely consequential of their circumstance and life situations. C&YP are active citizens with the right to opportunities to influence their lives through their own empowered self-expressed independent voice.

The legislative, rights and socio-political context referred to above highlights a positive change towards greater consideration of the role of C&YP in western societies. With this development of a more equal paradigm of childhood, C&YP are no longer perceived as being 'seen and not heard'. They are recognised as social agents with an independence within their childhood dependency, they possess the ability and have the right to shape their own childhood and life experiences (James & James, 2004; James & Prout, 2015). It is evidently important therefore to engage C&YP directly in research to enable their voices to be heard (Greene & Hogan, 2005). That is not to suggest that C&YP are wholly empowered as political actors in society. There is no intention for this study to misdirect or ignore consideration of the power imbalances and disempowered realities that C&YP continue to experience in the UK and globally. The point is rather to support and value this paradigm shift towards recognising C&YP's unique perspectives and to find means, such as through research participation, to elicit their contribution as co-authors of their childhood experience. There is potential to realise for and with them, greater understanding of their experience and perspectives, surfacing more informed intervention and support, and more positive future life outcomes (James & James, 2004;

Seligman & Darling, 2007). This role of C&YP as research participants is further explored in chapter four, with ethical considerations.

3.3 Conducting the literature review

This section outlines the process of undertaking the literature review, validating the research question. It places this study in the context of relevant and contemporary research of siblings' experience of ID. The databases accessed and the process of undertaking the review are outlined. Key terminology related to this study is highlighted. The inclusion and exclusion criteria are provided. Consideration of quality and validity of the literature is explored.

3.3.1 Timeframe and approach to undertaking the review

The literature review was first conducted in 2015, at the commencement of the study. This informed consideration and refinement of the research questions and aims, as well as providing a mechanism for the exploration and identification of the method and appropriate methodological approach. In addition, this supported the identification of the inclusion criteria, developed and validated ethical considerations and highlighted other related aspects of conducting the research. Such as consideration of underpinning theoretical frameworks; identifying pertinent legislation and policy; giving due consideration to issues of power and agency for C&YP, highlighting considerations for best research practice, and ensuring safeguards for the participants and for my role as a novice researcher. The literature review was updated notably in 2019, to support the submission of the initial progression report, and latterly updated in 2024 using the same search terms and databases to support the write up phase of the research, thus capturing relevant contemporary research available over the timeframe of this work. Smith et al. (2022) noted that the literature review in an interpretative phenomenological analysis (IPA) study helps to develop a greater awareness of any pre-

conceptions. This was important not only to inform the knowledge base for the research but also as a support for my reflexive considerations throughout this study.

3.3.2 Terminology related to intellectual disabilities

Chapter one introduced the definition of ID applied to this study (DH, 2001). It was recognised that different terminology has been adopted over time and in different countries aligned to social constructs, equity, diversity and inclusivity for people with ID, alongside the acknowledgement of their rights and value as equal citizens in society. Therefore, the search terms for the literature review included intellectual disabilities (ID) or learning disabilities (LD). The term 'learning difficulties' was excluded, as this terminology described conditions such as dyslexia or dyspraxia and was therefore not aligned with the definition of ID (DH 2001) adopted for this study.

There is considerable misunderstanding, misinterpretation and debate, regarding the interchangeable use of terminology describing conditions of intellectual disabilities, people with learning difficulties or neurodiversity. Mencap (2024) explained that learning difficulties do not affect general intellect. Learning difficulties can co-exist for people with ID, but having a learning difficulty or neurodiversity does not affect general intelligence. Therefore, for the purposes of the review, the term 'learning difficulties' was excluded (Mencap UK, 2024). Similarly, papers solely referring to Autistic Spectrum Disorder (ASD) only, were generally excluded, as ASD was described as a broad ranging term for conditions of neurodivergence, accompanied by social and communication difficulties. While ASD can co-exist with ID, this is not solely related to having ID. However, papers where the broader inclusion criteria were met that referred to ASD alongside ID were included, as these were frequently cited by other authors. Consequently, the review included the following key terms as a search string,

"learning disab*" OR "intellectual disab*", AND "sibling*", AND "family" OR "families". Further key terms were added to include, AND "sibling experience*", AND "child*".

3.3.3 Database sources

Papers available in the English Language were obtained through the university databases. The databases CINHAL Plus, SCOPUS Plus, PubMed, APA PsycNet Psych articles, Google Scholar, and Social Care Online were identified as search engines that most commonly host literature related to the subject area, being readily accessible through the university systems. Grey literature was explored through the University of Hertfordshire health subjects' toolkits, 'Open Grey'. Articles included were mainly peer reviewed journals, with some evaluative articles. Further hand searching of articles was conducted to identify any frequently referenced studies, or those also meeting the inclusion criteria but not found in the original search. Google books and the University online library resources were accessed to identify key texts.

3.3.4 Inclusion and exclusion criteria

The **s**ample, **p**henomena of **i**nterest, **d**esign, **e**valuation, **r**esearch (SPIDER), search tool was used as a guide and supported the development of the inclusion and exclusion criteria. This also helpfully supported the quality review, tabulation and collation of the literature (Aveyard et al., 2021). Additionally, this helped to manage the process of reading and reviewing a volume of literature, ensuring the captured literature related to the research participant population, and that it remained relevant to the research question (Aveyard et al., 2021; Cooke et al., 2012). Using the SPIDER tool, the inclusion and exclusion criteria was developed. The sample included C&YP up to 18 years old who had with a brother or sister with ID. The phenomena of interest related to the research question and focused on exploring siblings' experience of ID. For the design, this was not specified, to capture a broad range of research. The search term of

'sibling experience' was used, it is acknowledged that such a term is likely to capture more qualitative studies as a qualitative design lends itself to studies exploring experience. While it was important to acknowledge this, given that the study adopted a qualitative approach, the inclusion of broader research methods still provided appropriate accessible qualitative research comparators and supported this study as an interpretative phenomenological analysis (IPA). Where the literature review identified quantitative and mixed methods studies these were included and reviewed where they met the inclusion and exclusion criteria.

When evaluating the quality of the studies the authors' recognition of credibility and validity was noted. Reference made by the authors of measures adopted for the inclusion of C&YP as participants was highlighted. Ethical considerations for the studies reviewed was also considered to be an important quality measure. Given the diversity and range of studies identified, traditional quality measures were more challenging to apply, e.g., participant cohort size was not always comparative as expected, where qualitative and some quantitative or mixed method studies were included. The content and findings related to the research question and inclusion exclusion criteria were prioritised. The research impact and the application or implications of the research was noted. Key findings, gaps and considerations for future research were identified.

Adopting the SPIDER approach helped to manage a broad range of literature and supported the emergence of the subsequent themes that informed this review. (see appendix one). Table 3.1 presented below, provides a summary of the inclusion and exclusion criteria applied to the review.

Table 3.1. Summary of inclusion and exclusion criteria for literature review

Inclusion criteria	Exclusion criteria
1999 - 2024	Prior to 1999 published up to March 2024.
English language	
Peer reviewed literature	
Available through University search engines	
Studies referring to siblings' experience of intellectual disabilities (ID) involving siblings as participants.	Accounts of siblings' experience elicited from parents or others' only i.e., not including siblings directly.
Research conducted with children and young people up to 18 years.	Research with adult siblings. Parents perspectives only.
Obtained via search term string "learning disab*" OR "intellectual disab*", AND "sibling*", AND "family" OR "families". Further key terms were added to include, AND "sibling experience*", AND "children".	Participants with Autistic Spectrum Disorder only, no reference to other ID in the studies.
Qualitative, quantitative, and mixed methods included as further exploration of "IPA" OR "Interpretative Phenomenological Analysis" returned limited papers.	

3.3.5 The literature review process

CINAHL Plus provided the initial database search, returning 241 results, further search terms, and "sibling experience*", and "children" reduced this to 77 articles, date criteria reduced the abstracts to 62 articles, full text access was applied, this produced 31 papers to be reviewed. Abstracts were reviewed and 12 papers were identified as addressing the inclusion criteria, one overseas paper was unobtainable. PubMed was accessed applying the same advanced search criteria, initially returning 49 texts which were then cross referenced against papers from the CINAHL Plus search returns, the remaining 18 abstracts were reviewed. Social Care Online returned six additional abstracts. SCOPUS advanced search, applying the same search criteria initially returned 94 articles, date criteria reduced this to 68, "sibling experience" reduced this to three and "children" to one. Subsequently, 68 abstracts were initially reviewed and cross referenced with the previous searches as the refined return of one was considered too limited. Thereafter seven further abstracts were identified.

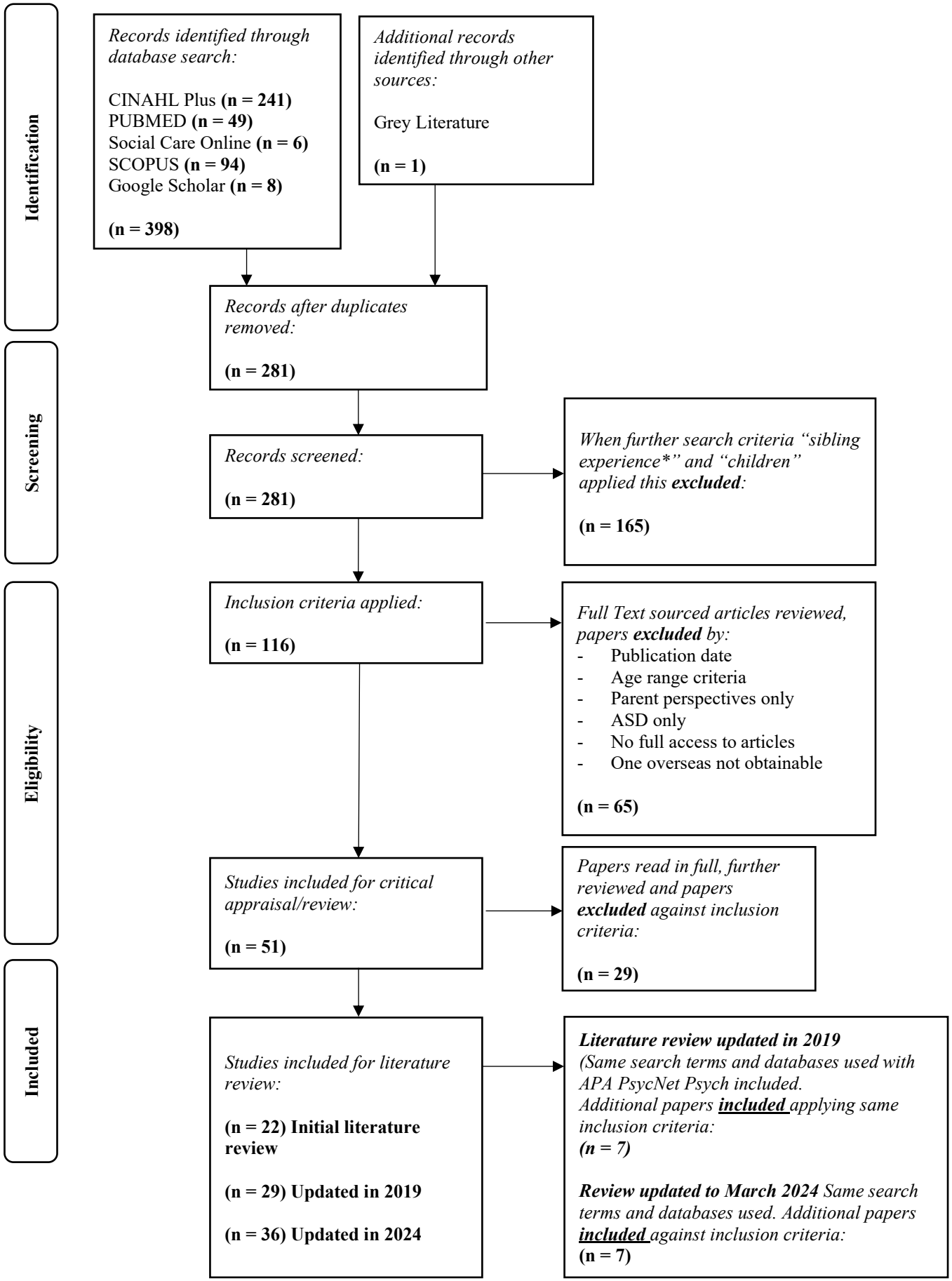
The University intranet site was explored for grey literature and one paper was reviewed. This related to parents' experience and was therefore eliminated from the review. Google Scholar returned a further eight abstracts not already identified from other searches. These 51 abstracts were re-read, checked against the inclusion criteria with 44 papers read in full. Three further articles were included as they were frequently cited as relevant in the papers reviewed. They mainly related to research in ASD and had therefore previously been eliminated from the original abstracts. Subsequently 22 articles were included in the initial review.

In 2019, the literature review was re-run using the same search terms and databases with the addition of searches in APA PsycNet Psych (not previously available), to ensure any recent literature was captured. An additional nine papers were identified; the same inclusion and

exclusion criteria were applied, two papers were excluded, seven papers were included and added to the previous 22, with 29 studies included.

Between 2019 and 2024 a further seven papers were identified and these were added to the 29 previous studies with a final 36 papers subsequently included. Table 3.2 provides a PRISMA diagram of the search process undertaken (Aveyard et al., 2021).

Table 3.2. Literature search process, (PRISMA diagram) (Aveyard et al., 2021)



3.3.6 Quality and validity

The quality of articles was initially interpreted in line with Lincoln and Guba's (1985) validity concept, i.e., credibility of the findings; potential for wider application; did the authors try to demonstrate that these were consistent and explain how validity and researcher bias was considered (Lincoln & Guba, 1985; Whittemore et al., 2001; Yardley, 2000). Many of the articles adopted a qualitative approach and as the research progressed, the application of this validity concept was adapted related to guidance for reviewing qualitative research and the approach developed by Yardley (2000). Articles were re-read considering due diligence to the principles of sensitivity to context, commitment and rigor, transparency and coherence, impact and importance (Yardley, 2000).

Qualitative papers, such as those using IPA often take a 'deep dive' approach which is a strength but makes it more challenging to interpret the quality of the work in the context of more traditional validity models. In this regard Yardley's principles were helpful (Smith et al., 2009; Yardley, 2000). The validity of the research questions, clarity of intent, context of the research and of the participants, assurance and transparency of the methodology, method of approach and rigor of process were considered. The inclusion of transparent discussion of the limitations of the study, the importance of the work and potential impact was also reviewed.

Quality and rigor were recorded in a table using the SPIDER tool headings, with recurrent and divergent findings noted. This was helpful in providing an overview of emerging themes arising from the studies and recommendations or gaps were identified for future research. The emerging themes were collated, and each theme subsequently discussed. This approach followed an interpretation of a narrative synthesis analysis (Aveyard et al., 2021; Cooke et al., 2012; Popay et al., 2006) (see appendix one).

3.4 Themes from the literature

In this section, an outline of the interpreted narrative synthesis review of the literature is provided. Key themes are presented and discussed in detail. A narrative synthesis review is an approach that supports the analysis of the literature towards defining the research question, by undertaking a comprehensive search related to the subject area, appraising and describing the studies, collating findings, and grouping emergent themes, highlighting similarities and differences from the studies captured within the review (Aveyard et al., 2021; Popay et al., 2006). It is acknowledged that the approach to the narrative analysis of the literature for this study did not identify a specific theoretical model and therefore did not cover all the elements of a narrative synthesis analysis approach. Thereafter however, the approach was consistent with suggested value and appropriate application of the interpreted narrative synthesis review (Aveyard et al., 2021).

From the 36 papers reviewed, core themes emerged, these were noted down and coded numerically in the margin on the literature review table, (see appendix one). The papers were re-read and textual narrative searches conducted. Common and differing findings across the studies were identified and provided an eventual saturation of themes. Adopting this approach to coding the themes was time consuming, however, it enabled submersion and familiarity with the literature and ensured that a comprehensive representation of the findings was captured in the emergent themes. A final six (vi) broad themes were identified from the literature, (i) siblings' positive and negative experience; (ii) caring role and future responsibilities; (iii) nature and degree of intellectual disabilities; (iv) cultural context and socio-economic factors; (v) the family system and inter-relationships; (vi) value of self-reports and sibling resilience. Each of the themes is discussed in the following sub-section of this chapter.

3.4.1 Positive and negative experience

Both positive and negative experiences of ID and varied outcomes for siblings were reported in the literature. C&YP adjusted to having a sibling with ID in different ways, with parental response; family structure; resilience; effective communication in families; quality of the relationship between siblings, and the diagnosis of ID, cited as key factors that influenced more positive sibling experience (Giallo & Gavidia-Payne, 2006; Pollard et al., 2013; Reimers et al., 2023; Yaldiz et al., 2021). The literature identified that family resilience overall affected the experience of the siblings, with parental response and reactions inextricably linked to perceptions of ID and outcomes for siblings, and their wider family. Aksoy and Bercin Yildirim (2008) investigated 228 children with siblings with a range of ID. They acknowledged the sibling relationship as a sub-system of the family and found that parents' reaction, acknowledgement, family structure and environment, were all factors that lead to better or less favourable acceptance, understanding and experience for C&YP of having a sibling with ID, and this was supported by other authors (Cooke et al., 2007). Correia and Seabra-Santos (2022) identified that parental response impacted the wider family acceptance of ID which, in turn, impacted the harmony, wider experience and quality of relationships in the family and the way siblings perceive and experience their relationship with their sibling with ID.

A circumstance of 'disability by association' was identified in the literature (Burke, 2010). This suggested that siblings take on a new identity when they have a sibling with ID, not only in terms of their own lived experience of ID but also being impacted by the broader social construction of disability and the underlying assumptions and expectations of society therein. This was not only experienced by siblings themselves but, from a family systems perspective, this association impacted the whole family, given additional stressors, socioeconomic factors, social isolation and a real or perceived experience of not meeting, so called, societal norms.

However, this was not viewed solely in a negative sense in the literature, linking this to Goffman's (1963) work on 'courtesy stigma' by association. Disability by association was viewed as both a strength, with the development of a sense of specialness, a closeness, in terms of a shared experience, a collective protective response, yet also presenting additional circumstances of challenge for individuals and families (Burke, 2010; Stalker & Connors, 2004; Zaidman-Zait et al., 2020).

Freitag et al. (2022) in a study of 20 siblings, explored phenomenological considerations of siblings' perceptions of ID. The authors reported positive responses to the child with ID by their siblings. A perspective emerged that the 'person is the person', including having ID. The study identified that having a sibling with ID was accepted as a regular part of their lives. 'So, if disability is understood as an existential facticity, through which the person exists in the world, and not as a limitation or difference, they are perceived as normality' (Freitag et al., 2022:4). The study recognised the social constructs of ID and acknowledged additional stressors to which families and siblings are exposed, recognising the impact. However, the overall experience was one of acceptance of their brother or sister with ID for who they are, with a positive attitude to their 'specialness' in having ID. The authors noted, from Heidegger's perspective, in this context, the siblings have only ever known their brother or sister as having ID, hence this is an integral part of who they are and part of their shared and normative lives. This was supported by other studies that explored quality of life measures as an indicator of siblings' experience of ID. Authors found that siblings value their brother or sister, seeing ID as an intrinsic part of who their siblings are, bringing unique experiences to their sibling relationships (Moyson & Roeyers, 2012).

Hayden et al. (2023) conducted surveys of 500 sibling dyads in the UK. They explored the pro-social behaviour of children with ID and their siblings and explored their perception of the quality of their relationships. They identified a reciprocity of the sibling relationship and concluded that children with ID and their siblings have both positive and negative impacts on one another and expressed some similarity with siblings' experience in typically developing dyads. It was found that both experiences co-exist, with the authors terming this a 'binary construct' (Hayden et al., 2023). They also pointed to the impact of wider family experiences in terms of reciprocal responses to one another, i.e., parental response influences sibling experience, as noted earlier.

A previous study by Hayden et al. (2019) concurs with that of Petalas et al. (2009a) who conducted interviews with 22 siblings who had a brother with ID and ASD, identified themes related to siblings' perception of the impact of ID and ASD on their lives; perception of the attitudes of others; tolerance and acceptance towards others; positive attitudes and experiences, and views of support. A further study from a sub-group of 12 adolescent siblings of the same cohort Petalas et al. (2012b) also reported varied themes, but with continued emphasis on siblings valuing their sibling(s) with ID. Findings suggested having a sibling with ID, helped C&YP build their ability to adapt to other life circumstances. As adolescents, from a retrospective viewpoint, siblings reflected their growth in understanding and tolerance, and reflected their experience of ID as siblings, potentially influenced their future lives. Early support and intervention increased the likelihood of more positive experience, especially when managing relationships with those outside the family and with friends and peers (Hames, 2008). Communication provided by parents positively enhanced siblings' experience. They appreciated the achievements of their siblings with intellectual disabilities, with an enhanced sense of pride, in the context of challenges presented by having ID, and did not want to change

them (Moyson & Roeyers, 2012; Hayden et al., 2023). Siblings highlighted having fun together although this changed somewhat in adolescence where the same shared experiences were less frequently replicated. A greater sense of maturity and understanding of relationships were identified as positive aspects of siblings' experience (Aksoy & Bercin Yildirim, 2008; Begum & Blacher, 2011; Burke & Montgomery, 2000; Kao et al., 2011; Lobato et al., 2011; Naylor & Prescott, 2004).

Negative experiences were evident from findings in the literature, though these were not linear experiences. There were often conflicts for siblings, caring about their sibling with ID, yet e.g., siblings experiencing psychosocial and emotional impacts of behavioural challenges for their brother or sister (Hayden et al., 2019; Mascha & Boucher, 2006; Petalas et al., 2012a; Shivers & Dykens, 2017; Shojaee et al., 2020).

Kaminsky and Dewey (2001) identified greater intimacy, better relationships and acceptance for siblings who had a brother or sister with Down's syndrome than those with siblings with ASD. They related to more behavioural challenges for C&YP with ASD and this was found to impact siblings' experience. Fear and anxiety about their sibling with ID with additional associated health concerns also added to siblings' anxiety and suggested more negative experience and outcomes (Giallo et al., 2012; Kaminsky & Dewey, 2001; Petalas et al., 2012b; Shivers & Dykens, 2017).

Mascha and Boucher (2006) interviewed 14 siblings, also finding that exposure to their siblings with ID' expressed behavioural issues and challenges resulted in more negative experiences being reported. In this study, siblings with ID had a diagnosis of ASD and Aspergers. It was suggested, but unclear if there were overriding ID as this may have impacted the results.

Siblings reported being embarrassed by the behaviours of their brother or sister and were more likely to have potential concerns for the future, for themselves and for their sibling. The impact of these concerns reduced with open communication and information being provided to and within the family, as noted earlier (Kao et al., 2011; Petalas et al., 2009a). This was consistent with other studies that explored the wider impact of ID and supported the interconnected and contextualised paradigm of sibling experience within their family system (Cooke et al., 2023).

In several studies, siblings accepted they sometimes get less attention than their sibling with ID or are impacted by their exposure to parental stressors (Burke & Montgomery, 2000; Cooke et al., 2023; Correia & Seabra-Santos, 2022; Giallo & Gavidia-Payne, 2006; Graff et al., 2012; Moyson & Roeyers, 2012; Pollard et al., 2013). This was experienced in a reciprocal manner, further described by Hayden et al. (2023), with siblings also being protective of their parents, expressed as a need to 'take a back seat'. Siblings demonstrated consideration and concern for their parents, eliciting a sense of responsibility of trying to protect their parents, perhaps by being the good or successful child. Equally they may present with difficulties, rebel or fail to achieve, in order to attract attention. From both perspectives, siblings are aware of the needs of their sibling with ID, alongside potential parental stressors and demands in meeting those needs.

Other studies supported the findings of the potential for siblings to miss out on parental time and identified their sense of loss if this was not facilitated (Moyson & Roeyers, 2012). Guilt was associated with differentiated life experiences between siblings, e.g., if siblings with ID were taken away from the parental home, placed in residential support services, school or nonfamilial care. In these cases siblings experience a sense of guilt, of potentially having better life experiences than their sibling with ID (Jacobs & MacMahon, 2017).

The positive impact and value of sibling support groups was referenced in much of the literature and positively impacted siblings' enabling them to deal with more adverse situations in their family life. It was found that this supported better outcomes, quality of life, and positively impacted their overall experience (Correia & Seabra-Santos, 2022; Giallo & Gavidia-Payne, 2006; Kaminsky & Dewey, 2001; Petalas et al., 2009a). Peer groups were found to be not only therapeutically beneficial, but also allowed siblings to be themselves, be with people in similar circumstances, thus bringing a degree of respite from more negative experience e.g., of having to explain ID, or their siblings' presented needs, to others (Moyson & Roeyers, 2012). Luijkx et al. (2016) reported this as particularly important when siblings have profound ID and multiple disabilities, given shared sibling experiences are more limited, and potential health needs and subsequent concern for their siblings may be heightened due to the multiple and complex needs of their sibling.

This pointed importantly to the value of enabling the sibling voice, not only in terms of family assessment and support, but in conducting research and developing insight and knowledge informed from the lived experience of siblings themselves, as in this current study. Given the socio-political positioning of support for C&YP, the influence of legislation, policy and the recognition of C&YP's agency and rights referred to earlier in this chapter, studies contributing knowledge elicited directly from sibling accounts were advocated, and this was supported from the literature reviewed (Kao et al., 2011; Luijkx et al., 2016; Macks & Reeve, 2007).

3.4.2 The caring role

Issues of increased caring responsibilities were evident from the literature, for parents and for siblings (Aksoy & Bercin Yildirim, 2008; Burke, 2010; Burke & Montgomery, 2000; Davys et al., 2010; Graff et al., 2012; Petalas et al., 2012b; Seligman & Darling, 2007; Sharpe &

Rossiter, 2002; Safer, 2002; Strohm, 2005). The level of responsibility and subsequent impact of care needs in families was influenced by several factors, including ID diagnosis and the associated level of support needs for the child with ID. The enduring nature of the sibling relationship also influenced the consideration of a caring role and the responsibilities placed on siblings in childhood, as well as anticipation, worry and assumptions about potential responsibilities for the future (Burke, 2008, 2010; Burke & Montgomery, 2000; Graff et al., 2012; Sharpe & Rossiter, 2002).

Burke (2010) studied 116 families, he included 344 children, and Burke and Montgomery (2000), referred to a sub-set of eight families as part of a pilot research project of sibling experience. They highlighted gender differentiation when considering caring roles and suggested girls more readily considered their role as carers. They identified gender differences as an important consideration when assessing and supporting families. Begum and Blacher (2011) compared sibling relationships of 70 adolescent sibling dyads, with and without ID, they explored factors such as birth order, age, as well as gender of siblings. They suggested adopting a caring/caretaking role was less 'awkward' for same sex dyads, particularly in adolescence. Age was considered as a factor in the caring role. This impacted the quality of sibling relationships, with older siblings potentially taking on more caring responsibilities. This impacted intimacy with a less reciprocal relationship where there was a higher caring need for the sibling with ID, i.e., they were not on an equal footing in their relationship (Hayden et al., 2023). Siblings felt less pressure and reported better relationships with their siblings with intellectual disabilities, where caring responsibilities were shared e.g., with multiple siblings (Seligman & Darling, 2007). This highlighted not only the importance of consideration of the context of the family system, e.g. size and structure, but also the impact of the caregiving role in day-to-day life, and that envisaged for the future (Reimers et al., 2023; Graff et al., 2012;

Petalas et al., 2009a). Kao et al. (2011) identified cultural and socio-economic factors in both the perception and expectation of the caring role for siblings and reported greater acceptance of the caring role, in this case in the Latino community. The necessity to involve siblings in caring roles due to socio cultural expectation and context, as well as socio-economic pressures was indicated, related to parental stressors, and emphasised the interconnected and systemic nature of family experience.

Siblings viewed caring responsibility differently at different life stages (Hayden et al., 2023; Moyson & Roeyers, 2012; Petalas et al., 2012b), with younger siblings often being less involved in caring at an early age or viewing this more positively as a helping role. A number of studies advocated a longitudinal approach to inform future research to explore caring responsibilities for siblings and linked this to expectations and understanding of future care roles and responsibilities siblings may expect, or be expected to undertake (Begum & Blacher, 2011; Graff et al., 2012; Hames, 2008; Kaminsky & Dewey, 2001; Luijkx et al., 2016; Macks & Reeve, 2007; Orsmond et al., 2009).

Mazaheri et al. (2013) highlighted a whole family impact of ID in their study of quality of life and caregiving in families with children with Prader-Willi syndrome (PWS). They used a measure of post-traumatic stress disorder, (PTSD), to explore the experience of siblings and concluded that siblings of a child with PWS were more susceptible to symptoms of PTSD. As siblings' with PWS often experienced multiple health impacts, related to physiological needs as well as social impacts, e.g., the need to lock food away and manage the home and external environment, this increased the caring demand and impacted the whole family. Throughout the literature, the caring role for the whole family was evident. How this was managed, parental approach, ID diagnosis and associated health and care needs for their sibling with ID, siblings'

age, gender and socio-economic factors impacted the expectation and experience of the caring role for siblings.

3.4.3 The nature and degree of intellectual disabilities

The literature identified that the specific ID, the nature and degree of disabilities and associated support needs of siblings with ID, impacted siblings' experience. Pollard et al. (2013) explored the relationship quality of 119 siblings 11-16 years old, as a moderator of anxiety for siblings of children with Down's syndrome, (DS) and those with siblings diagnosed with Autistic Spectrum Disorder, (ASD). For the latter it was not clear if siblings also had associated intellectual disabilities. They concluded that siblings with a brother or sister with DS typically had a better quality of relationship with their sibling(s) and experienced less anxiety, than those with a sibling with ASD. They acknowledged that children with ASD expressed a range of symptoms and behaviours associated with a broad-spectrum diagnosis and highlighted that where more negative behaviours were experienced this was associated with more negative outcomes for siblings (Mascha & Boucher, 2006; Pollard et al., 2013; Seligman & Darling, 2007; Shivers et al., 2019).

The nature of the ID diagnosis, associated needs and behaviours were varied and individual and this in turn impacted the day-to-day life for the family. This manifested as increased parental stressors and inevitably impacted siblings' experience (Aksoy & Bercon-Yildirim, 2008; Benderix & Sivberg, 2007; Kaminsky & Dewey, 2001). Where ID was associated with more negative behavioural challenges this impacted the attitude and experience of siblings, as well as the perception and acceptance of others outside the family. This led to conflict for siblings with potential for social isolation as they tried to understand, advocated for and supported their sibling with ID, while recognising the impact expressed behaviour, physical

needs, or other aspects of their ID might have on others. Siblings grappled with their siblings' needs or more challenging observable behaviours, while at the same time wanting to protect them and their families (Petalas et al., 2012b).

Siblings were often aware of their siblings' ID and broader diagnosis. As C&YP they relied on others, especially parents, who shared their knowledge and provided explanations. Parental response, early intervention, accessible age-appropriate knowledge and support provided for siblings were reported as beneficial leading to more positive outcomes for siblings (Hames, 2008). There was also potential for concern and anxiety related to the wellbeing of their sibling, especially where the ID was more profound and complex. Where diagnoses were associated with co-morbidities and wider health and care needs this added to sibling and parental stress and anxiety in the here and now and for the future (Correia & Sebra-Santos, 2022; Luijkx et al., 2016).

3.4.4 Cultural context, ethnicity and socio-economic factors

The literature lacked a significant focus on culture, ethnicity and socio-economic factors, this was acknowledged by many authors. Subsequently few studies highlighted significant information of siblings' experience of ID in this regard. Several authors highlighted culture and socio-economic status to some extent in their studies and discussion, but less so ethnicity (Hayden et al., 2019; Kao et al., 2011; Lobato et al., 2011). This limitation may have reflected the scope and inclusion criteria of the literature in this review, conducted in the UK, but nonetheless pointed to a lack of diversity considerations. Kao et al. (2011) explored the experience of 15 Latino families of children with ID. They identified that siblings do talk to their mothers about their sibling with ID. They suggested a context of open communication, cultural values and characteristic behaviours in Latino families, especially with mothers,

impacted acceptance by siblings, and resulted in their perceptions of more positive experiences of ID. Siblings reported mixed feelings both in terms of their relationship with their sibling, as well as regarding their caregiving roles.

Lobato et al. (2011) from their observational study of 100 Latino and 100 Non-Latino families, conducted in North America, suggested Latino families appeared to experience lower socio-economic status, placing greater demands on parents, and for caring needs. They highlighted siblings were more likely to miss school, had lower academic achievement and experienced heightened separation anxiety and problems with wider relationships. The authors speculated that this related to a direct and indirect impact of having a sibling with ID. More directly perhaps being worried about their brother or sister and their wellbeing, this reflected the closeness of their relationships. Disruption experienced in their life given socio-economic pressures and cultural expectations to care for one another, impacted their relationships with their parents and siblings (Lobato et al., 2011).

Other studies referenced both the importance and the challenge of accessing broader representation of cultural, ethnic and socio-economic diversity for participant cohorts in future research (Burke, 2010; Graff et al., 2012; Hames, 2008; Kaminsky & Dewey, 2001; Kao et al., 2011; Lobato et al., 2011; Mandleco & Webb, 2015; Moyson & Roeyers, 2012; Petalas et al., 2009a; Shivers & Dykens, 2017). These considerations were relevant in the context of the scope of the current study.

3.4.5 The family as a system and interrelationships

A fundamental aspect of the current study related to understanding siblings' experience from a systemic perspective, underpinned by family systems and bioecological theory. This

recognised the interconnective nature of relationships and the influence and impact on siblings' experience. Much of the literature referred to siblings' experience within this broader context, and discussed the interrelationship between the CY&P, their sibling with ID, their family and wider networks. Petalas et al. (2012b) illustrated this interconnectedness and reported siblings' sense of pride in their sibling's skills or achievements and noted that parental stressors and wellbeing influenced siblings' experience. They suggested behaviours of the sibling with ID impacted typically developing siblings' social interactions with others, and potentially restricted peer relationships (Benderix & Sivberg, 2007; Petalas et al., 2012b). The value of extended family support and a whole family perspective impacted siblings' experience (Hayden et al., 2023; Giallo et al., 2012).

Several studies discussed C&YP becoming aware of the psycho-social-emotional aspects of ID for them, their siblings and their families, with growing awareness of issues of difference, expressed as the reciprocity of experience, with whole family impact of ID (Hames, 2008; Kaminsky & Dewey, 2001; Luijkx et al., 2016). Siblings viewed their needs as less of a priority than the child with ID at times, as families coped with caring needs (Kao et al., 2011; Lobato et al., 2011). Other studies reported siblings' tolerance and maturity (Petalas et al., 2009a; Orsmond et al., 2009). The literature review highlighted a diversity of sibling experience of ID, with a multiplicity of factors influencing them and their outcomes. The importance and influence of the family system and the relationships between family members being intertwined with siblings' experiences was a significant consideration and a theme throughout the literature.

3.4.6 Value of self-reports and sibling resilience

Earlier research that considered the experience of families of children with ID often focused on parents' experience and advocated the importance of early intervention for parents to enable

best outcomes for the family (Benderix & Sivberg, 2007; Giallo & Gavidia-Payne, 2006; O'Brien et al., 2009). In other studies, sibling views were represented but often through parent or teacher's reports and perspectives (Tsuchie et al., 2006). More recently, research using sibling self-reports is more evident (Burke, 2010, Kao et al., 2011; Lobato et al., 2011; Mascha & Boucher, 2006; Moyson & Roeyers, 2012; Petalas et al., 2009a; Macks and Reeve, 2007; Wakimizu et al., 2020; Zaidman-Zait et al., 2020).

Several studies advocated for more research involving sibling self-reports and the inclusion of C&YP in research and suggested their subjective perspectives often differed significantly to that of their parents' views (Liamputtong, 2006; Luijkx et al., 2016; Moyson & Roeyers, 2012; Hudson, 2014; Naylor & Prescott, 2004; Petalas et al., 2009a). The challenges presented when involving C&YP in research and the ethical considerations therein are important considerations for researchers and highlighted throughout the literature. Careful and pro-active attention to these considerations is advocated to enable C&YP to engage as research participants, all the while being safe, and sensitively supported. C&YP were recognised as experts in their own lives and should be given the opportunity to participate in and inform research (Burke, 2008; Cooke et al., 2023; Gallacher & Gallagher, 2008; Giallo et al., 2012; Moyson & Roeyers, 2012; Múries-Cantán et al., 2023b; James & Prout, 2015).

Moyson and Roeyers (2012), in a study of 50 siblings between the ages of 6-14 years sought to ascertain siblings' views of their quality of life as a sibling of a brother or sister with ID. The study conducted three consecutive interviews to build a relationship and used member checking to verify the transcript of previous interviews with the siblings to ensure enhanced validity. The authors commented on access to children as participants, recruitment was through parent associations, acknowledging that some parents may not have wanted their children to

participate, so a population of children may have been excluded. They concluded, similarly to other studies, that parents' perceptions often differed to that of their children and they highlighted the importance of engaging C&YP and affording them a voice (Burke, 2010; Burke and Montgomery, 2000; Lobato et al., 2011; Macks & Reeve, 2007; Moyson & Roeyers, 2012; Petalas et al., 2009b). Other studies reported limitations in accessing C&YP as participants, e.g., those who were already in receipt of support groups or family intervention may be more willing to come forward but are not always representative of a diverse cohort of C&YP and would already be impacted by the services and support they received. Or potentially perceived a deficit perspective given the need for nonfamilial support services (Benderix & Sivberg, 2007; Kaminsky & Dewey, 2001; Macks & Reeve, 2007; Moyson & Roeyers, 2012).

Kao et al. (2011) supported the value of engaging sibling self-reports, commenting on the value of multiple perspectives to enhance research findings. They recognised commonality and difference of the impact of a child with ID between parents', siblings' and others' perspectives (Kao et al., 2011). Self-reports suggested that siblings were not always necessarily so negatively impacted in their life experience as their parents perceived, further validating research methods of sibling self-reports. This also suggested greater resilience of siblings, and linked to findings of loving, caring for and being proud of their sibling with ID (Hayden et al., 2023; Moyson & Roeyers, 2012). Sibling resilience was found in other studies (Lobato et al., 2011; Macks & Reeve, 2007; Mascha & Boucher, 2006; Mazaheri et al., 2013), siblings reported more positive psychosocial impact than reported by their families, (usually parents, mothers) (Kao et al., 2011; Lobato et al., 2011). A greater level of maturity and understanding of ID and of their siblings' needs was suggested, awareness of the broader impact on parents through socioeconomic considerations and stressors. The findings validated the authenticity of

siblings' unique perspectives of their subjective reality, such as that sought from the current study.

3.5 Conclusions, gaps identified from the literature review

The literature identified the importance of accessing the sibling voice. Studies tended to focus on various aspects of behavioural and emotional adjustment when including siblings. Others included parental reports, with the siblings' self-reports being secondary or a component of broader studies. The literature recognised the deficit and value of research accessing sibling self-reports and recognised that each family member brings a unique perspective. There were limited studies specifically framed from the outset solely exploring siblings' self-reported experiences of ID.

Both positive and negative sibling experiences were evident. There was a propensity to elicit information to inform interventions or identify psychological maladjustment and this suggested a supposition of disempowering siblings, implying that help was needed, potentially supporting a disabling social construct of 'need' for families who have a child with ID. Valuing C&YP as social agents was advocated for future research. The current study adopted such a stance from the outset, valuing siblings' perspectives and interpretation of their experience.

The literature was critical of methodology that explored sibling experiences in isolation from their wider context. Considering different theoretical frameworks, such as a family systems theory was advocated. This study therefore aimed to give due consideration to siblings as a purposive sub-group, to frame this within their wider family perspective. Recognising siblings' experience of ID cannot be viewed in isolation from their family system. This was potentially empowering for siblings, recognising their social agency, allowing the flow of knowledge and

interpretation to be led by them and therefore referencing siblings' self-reports authored from their direct experience offers opportunities to make a unique contribution in that regard.

Research considering type of ID, diagnosis and wider needs for C&YP with ID, was identified as a gap in the literature. Participants for the current study were not recruited according to one diagnosis for the C&YP with ID. Diagnosis was not ignored, but as the study aimed to explore siblings' subjective experience, this was prioritised over specific ID diagnosis for their sibling.

Gaps in the literature highlighted the importance of accessing younger siblings' contributions, informing future support for siblings and their families. Given the emphasis on potential caring needs, and the longitudinal nature of the sibling relationship C&YP play an important part in each other's lives, and for their future. Participants for this study were drawn from C&YP at a fundamental life stage from 11 to 16 years old. This was an underrepresented cohort from the literature. This life stage represents a unique period, a time of significant change, growth and considerations of self-identity. The literature supported the need for further research with this demographic, attending to this life stage and the potential differentiated experiences for C&YP therein, as opposed to that of much younger or adult siblings (Burke & Montgomery, 2000; Correia & Seabra-Santos, 2022; O'Brien et al., 2009; Petalas et al., 2012b). The current study related to previous literature and aimed to advance understanding of the differentiation of views of siblings at this pre-adolescent and adolescent stage of development, enabling greater representation in the future body of literature thus contributing to current and future priorities for research, in exploring siblings' experience of having a brother or sister with ID.

Gaps in the literature identified limitations in the diversity of participants related to their identified culture, ethnicity, religious background and broader socio-economic factors that may

impact siblings' experience of ID. The present study focused on a geography in the East of England and Greater London, in England, thereby accessing a unique population not replicated in the literature. While the diversity of the cohort was self-selecting, consideration of culture, beliefs, religious background and siblings' perspectives was considered, adding to the literature source, and in the UK context.

Informed by the literature review, analysis and identification of gaps in the literature, within the parameters of the cohort and the context outlined above, this study identified and explored the research question:

'What are siblings' experiences of having a brother or sister with intellectual disabilities?'

CHAPTER FOUR: METHOD

4.0 Overview

This chapter gives an outline of the context of the study, providing further background of my interest in exploring siblings' experience of intellectual disabilities (ID). An overview of the design and discussion of my epistemological positioning that informed the research is presented, as related to the context, aims and development of the research question for this study. A rationale for the methodological approach and choice of method of analysis is discussed. Important aspects of conducting research with children and young people (C&YP), including ethical considerations; establishing trust; parents as gatekeepers; obtaining consent; issues of power; my role as a researcher and considering C&YP as research participants in conducting the research, are explored. Additionally, assessing quality in the research is considered.

4.1 Context, research interest and aims

This section outlines a brief contextual background to the researcher's interest and development of the research question. It will also outline the research aims and consider these in relation to population data for the participant cohort, i.e. siblings with a brother or sister with ID, in the UK.

4.1.1 Background context to the study

As noted in chapter one (section 1.2) and chapter two, my interest in conducting a research study exploring siblings' experience of ID was influenced by my professional career and personal life. Having conducted a small-scale qualitative study with adult siblings who had grown up with a sister with ID in 2002, my curiosity and interest developed to explore the lived experience of children and young people who have a sibling with ID. My interest and the gaps

identified in conducting the literature review informed the direction of the current study, undertaken as part of a Doctor of Philosophy (PhD) study. The study was conducted in the UK in the East of England and Greater London, given the practical considerations of conducting the research and accessing participants as a lone researcher, a part-time student and working full time with family responsibilities (Finlay, 2011). The participant population from this geography was not represented in the literature and included siblings between the age of 11 and 16 years old who had a brother or sister with ID. The rationale for choosing this participant population was discussed in chapter one and will be referred to later in this chapter. Further considerations related to quality, rigor, transparency, and potential impact of the research undertaken is also included (Smith, 2015).

4.1.2 Identifying the participant population, value and importance of sibling relationships

As explored in chapter one (section 1.3) it is challenging to identify the population of C&YP with ID in the UK. It follows that current data available identifying the number of siblings with a brother or sister with ID is equally difficult to define. However, as estimated by the organisation Sibs UK (Sibs UK, 2014), there are over half a million siblings of children with disabilities in the UK, 5.1% of whom are under the age of 16 years. The siblings of C&YP with ID therefore represent a significant population. This reinforces the importance of research that focuses on the siblings of C&YP with ID, as such studies provide deeper insight and understanding of their experiences.

As noted in chapter one, (section 1.3.1) sibling relationships are important, life enduring, and often complex where one or more C&YP in the family have ID (Burke, 2004; Davys et al., 2010; Seligman & Darling, 2007). Several studies explored this enduring relationship for siblings and pointed to the importance of enhanced understanding of typically developing

siblings' experience given the potential lifelong impact of siblings' responsibilities and connected future lives (Burke 2000, 2004; Burke & Montgomery, 2010; Graff et al., 2012; Seligman & Darling, 2007). The literature review highlighted gaps from previous research, with an underrepresentation of studies exploring the subjective experience of C&YP as siblings. It is in this context that the current study is important for accessing and interpreting siblings' experience, to inform support for siblings themselves, for their brother(s) or sister(s) with ID and their families.

4.1.3 Research aims

The research aimed to explore siblings' experience in the context of their familial relationships in families who have a child or young person with intellectual disabilities (ID). The study focused specifically on the lived experience of siblings with a brother or sister with ID, gaining insight from their accounts of day-to-day life and their experience of ID as a typically developing sibling. The aim was to give a 'voice' to siblings by interpreting their subjective accounts and observations, and to enhance the understanding of their experiences through exploring and interpreting their sense-making of their lives (Finlay, 2011; Green & Hogan, 2005; Smith, 2015). The study also aimed to enhance the understanding of adults, family members, and professionals who provide support to families who have C&YP with ID, with particular attention to the experiences of their siblings. This study aspired to contribute to the body of knowledge available to non-familial services, thereby informing and enhancing professional practice and policy in England.

4.2 Design

This section will outline the research design, giving due consideration to the development of the research question and my own epistemological position in designing the study. The

methodological approach and method of data analysis adopted will be presented, providing a rationale and subsequent discussion of both.

This study adopted a qualitative approach that enabled the research question to be addressed. Qualitative research seeks to identify and attribute meaning, providing an approach to support studies where the potential for new interpretations and understandings can emerge. Qualitative research aims to be inductive and exploratory. It poses questions related to description and understanding, seeking to explain or potentially prove a given situation, or set of circumstances and presenting an interpretation, while acknowledging and attending to my own subjective influences and what is prioritised through the method of the analysis and interpretation of the data and findings emerging from the research (Finlay, 2011; Willig, 2013).

A qualitative approach was supportive of my epistemological position of valuing the capacity and unique contribution of individuals, embraced in both my working and personal life. Working with people with ID, who are often assumed to have limited capacity and agency, my philosophical approach as a nurse in this field of intellectual disabilities, has been to explore creative ways to engage with people and their families to optimise support and their health and wellbeing outcomes. In the same way, recognising from my experience, and in reviewing the literature, a deficit in my own understanding of siblings' experiences of ID was also an influence, with a desire to improve their outcomes and that of their families. Accessing siblings' voices through their interpretations and subsequently exploring the meanings they attribute to their lives and experiences of ID, aligns with the view that siblings hold unique knowledge and perspectives not accessible to others, grounded in their lived, day-to-day experiences. As a participatory approach to research the study aims and research question were concerned with understanding siblings' experiences through a collaborative process, drawing

from this towards the creation of new knowledge (Silverman, 2014; Smith et al., 2009; Veale, 2005; Green & Hogan, 2005; Willig, 2013).

4.2.1 C&YP power and agency

As outlined in the introduction (see section 1.3.1) C&YP have traditionally been seen as passive participants in research, mirroring their daily lives, where they can experience a lack of agency, power, and control. The research sought to acknowledge and try to address this imbalance, by using a qualitative approach to give 'a voice' to siblings' specific experiences of ID (Green & Hogan, 2005; Grieg et al., 2013). From this epistemological stance C&YP were valued as the experts and social agents in their own lives (James & James, 2004). By privileging their direct accounts, I considered the research to be more authentic, generating knowledge from C&YP about themselves, their lives, and their experiences (Christensen & Prout, 2002; Gallacher & Gallagher, 2008; Finlay, 2011; James & James, 2004; Smith, 2015).

It was essential to consider the issue of power imbalance in the context of this work, attending to the potential in the research for me to be in the roles described by Willig (2013), of both author of and witness to the findings. This was an important consideration not only as a researcher but given my broader personal context, considering the authenticity of my approach was essential in ensuring that privileging of the participants voice was fundamental to the research. Alongside this, it was important to recognise that as a researcher undertaking the analysis, the influence of my context, potential biases, and views meant that any conclusions drawn could only ever be an interpretation of the data, rather than the only 'truth' or possible interpretation therein (Willig, 2013).

4.2.2 Choice of methodology

This section will discuss the choice of methodology providing a rationale for the approach and the specific qualitative method of analysis chosen in addressing the research question and meeting the aims of this study.

Methodology is described as a general approach to the research topic. Method of analysis is the specific technique adopted by the researcher in managing the data (Silverman, 2014; Willig, 2013:8). Three questions were helpful in considering and reflecting on my epistemological stance, and these informed the methodological approach adopted for this study. Firstly, what kind of knowledge I aimed to produce; secondly, my own assumptions about the world, beliefs, values, and privileging the unique subjective experience of siblings as a source of authentic knowledge. Finally how a particular methodological approach might conceptualise my role as a researcher, particularly within the research process, when undertaking research that sought to explore the subjective experience of others (Willig, 2013:96-97). In summary, my own epistemological position, the aims of the research, by seeking to access siblings' unique experience of ID through the voices and accounts of a purposive group of C&YP, directed and informed the choice of a qualitative research methodology, as most appropriate. The choice of qualitative methodology in turn informed the method of data analysis adopted.

Subsequently this study explored siblings' experience of ID from a phenomenological perspective, privileging the experiences of siblings with a brother or sister with ID as a purposive cohort and most authentic source of knowledge and experience of 'being' siblings in this context. Adopting a qualitative approach acknowledged that siblings' experience was not something I could 'know' directly. The intention, and the knowledge this study aimed to produce, was to elicit an enhanced understanding of siblings' experience by accessing and

subsequently interpreting their responses and subjective interpretations of their experiences (Smith et al., 2009).

The research interest area, research question, aims, and consideration of personal and professional context also framed this research in an interpretivist paradigm (Rehman & Alharthi, 2016). As Smith et al. (2009) described, as a researcher I can only ever interpret from a position of empathy and of questioning, siblings' experience is just that, their experience. The approach also attended to my role as an interpreter of the data, influenced by my own context and informed by wider research. Acknowledging my potential to privilege certain perspectives and interpretations was ever present in my mind when conducting the research. This emphasised the importance of reflexivity, and consideration of my own context and potential biases to ensure credibility, sensitivity of context, coherence and auditability of the research process. This is discussed further in section 4.2.5, related to the choice of method of analysis as interpretative phenomenological analysis (IPA) (Smith, 2015).

This study engaged participants' subjective 'embodied' experience and related this to their existential engagement, i.e., how they live their lives, their experiences of ID, and their interpretation of their experiences as siblings. In asking participants to explore being a sibling, the research was seeking to access their relational experience with their siblings with intellectual disabilities, with their family and their non-familial networks with the intention of providing an affective perspective. For the participants, engaging in the research itself focused a lens of attention on being a sibling with a brother or sister with ID. In other words, it drew attention to this and in phenomenological terms this involved cognitive considerations for participants (Smith et al., 2009). By asking about their experience, they may have further questioned their own sense of being a sibling, outside of the research activity, and what this

means to them and to their families. Adopting a qualitative methodological approach for this study enabled the research to attend to these considerations and provided safeguards for the C&YP, i.e., through their parents as gate keepers, and in providing information of wider support available as part of the recruitment process and ethical considerations (see section 4.4).

4.2.3 Choosing a method of analysis

For this study, the choice of a method of analysis linked to a humanistic interpretation and an approach valuing the sibling as a whole person, understanding that each sibling was unique, with possibilities for varied and unique constructs of their experience to co-exist both positive and less positive (Grieg et al., 2013).

The research question sought to explore siblings' experience of intellectual disabilities. The study aimed to access siblings' lived experiences, to hear and interpret their voice as authentic authors, bringing an enhanced understanding from their perspective as a sibling rather than through the accounts or assumptions of others. These considerations were central to the investigation of several methods of analysis before the chosen method was adopted.

4.2.4 Consideration of other methods of analysis

This subsection will provide a rationale for preferencing the chosen method of analysis, relating this to the research question, the aims of the research study, and my own positioning as a researcher.

Grounded theory was explored as a potential method of analysis, given the interpretative elements that have evolved in this approach in more recent times, with a more constructivist lens, i.e., recognising my role in the co-construction of the data and my inherent subjectivity.

Grounded theory therefore had potential value in the context of this research (Charmaz, 2000, 2015; Flick, 2023). However, the research question and aims of this study were not concerned with developing a new theory or building this from the experience of conducting the research, hence grounded theory was discounted.

Given the emphasis of the study to attend to and privilege the voice of the siblings themselves, discourse analysis was considered. This method attends to language, both the characteristics and the role of language in social constructs (Charmaz, 2000, 2015; Flick, 2023). The social constructs of families, the discourse and social constructs of ability and disability and the positioning of the study suggested discourse analysis might have potential as a method of analysis. While this method had value in considering social constructs and narratives of disability for this research study, the research question and aims did not seek to explore the characteristics of language used by the participants. Neither was the basis of the research question looking to explore language in the social construction of families, siblings, or ID. Therefore, discourse analysis was also discounted.

In exploring siblings' experience of intellectual disabilities the research had potential to elicit shared or common experience from the analysis of the data. Thematic analysis is described as an approach for 'identifying, analysing and reporting patterns (themes) within the data' and was therefore an approach worthy of consideration (Flick, 2023). However, the aim of the research was to explore siblings' experience of ID drawing from each individual's lived experiences to access siblings' personal meaning making and not primarily to seek common patterns or develop shared themes. The uniqueness of their subjective expert experience of ID as a sibling, for each of the participants, their perceptions and sense making was the central interest. In addition, thematic analysis is not connected to any particular theoretical position

unlike methods such as interpretative phenomenological analysis, and therefore this was not considered to be the most appropriate method to support the primary aims, epistemology and theoretical underpinning of this study (Flick, 2023; Smith et al., 2022). Therefore, thematic analysis was discounted.

The aim of the study was to explore the siblings' experience of ID, within their context, given their unique relational position of having a brother or sister with ID. The aim as a researcher, was to access siblings' direct experiences, their interpretations and sense making of their experience, and to interpret their accounts. Interpretative Phenomenological Analysis, (IPA), was therefore considered the most appropriate method of analysis, aligned with the epistemological position of the study, to address the research question and support the aims of the study (Smith et al., 2009). The characteristics of, and rationale for adopting IPA as the method of analysis are discussed in the following sub-section.

4.2.5 Interpretative phenomenological analysis

This sub-section discusses the choice of IPA as the method of analysis, outlining the rationale for adopting this approach to support the management of the data collection and in addressing the research question and aims of this study.

IPA is a qualitative approach to data analysis. It enables the researcher to examine how people interpret and make sense of their experience and therefore it related well to the research question for this study (Smith et al., 2009). Three influences underpin IPA, phenomenology, hermeneutics, and idiography. These are discussed below as they relate to the current study.

Phenomenology has its basis in several philosophical traditions and movements and has given rise to a range of phenomenological methodologies. Transcendental phenomenology, as attributed to the philosopher Husserl, was concerned with our experience of the world in particular times and contexts. Described as bracketing or transcending our bias and presuppositions to understand phenomena purely as we see and experience it in the here and now (Finlay, 2011; Willig, 2013). This philosophical position was further developed by Heidegger in considering the state of 'being in the world'. Heidegger and subsequent philosophers developed the consideration of hermeneutics, the context of sense making and interpretation of experience. In this study, siblings' interpretation and sense making of their experiences, as presented in the research process, lends itself to this philosophical stance (Finlay, 2011; Willig, 2013).

Central to IPA and relevant to this study, is the consideration of the 'double hermeneutic' (Smith et al., 2009). Siblings shared their experiences from their perspectives and presented their interpretation of the phenomena of being a sibling with a brother or sister with ID. Through conducting interviews and engaging in conscious, reflexive processes both in undertaking the research, and when conducting the data analysis, my role as the researcher provided a further level of interpretation. Importantly, both the siblings as participants and myself as the researcher are inevitably influenced by our own context and experiences, this is a central principle to acknowledge when conducting IPA. The double hermeneutic involves two levels of interpretation; the participants' meaning making, which constitutes the primary 'first order' participant account, and my subsequent sense making and interpretation, which forms the secondary 'second order' account, interpreting what it looks and feels like to be in their world (Smith et al., 2009:36).

This study sought to gain an insider's view, from the siblings' perspective, to understand what it is like for them, having a brother or sister with ID. Equally, in conducting this kind of research, and when analysing the data as a researcher, it was important for me to question and consider my own influences, and how that might in turn, influence the research process and interpretation of the participants' accounts. As a researcher I was 'present' in the interviews and therefore interacting directly with the C&YP.

Recognising adult-child power constructs and considering the agency of the C&YP were important factors to keep at the forefront of my mind. Considering both my personal context as a mother and my professional background and connections to ID, potential influences on the research process and interpretation were also important contextual factors to consciously attend to. Reflexivity was important, considering how I engaged in the interviews, when building the research relationship with the C&YP, and when analysing and interpreting the data. This involved attending to and acknowledging potential influence on the process and the outcomes of the research.

Being alert to the double hermeneutic ensured conscious consideration of my own biases and reinforced the importance of constant alertness to issues of power imbalance, as noted earlier. As an IPA researcher, Smith et al. (2009), describe the researcher as 'in part wanting to adopt an insider perspective to see what it is like from the participant's view and stand in their shoes', in this case to stand in the shoes of a sibling. Yet, as a researcher I was also standing alongside the participants, questioning, analysing, and interpreting the siblings' interpretations and meanings and in doing so, aiming to reach a more authentic and enhanced understanding of siblings' experience of ID (Smith et al., 2009:36).

When considering the insider view, I was conscious of my personal context as a mother of four young people, one with ID. I am not a sibling, but have the context of my own lived experience as a mother, whereby my son with ID and his brothers, will have their own perspectives and experiences as siblings. Active consideration of this context was essential, both for me as a researcher and for the research process, as the study aimed to explore how C&YP interpret and construct meaning from their experiences of having a sibling with ID.

Merleau-Ponty, explored what was described as our existential position in the world, the mutual relationship between the self, the body, and the world (Finlay, 2011). For this study, bodily experience in research was relevant, considering this was research undertaken with C&YP and giving due consideration to power and agency of the participants as C&YP with my position as an adult researcher. IPA as a method of analysis, requires the researcher to be attuned to the responses of the C&YP, all the while attending to and adapting responses in the direct interactions with the C&YP. Using a reflexive diary, and by adopting reflexivity throughout the process of analysis, I remained alert to my own position as a co-participant as well as an observer in the research process. IPA enabled me as a researcher to stay true to the siblings' experience, to be immersed in and engaged with the emerging data, using the C&YP's words to draw out deeper levels of sense-making and interpretations. In conducting the analysis and by continually referring to and checking back with the original transcripts, my interpretation stayed as true as possible to the original text and subsequently remained embedded in the siblings' existential experiences (Smith et al., 2009:35-37).

Idiography in IPA is concerned with the experiences of a particular group of people (Finlay, 2011; Willig, 2013). In this study the purposive participants were siblings with a brother or sister with ID, a homogenous group. IPA recognises the importance of the lived experience of

the participant group and is supportive of an in-depth focus on smaller cohorts (Smith et al., 2009). This study was focused on 'the particular': interpreting the experience of 'being a sibling', for the C&YP themselves. The C&YP were not identified as separate from their world and relationships. In using IPA, idiography enabled the researcher to recognise the perspective of the individual as experienced in a worldly and relational context, and to value their individual perspectives, drawing insight from their experience as a specific phenomenon with interpretations that were therefore more accessible to others. This further supported the choice of IPA as a method of analysis for this study. From an idiographic position, the study considered sibling relationships from a systemic perspective using siblings' familial relational context as a lens through which the interpretation of the evolving themes and data analysis were discussed. When undertaking qualitative research, Goldenberg and Goldenberg (2004), highlighted the importance of including consideration of the uniqueness of the individual's experience, acknowledging individuality, while recognising the diversity of family structures and the wider influences that affect people and their families. For this study, attention was given to family structures and to the position of siblings within their families. The inherent nature of sibling relationships placed the C&YP's experiences within the context of their interrelationships with their brother or sister with ID, as well as in shared experiences across the family unit. In conducting the research, simple genograms were used as a visual tool a 'pen picture' to support the understanding of the siblings, their immediate family and day-to-day environment (McGoldrick et al., 2008). The systemic perspective is further explored in the discussion (see chapter six).

As noted earlier, an important consideration in using IPA was staying true to the transcripts and undertaking intense and detailed engagement with and immersion in the data for each interview (Smith et al., 2007). Through the process of analysis, subsequent emergent themes

and relational connections presented. From these connections, as a researcher I began to draw possible individual as well as collective conclusions. This was only after detailed analysis of each individual interview and could only ever be presented as one interpretation of the data and for this purposive group (Willig, 2013).

IPA was therefore considered the most appropriate and authentic method of analysis to support the research question, the aims and epistemological positioning of the study, interpreting siblings' experience of ID, in the context of their familial interrelationships. This method of analysis enabled me as a researcher to attend to the siblings' interpretation of their experiences of ID, with a constant reflexive awareness of my own influences, giving due consideration to the double hermeneutic in the subsequent interpretations, findings and proposed conclusions.

4.3 Ethical considerations

This section will provide an overview of the ethical considerations as applied to this research study, including discussion regarding participatory research and further considerations of power and agency when undertaking research with C&YP.

Research ethics relates to participants and researchers, as well as to their institutions and the 'good name of research' (Alderson & Morrow, 2011:3). From the outset ethical considerations have been very important, when choosing the research topic, identifying participants, devising the research question, throughout the design, and in conducting, analysing and writing up the study.

This study involved C&YP as participants. It was essential to identify and consider all risks and ensure appropriate strategies were in place to safeguard the C&YP, their families and for

me as the researcher (Grieg et al., 2013). Appropriate ethical approval was sought throughout. Changes required were discussed with supervisors and additional ethical approval obtained. In the main changes related to expanding the search criteria and extending the timeframe for recruiting research participants given the difficulties experienced in recruiting C&YP, (see appendix two (a–e), aHSK/PGR/UH/02318; aHSK/PGR/UH/02318(1); aHSK/PGR/UH/02318(2); aHSK/PGR/UH/02318(3); aHSK/PGR/UH/02318(4)). A risk analysis was completed in the context of undertaking interviews with C&YP, and as a lone researcher and PhD student, to safeguard the participants and me as a student and researcher, and to align with the host university's requirements, (see appendix three).

Issues of confidentiality were at the forefront of conducting this research, including safe storage of data and anonymity. Data was stored in line with approved ethical protocols on secure servers in the university. Participant information for the study was anonymised and information was shared with supervisors in line with agreed support mechanisms for a PhD study. In the context of the current study, as a researcher I was not engaged with the C&YP in a therapeutic capacity. However, recognising their potential vulnerabilities was important therefore information of how to access local support services was provided to families and participants before they agreed to engage with the research. Consent was sought, with consent forms discussed with and signed by the C&YP, their parent and the researcher before any interviews commenced, (see appendix six).

4.4 Data collection tools, co-production power and agency

This section outlines the approach developed to gather the data. Co-production and design of the research tools is explored giving due consideration to power, agency, and the involvement of C&YP in the design process.

This study used semi-structured one-to-one interviews as a data gathering tool, enabling a degree of structure in supporting data collection. As the research involved C&YP, and recognising the uniqueness of each participant's experience, semi-structured interviews were considered a valuable approach to support the aims of the study. As a novice researcher this also provided a frame within which the questions and conversations could be engaged, allowing for this to be adapted and supporting natural conversational responses within each participant interview (Smith et al., 2009).

Addressing the issues of power and agency, and to ensure the design of the questions was as authentic as possible, I was acutely aware of the need to engage participation and inclusion of C&YP in the approach to and design of the research from the outset. Participatory research and co-production of research with C&YP is discussed in the next sub-section of this chapter.

4.4.1 Participatory research and co-production with children and young people

Participatory research is a collaborative process and important for this study, with siblings being valued as expert participants (Smith et al., 2007; Veale, 2005; Grieg et al., 2013). Participatory methods enable acknowledgment and consideration of the potential lack of agency for the participants. This was very important in conducting the research with C&YP. Valuing the C&YP as social authors offered an opportunity to produce more authentic knowledge about their experiences (Christensen & Prout, 2002). In addition, it was considered important to enable the inclusion of C&YP in the development of the information and data collection tools, supporting greater authenticity in their design.

The concept of participation of C&YP in research is complex, embedded in the social construction of childhood and a myriad of socio-political, cultural constructs and influences.

This is described by Burnham (2012), as 'social GGRRAAACCEEESSS', i.e., gender, geography, race, religion, age, ability, appearance, class, culture, ethnicity, education, employment, sexuality, sexual orientation, and spirituality (*SG*) (Burnham, 2012; Totsuka, 2014). Considering SG, power, agency, influence, behaviour, interactions, and influences on interpretations are essential when engaging in research with any group, though especially so when undertaking research with C&YP (Christensen & Prout, 2002; Grieg et al., 2013; James & James, 2004; Prout, 2011). To address these considerations, a reference group of 14 C&YP was recruited to support the development of the research tools. This is discussed in the next sub-section of this chapter.

4.4.2 Use of an expert by experience C&YP reference group

The reference group approach was used to engage the C&YP's voice and to support the authenticity and design of the information, recruitment and data gathering tools. The reference group were 14 young people who were not participants in the research study directly, but as an advisory group to check the research materials and highlight any biases or assumptions made. Reference groups are helpful when working with C&YP to promote a values-based approach, providing a means to actively engage C&YP in research design (Mercieca & Jones, 2018). This approach enables adult researchers to access knowledge that might otherwise be inaccessible in the approach to research design, engagement, and analysis when conducting research with C&YP (Moore et al., 2016). In supervisory discussions, it was agreed to engage young people through local networks, and to form a suitable reference group. Various methods of recruitment were adopted to recruit a reference group. Firstly, through advertising within the researcher's university student union, as agreed via the Dean of Student's Office and the Students' Union Officers. Despite repeated advertising and promotion by Student Union Officers, this route of recruitment proved unsuccessful.

A reference group of 14 young people aged between 17 and 18 years old were finally recruited following a successful approach to a local secondary school. This group was established through a direct contact via telephone and follow up emails. A school outreach staff member arranged the introduction and ensured all required protocols were followed, i.e., verification of the ethics approvals and context of the research being undertaken were provided, (see appendices four & five). A reference group meeting was arranged and conducted in a familiar and relaxed environment within their school. The researcher provided light refreshments and facilitated the discussion, providing an outline of the research question and aims, and sharing an example of a draft information booklet, prepared beforehand.

The young people were very engaged and they discussed and supported the adaptation of the information booklet to support the study. The group shared views on the value and importance of this type of participatory research. They identified the need to differentiate the research materials by age groupings, to support accessibility for C&YP from different age groups participating in the research. The advisory group were very attentive to detail, for example, in the use of language, definitions, and imagery to be included. The group advised on the types of questions for the booklets and on the interview schedule, being attentive to the cohort of participants and ensuring optimised accessibility. Their committed engagement and attention to detail was both striking and encouraging, considering the context of this research study, being designed with and for C&YP. Their insights validated this inclusive approach, respecting C&YP as social agents, and knowledgeable participants informing the research process. This supported the authenticity of the design of the research tools and approach (Alderson & Morrow, 2011; Grieg et al., 2013). Thus, I was able to adapt the resources with greater confidence, enhancing the accessibly and authenticity of the recruitment and data collection tools.

Letters of acknowledgment for the young people in the reference group were provided to add to their curriculum vitae, with an amazon voucher (value of £5.00) given as a gesture of thanks. This recognised the value of their contribution and was appreciated by the young people, as advised by the feedback from the school facilitator's correspondence, (see appendix five).

The approach of direct engagement with a cohort of young people enabled me as a researcher, to be attentive to their views, appreciating for example, that C&YP of different ages perceive the world differently and adjusting resources to address this (Grieg et al., 2013). Subsequently, two booklets were produced, with the language and imagery adjusted to reflect age bandings as suggested by the reference group. One booklet was prepared for C&YP aged between 11 to 14 years, and one for those aged 15 to 18 years, (see appendices nine & 10). The Flesch-Kincaid reading score was used to support this process (Readability formulas online, n.d), to ensure language was pitched to an age appropriate level and this was also helpful in the formulation of the semi-structured interview schedule, (see appendix 11).

4.4.3 Recruiting research participants

This section will provide an overview of the process of recruiting participants to the study and highlight issues of consent, gatekeeping, and the approach used to build rapport and trust with the C&YP and their parents.

Initially participants were sought through the platform of NetMums, as suggested in supervision. NetMums is an online parent support resource and was considered a good option as other researchers in the university had previous success using this as a participant access platform. Adverts were also placed with the university Students Union both online and on physical noticeboards. Despite several relaunches of the request on the NetMums site, with

repeated advertising and the support of the student union team, no participants were secured via either of these routes.

Participants were also sought through contacting mainstream secondary schools in the geographical region in scope for the study. Schools were contacted via email, and with follow up telephone calls. Flyers were produced to introduce the research and to present myself as the researcher to the schools, (see appendices six & seven). Initially five secondary schools were contacted in each catchment area in the counties approved in the ethics protocols. Limiting the numbers of schools at this stage was to prevent potential overload of participant numbers, however, this was an unfruitful route for participant recruitment.

Recruitment activity was expanded, and more secondary schools were contacted across the counties in scope. Despite telephone contacts, follow up emails, in person visits to distribute flyers, and the offer to attend in person to speak to student groups, no participants were secured via this activity.

Following discussion with the Postgraduate Research Tutor, with supervisors, and through engagement with other research students to share experiences, as well as via the online IPA discussion group (ipaqualitative online forum), further ethics approvals were sought to expand recruitment activity, to include special needs schools and family centres. These were approached across the same region for geographical accessibility. Posters were produced to advertise the study, and further distribution of flyers undertaken, directed to additional mainstream schools, both primary and secondary, and including schools specifically supporting children and young people with special needs. Family centres were contacted, and personal visits were made to meet group leaders to explain the research in person, and to gain their

support and agreement to promote the study, display posters, and distribute flyers to the families accessing the service, (see appendices seven & eight).

Distribution of flyers was further expanded to include local and national organisations supporting people with intellectual disabilities and their families e.g., Families in Focus, Down's Syndrome Association, Angelman's Association, and Mencap. Once again, contact was made through emails and direct telephone calls, follow up emails were sent to provide further information. Permission was granted to complete blogs on local and national associations' "Facebook" and other media sites, to attract applicants. Contacts via other schools of study in the university were also explored, e.g., distribution of the research information flyers at the university's School of Education annual conference. Personal contact with fellow research students was explored as a potential recruitment mechanism. Participant recruitment proved challenging, and ethical approvals were revised several times to expand the range of options, geography, and opportunity for recruitment, (see appendix two (a - e)).

The literature acknowledged the potential challenges of recruiting C&YP as research participants (Grieg et al., 2013; Campbell, 2008; Greene & Hogan, 2005), therefore challenges were anticipated for this study from the literature review, but not to the extent experienced. Recruitment was a frustrating part of the research journey as the effort and time frame for this activity needed to be significantly extended and presented a risk to conducting the study. This was also challenging as a part-time student researcher working full time while undertaking a PhD study. Participants were finally successfully recruited, mostly via a local organisation, Families in Focus', through the Down's Syndrome Association blog, via direct advertising on the university staff networks, and via a follow up contact from the School of Education conference.

Additional flyers were distributed to the recruited participant families, with a request to share with their networks, to promote a potential snowballing approach to increase the participant sample. One participant was recruited via this route (Grieg et al., 2013). The eventual responses received, came directly from parents (eight mothers and one father). All the participants recruited were linked to one of the organisations who had been contacted and had endorsed the study. This highlighted the importance of trusted links and gatekeepers in enabling access to research participants. Recruiting participants through trusted links is important for all research participants, but even more so when accessing those who are potentially more vulnerable and where power imbalance exists between participants and the researcher, such as with the C&YP in this study (Grieg et al., 2013:258).

IPA supports the validity of smaller participant samples when adopting an in-depth immersion approach to data analysis, characteristic of phenomenological studies such as this, exploring the experiences of individuals or a purposively selected group. The participants who were subsequently recruited for the study, and the rich data collected, enabled this immersive approach as in IPA, exploring siblings' experience of ID (Smith et al., 2009). In all, nine sibling participants were recruited to the study.

4.4.4 The interview schedule

A semi-structured interview schedule was developed, (see appendix 11). This was informed by the literature review, (see appendix one), drawing on the feedback from the reference group discussion, from the literature review, and wider reading, and informed by supervision discussions. The schedule was helpful for me as a novice researcher, providing structure, while also allowing flexibility to paraphrase questions during the semi-structured interviews to accommodate the flow of conversations with participants. Using semi-structured interviews

helped to elicit in-depth rich data from the participants' own words and responses, essential for this type of qualitative research (Smith et al., 2009; Finlay, 2011).

The interview schedule consisted of 27 questions and associated prompts grouped into themed areas, informed by the literature review. The schedule, the questions, groupings, and overall aims of each section are outlined in the interview schedule, (see appendix one).

4.4.5 Consent, building rapport and establishing trust

First contact with all participants was made via their parents, (eight mothers and one father), who were contacted by email or telephone as detailed on the flyers. This supports the point noted earlier regarding positive engagement and establishing rapport with gatekeepers (Grieg et al., 2013: 260). This contact was followed up by the researcher to establish the initial engagement. Parent information sheets and booklets for the potential participants were provided by email and or posted out as a hard copy as requested. Initial 'entry gate' meetings were arranged to ensure parental consent. Given the ethical dilemmas inherent in research involving C&YP, it was necessary to engage with associated adults to facilitate access to children and young people as participants (Fargas-Malet et al., 2010).

Participants were offered the opportunity to meet at their home, or an alternate venue where they would feel comfortable to speak to the researcher. All but one of the participants opted to meet in their family home. One participant's introductory meeting took place at a local café, at their parent's request. All participants were accompanied by their parent, (their mother in all cases). The researcher discussed the project further, elaborated on the information sheets, booklets, and flyers, and answered any queries. A basic genogram 'family tree' was drawn in the initial introductory conversation with the participants and their parent(s) and these were

anonymised (see appendix 12). This provided a visual means of gaining an overview of the family, in a shared exchange, and the C&YP enjoyed helping to create this simple representative diagram of their family. This was also helpful for me as the researcher and used as a point of reference for future interview conversations, and when undertaking the analysis (McGoldrick et al., 2008; Rempel et al., 2007; Seligman & Darling, 2007).

The intention of the initial meeting considered good ethical practice when conducting research with C&YP. This ensured transparent parental consent and enabled the siblings to be more comfortable about sharing family and personal information. This commenced a relationship with me as the researcher, establishing the potential for mutual trust with the participant and with their parent (Grieg et al., 2013; Alderson & Morrow, 2011). It is acknowledged that having a parent present may have influenced what the young people said or shared in the interviews. The principle here, considered the view of Grieg et al. (2007): 'If research involving young people is to be successful, then it is of prime importance that the relationship with parents is good. Fundamental to this process is gaining trust, which requires that you are honest and reliable and communicate well.' (Grieg et al., 2007:260).

Siblings and their mothers were given time to discuss the information and contacted the researcher thereafter to advise of their agreement to participate. This ensured the siblings had the opportunity to consider the information at their own pace after our meeting, and the opportunity to ask follow-up questions if required, with parental support.

All nine families agreed thereafter to participate in the study. Follow up contact was made by email and telephone, consent forms were sent via email and signed by the participants, their parent, and me as the researcher, (see appendix six). Arrangements were made to visit the

participants to undertake the semi-structured interviews at a convenient date and time for the siblings and their family.

4.5 Conducting the interviews

Following the initial meeting, arrangements were made to meet the participants in their own homes. Parents (mothers on all but one occasion) were present in the home during the interviews but remained in the background by shared agreement, while being available if needed. Parents did not participate directly in the interviews. Participants were reminded of the overview of the study, that they could withdraw from the study at any point, and their consent was reaffirmed. Interviews were tape recorded and lasted between approximately forty-five minutes to an hour.

It is important to acknowledge the participants' mothers being present in the home during the interviews. The meetings with the C&YP took place in either their bedroom, a shared room in their home, e.g., dining or living room. For all but one of the interviews the discussion took place in a room with the door closed by collective agreement with the C&YP, their mother and me as the researcher. For one of the C&YP their mother was in the kitchen preparing an evening meal, and the interview took place in the adjacent living room. In this instance, the doors to both rooms were left slightly ajar, there was no obvious engagement by the mother with the interview, and the participant appeared to speak freely.

The presence of their mothers may have impacted the nature of the siblings' discussion and the information they chose to share. They may have felt inhibited in sharing their experience openly, particularly for experiences that were more difficult to discuss, or where it might be perceived they were being critical of their parents, their sibling, or were challenged by their

experience as a sibling. However, having a parent present also had the potential to free the C&YP to express their views openly, given prior shared consent had been agreed with their parents. Parents had in all cases been the primary contact for engaging with the research and openly encouraged their C&YP to participate. While the influence of mothers being present cannot be directly assessed, it is important to acknowledge as a fundamental aspect of conducting this research with C&YP.

In addition to the interviews, participants were invited to complete a blog/diary in a format accessible to them, e.g., a paper diary, computer blog or video diary, over a six-month period identifying significant events and situations, e.g., birthday or a self-defined event or circumstance. I sought assurance that the C&YP had access to a tool to support this, e.g., notebook or a computer, and offered to provide paper diaries that I brought with me, if needed. Diaries are considered a valuable additional source of data complimenting other methods (Hyers, 2018; Willig, 2013).

C&YP were invited to make an entry twice per month minimally, no restrictive guidance was given to ensure participants were given agency to input from a personal perspective and preference as situations occurred naturally. The aim of the blog/diary was to offer a further source of data over a longer period. The rationale was also to support the participatory approach and address the influence of the researcher being in the room at the semi-structured interview. Considering that children and young people might reflect differently without the researcher present, giving due consideration to issues of power and agency, and the societal realities of adults being in a position of power and influence over children (Alderson & Morrow, 2011; Grieg et al., 2007).

Monthly contact touch points were agreed with the participants, it was collectively agreed that these would be conducted via email. The intention was to prompt ongoing engagement, provide encouragement, act as a reminder and to support participants as needed. Email contact was via their mothers' email accounts to further ensure openness and trust with parents and the C&YP. Whilst this engendered trust with their parents, and provided safeguards for me as a novice researcher, and for the C&YP, it could be also be seen as an infringement of their privacy. While the siblings did not raise any issues about this it is acknowledged that this may have been a barrier to open communication.

I completed reflexive notes after each interview as an aide memoir of key observations and thoughts that occurred during the interviews, acknowledging my own subjectivity. Each interview was discussed in supervision to support further reflexivity.

4.6 Data management and interview analysis

Data was analysed following the process of IPA, as outlined by Smith et al. (2009). Once completed, each individual interview was listened to several times and subsequently transcribed. The first interview was transcribed and used as a basis to consider any changes required to the interview schedule. This was also discussed in supervision. The semi structured approach enabled flexible responses to and from each participant, and therefore the interview schedule remained appropriate. Subsequent interviews were transcribed, with a transcribing service approved by the university being used to support some of the process. This was agreed with supervisors as an acceptable approach in recognition of the volume of data, the time available as a lone novice researcher undertaking a study as part of a part-time degree, whilst in full time employment, and as a working mum.

For all interviews the audio recordings were listened to several times, while reading and re-reading the transcripts to ensure I remained fully immersed in the data. This also helped to reconnect with the experience of each individual interview over time, through both the audio recording and the typed transcripts. This process was revisited several times and essentially revisited when writing the discussion in chapter six.

Transcripts were analysed considering participants' experiences in their context, informed by an interpretation of their individual lived experience of ID. Interview transcripts were transferred to a typed table, line by line number references were populated alongside the interview text to support continual checking and as a means of tracking back to the original text throughout the process. Margins were set to the right and the left of the participant's transcript. In the right margin initial exploratory comments thoughts and specific linguistic, descriptive, and conceptual text from the participants were noted down. Exploratory noting was re-read, and initial groupings of emerging themes were recorded in the left-hand column, (see appendices 13(a) & 14(a)). This was revisited on several occasions to check and recheck each transcript. Each of the emergent themes were then transferred to a separate sheet for each interview transcript, listed in order of occurrence, alongside the corresponding line references, (see appendices 13(b) & 14(b)). This was adapted from the guidance of Smith et al. (2009), outlining the process of analysis of interview data using IPA.

For each participant interview, every emergent theme was then extracted and cut out individually. These were stuck to and arranged on separate large flip chart sheets. This enabled further grouping of emerging sub-themes to be identified from the individual transcripts, (see appendices 13(d) & 14(d)). These sub-themes were considered and adjusted over time as I became more immersed in the data after each interview. The sub-themes were transferred to a

separate typed sheet, to support clear organisation of the data and subsequently further groupings and sub-themes began to emerge, (see appendices 13(c) & 14(c)). This stage was helpful in supporting abstraction and subsumption i.e., identifying patterns and connections between the emergent themes, the sub-themes and connections for each participant, leading to the development of super-ordinate themes for each transcript (Smith et al., 2009). This was a lengthy, and at times quite overwhelming process, given the volume of the data from nine participants. However, this approach enabled the data to be managed, and the process was repeated until I was satisfied with the authenticity of the links for each theme, tracking these back to the original transcripts for validity. This was a time consuming and very manual approach, however, this felt authentic and ensured my immersion and connection to the original transcripts, supporting the ongoing interpretation of the data. Smith et al. (2009), describes this as a 'magnet' effect as connections begin to form with the researcher's ongoing engagement with the data, eliciting emergent interpretations.

The flip charts for all participants were arranged on a wall, enabling an overview of all the participants to be viewed together. This supported the review and considerations of common and divergent themes to be considered for each participant's analysis chart. As these were arranged on my home office wall, this enabled me to 'live' with the data over an extended period, providing opportunities for revisiting and revising connections. Superordinate themes for each transcript were transferred on to a further separate sheet and developed into nine master themes. The number of connections for each theme was numerically represented to provide an overview of individual and grouped themes. This approach enabled the management of what ended up being a vast amount of data for this type of study as IPA, however this provided a clear accessible audit trail to support the transparency of the process and verification

of the themes being traced back to the original interview transcript, (Table 5.2). These are presented in the results and discussion chapters.

4.6.1 Assessing quality in conducting qualitative research

The issue of quality and validity is much discussed in conducting qualitative research, with questions about sample size, rigor and application of findings being raised, alongside consideration of researcher bias (Flick, 2023; Silverman, 2014; Willig, 2013). Yardley (2000) identified four principles to consider in addressing validity of qualitative research, i.e., sensitivity to context, commitment and rigor, coherence and transparency, and impact and importance (Smith, 2015). These will be discussed in the next section of this chapter in the context of the considerations for this study.

4.6.1.1 Sensitivity to context

Sensitivity to context, related to the choice of the subject and the approach taken. For this study a central tenet was in valuing the uniqueness and interconnectivity of the lived experiences of siblings who had a sibling with ID. The literature review identified a limited body of knowledge presenting sibling experiences from their subjective views and valuing the uniqueness of their experience and interpretations. Undertaking this as a qualitative study, using an IPA method of analysis enabled the study to be transparent. In that, it identified a purposive group of siblings in a defined area of the UK, enabled access to this group and their individual experience of ID, and offered the potential for elicitation of common experiences across the nine participants. The approach ensured that the researcher stayed as true to the participants' experiences as possible, demonstrating sensitivity to their unique context. At the same time, it created the potential for new knowledge to emerge, making their experiences of ID accessible to a wider cohort outside of the participant group.

Attending to the considerations of power when conducting research with C&YP, and engaging their parents as gatekeepers, demonstrated sensitivity to context. This was further validated through the use of a reference group to support the development of the research design, recruitment, and development of the data collection tools.

Prolonged engagement with and immersion in the data and linking this to the literature also supported sensitivity to context in conducting this study. Staying true to the original transcripts', the siblings' words, and using verbatim references throughout the analysis and presentation of the findings, ensured claims made by me as a researcher were transparently grounded in the original transcript data. This provided an auditable trail of the process followed when conducting the analysis.

4.6.1.2 Commitment and rigor

As an IPA study of a purposive group of siblings, this research aimed to elicit the lived experience of the C&YP, who were recruited specifically for the study. They are presented as a defined group, with consideration given to their family context. The participants were recruited in a defined area of the UK, and this is acknowledged as a potential limiting factor in the diversity of the cohort. Nonetheless, the recruited siblings differed in gender and self-identified heritage, with consideration of faith explored as part of the interviews. This approach acknowledged the underrepresentation of diverse backgrounds, ethnicities, faiths, and familial constructs identified in the literature. Family constructs and context differed in the participant cohort, e.g., parents were married, divorced, widowed and single parents. Some participants had other typically developing siblings, as well as their brother or sister with ID. Faith and cultural identity differed, albeit this is a participant group recruited from a defined geographical context in England in the UK, a degree of diversity was captured.

IPA supports research undertaken through the in-depth analysis of smaller cohorts of participants. Adopting this approach did not diminish the study's commitment to rigor; rather, it is presented transparently in the articulation of the research question, the specification of the aims, and the rationale and process underpinning the recruitment of the participants.

4.6.1.3 Coherence and transparency

Coherence and transparency of the research were addressed by providing a clear and consistent account of the research process and the analytic process, enabling others to trace how the findings were developed and justified. Regular supervision and use of supervision as a mechanism of checking with others not directly involved in conducting the research supported this. The use of a reflexive diary also provided transparency and awareness of potential researcher bias.

Examples of interviews and analysis were sent to supervisors and supervision meetings were used to check the validity of emergent themes, therefore being verified by an independent view. This ensured independent readers could clearly track the process of identifying emergent themes and relate these directly back to the original transcripts' text. This supported an independent audit of the data and reinforced the thoroughness of the process adopted, as a novice researcher. The process of the analysis is described in the methodology chapter, with appendices and examples of the workings of the analysis provided as an audit trail for the independent reader, (appendices 13 & 14).

The aim and commitment of the study were to elicit the lived experiences of nine sibling participants, in relation to having a brother or sister with ID. In line with Smith (2015), the findings revealed both convergent (shared) and divergent (individual) accounts of their

experiences, reflecting the idiographic focus of the methodology. In conducting the analysis, emergent themes were subsequently developed to master theme level. Researcher interpretation of the C&YP's meaning-making identified potential connections, situating siblings' individual accounts within the broader experiential context. The inclusion of direct transcript quotations in the results chapter enhanced transparency by grounding the identified connections in the participants' own accounts, thereby embedding the themes directly within the primary data sources.

4.6.1.4 Impact of the research

This research explored a unique participant group who brought their own subjective experience, interpretations, and context to the study. Using IPA enabled the phenomena of siblings' experience of ID to be explored, bringing an interpretation of the connections between their experiences as a homogenous group.

Given the purposive nature of the participant group, and wider contextual factors, the generalisation of the research could be said to be restricted. However, the intention in conducting qualitative research and in using IPA for this study, was to elicit the experiences of this specific group. It was hoped that some broader application might emerge, while acknowledging that the specifics of the study could not be replicated exactly with any other group. Additionally, another researcher conducting the work would inevitably be influenced by their own context, preferences, and potential biases in how they might approach and conduct the research, interpret the data, and present the findings. The aim of this study was to explore the experiences of these nine participants. Transparency in the analytic approach, systematic attention to both confirming and disconfirming instances within the data, and the grounding of interpretations in participants' direct accounts collectively ensured coherence in the

presentation of the results and enhanced the transparency of the conclusions articulated in the discussion chapter. (Smith, 2015:27).

4.6.1.5 Reflexivity

The following section provides a personal and professional context, recognising the need for due consideration of self-reflexivity as a researcher in conducting qualitative research and in using IPA (Dallos & Vetere, 2005; Smith et al., 2009).

Emphasis in this study was given to the importance of self-reflexivity with an awareness of the influence and impact of the interactions between the participants with me as the researcher, as well as the influences from my own world, life, experience, biases, and interpretations, (see chapter two). These influences impacted the choice of the research question, methodology and method of analysis and was indicated in the transparency of my epistemological stance as a researcher, as well as in the priority given to the subsequent emergent themes and the interpretation therein (Finlay & Gough, 2003; Smith et al., 2009; Willig, 2013).

While conducting this study I continue to work in higher education in health and social care leadership. My previous context included completing an MA study in applied systemic practice and working professionally as a nurse, with people with ID, and as an applied systemic practitioner. These experiences heightened my awareness of the potential influence of my own constructions when engaging with the narratives of others. Potential power issues, prejudices, and motivations were therefore important and pertinent considerations in undertaking this study (White, 1997). A personal and professional desire to champion the cause of those perceived as being disenfranchised in society, i.e. those with ID and their family members, was

also at the forefront of reflexive considerations when developing and undertaking this research (Baum & Lynggaard, 2006).

As a mother of four children, one with ID, it was important to be aware of the influence of my subjective perspectives. Reflexivity enabled transparency and an understanding that my own background and context inevitably influenced the research and the way I engaged with and interpreted the findings (Smith, 2015). Sensitivity to the influence of my own context, and the need to be transparent in supporting the rigor of the research to ensure credibility and auditability in this regard, were very important. Transparency and open awareness of inter-subjectivity was essential, given this personal context. As acknowledged in chapter two and throughout the work, my personal context, experiences, and values were strong influenced the development of my interest in this subject. Equally, this context influenced the development of the research question as well as the design and approach adopted in conducting the study. This context presented possible challenges in relation to potential preferencing e.g., perhaps a desire to elicit positive narratives. However, it also offered the potential to bring a unique perspective to the research through transparent awareness of such biases. It required an approach of heightened attentiveness to the transcripts and siblings' narratives, ensuring that any claims were supported, with emergent themes and interpretations being scrutinised, sense checked and grounded in the transcripts.

The importance of self-reflexivity, self-awareness and understanding of my role as researcher, underscored the critical importance and value of supervision. This continued to be used as a mechanism to check interpretations, alongside the use of the reflexive diary. Cross-referencing the findings with direct quotations from the transcripts, and linking these findings to comparators in the literature, the validity to my interpretations was enhanced.

A reflexive diary was used, notes were taken following each interview. Further notes were jotted down while undertaking the analysis, recording thoughts and connections coming to mind. These were discussed with supervisors to ensure the interpretations could be connected to the transcripts. This supported the sense making of the emerging themes, ensuring these were embedded in the voice of the participants, all the while being transparent about researcher bias and potential interpretative preference. (see appendix 15).

CHAPTER FIVE: RESULTS

5.0 Overview

This chapter presents the results from nine semi-structured interviews with children and young people (C&YP) who had a sibling with intellectual disabilities (ID), which generated the data for this research study. An overview of the background and familial context of the participants is provided in Table 5.1. The themes that emerged from conducting an interpretative phenomenological analysis (IPA) of the data are discussed in detail and supported by direct quotations, bringing forward siblings' 'voices' from the interviews. This demonstrates how the themes were drawn from and embedded within the expressed experiences of the C&YP (Finlay, 2011). Finally, the use of diaries as an additional data collection tool is discussed.

5.1 Participants

A summary of the siblings recruited to the study, with an overview of their familial context is provided in Table 5.1, introducing the reader to the participants. The C&YP and their siblings with intellectual disabilities were identified using pseudonyms to protect their confidentiality, this was explained and agreed with the siblings and their parent(s) prior to conducing the interviews and aligned with the approved ethics protocols for the study (Alderson & Morrow, 2011), (see appendix two).

There were nine children and young people interviewed for the study; they ranged in age from 11 to 16 years old. All C&YP lived at home with one or both parents at the time of the interviews. For one of the C&YP (1) Shafeeq, their Father's was deceased. For one C&YP (3) Isy, her parents were divorced, and the core family lived primarily with their mother, having regular time and contact with their father. One C&YP (4) Lucy was a twin. All but one of the C&YP were the biological children of their parents. (5) Anna and her brother (Kevin) were

adopted and not biologically related. Seven of the C&YP were a sibling dyad, (1) Shafeeq, (2) Aayan, (3) Isy, (5) Anna (6) Olivia, (7) Iain, (8) Helene. Five C&YP were the eldest sibling, (8) Helene, (6) Olivia, (3) Isy, (2), Aayan, (1) Shafeeq. Two of the C&YP were the youngest sibling in their family, (5) Anna, and (7) Iain. One sibling was a twin, (4) Lucy, and had an older brother who did not have ID. One of the C&YP (9) Ryan was the third of four children, with an older brother and sister who did not have ID. The gender mix of sibling groups was varied, three of the C&YP, (3) Isy, (6) Olivia, (8) and Helene were the eldest sisters, with a sister with ID; one of the C&YP (2) Aayan, was the eldest brother, with a brother with ID; one of the C&YP (1) Shafeeq, was the eldest brother with a sister with ID; one of the C&YP, (7) Iain was a younger brother, with a brother with ID; one of the C&YP, (5) Anna was a younger sister with a brother with ID.

Two of the C&YP (1) Shafeeq, (2) Aayan, identified as having a strong faith, as practising Muslims. Four C&YP (4) Lucy, (6) Olivia, (7) Iain (9) Ryan, identified as having a Christian faith (two identified as Roman Catholic (RC)), most did not attend a place of worship regularly, (4) Lucy articulated her faith (RC) as a strong frame for her beliefs. The remaining two C&YP (3) Isy and (8) Helene did not identify as having a specific faith. All the C&YP expressed a sense of having a guiding value base, this is explored further in the discussion in chapter 6.

Table 5.1. Summary of research participants, siblings and family context information

No.	Pseudonym	Age	Gender	Name of sibling with ID	Age	Gender of sibling with ID	Identify as: - (heritage; faith, self-declared)	Birth order	Other siblings in family (Y/N) Names (age)	Further notes - Family
1	Shafeeq	15	M	Zahra	11	F	British Pakistani; Muslim, faith important	Eldest	N	Father deceased. Mother and Maternal Grandmother main carers living in family home.
2	Aayan	11	M	Isma'il	6	M	British Asian; Muslim, faith important	Eldest	N	Mother and Father, living in family home
3	Isy	13	F	Evie	9	F	British; no specific faith	Eldest	N	Parents divorced. Living with Mother in family home. Regular contact with Father.

4	Lucy	16	F	Thomas	16	M	British/Polish; Christian	Twins	Y - Brother Evan (19)	Twins. Mother and Father living in family home.
5	Anna	11	F	Kevin	15	M	British; /no specific faith	Youngest	N	Both siblings adopted. Mother and Father living in family home.
6	Olivia	12	F	Frances	10	F	British, Irish; RC non practicing	Eldest	N	Mother and Father living in family home.
7	Iain	13	M	Christopher	16	M	British; Christian, non-practicing	Youngest	N	Mother and Father living in family home.
8	Helene	12	F	Ellie	9	F	British; /no specific faith	Eldest	N	Mother and Father living in family home.
9	Ryan	13	M	Julian	5	M	British; Christian, non-practicing	3rd of 4 children	Y - Brother Gerard (20)	Mother and Father living in family home.

									Sister Elisabeth (17)	

5.2 Themes emerging from the interview transcripts

In the following section the themes that emerged from each of the nine interview transcripts are discussed. Master themes are explored in detail, direct quotations are provided from the transcripts of the siblings' interviews to illuminate and support the discussion of each theme, thus ensuring these can be traced back to the original transcript(s). Coding is provided, and each quotation is linked to its source by referencing the specific participant transcript number and interview line reference. This ensures transparency and tractability of the transcript quotations, enabling them to be traced back to the original words and interviews of the C&YP. The process adopted when developing the master themes is presented in Table 5.2. This represents from right to left, the superordinate themes, related transcript interview line quotations, sub-themes and subsequent master themes.

Master themes were created using IPA, from the emergent, superordinate, and recurring themes from all nine interviews. Where themes occurred in more than half of the interviews, these are identified as master themes. Given the diversity of the participants, atypical themes emerged at times. For example, there were some unique perspectives and experiences not replicated across all, or half of the interviews, e.g., the experience of a twin (4) Lucy, being adopted (5) Anna, being from a single parent widowed family (1) Shafeeq. These atypical themes are acknowledged and further illuminate the understanding of individual experiences, alongside variance and similarity for all nine of the C&YP's experiences of ID.

Nine master themes along with their corresponding sub-themes, are presented in Table 5.2. Sub-themes were created by collating common superordinate themes as shown in Table 5.2. Bracketed numbers represent the number of transcripts where this was a recurring superordinate theme. For the master themes, commonality was highlighted as well as

polarisation of the individual perspectives from different participants or sub-groups. Corresponding quotations from the transcripts were provided to continually check the discussion with the original siblings' narratives. Given the interpretative nature of the analysis, it is acknowledged that although reflexivity was adopted throughout the research process, the analysis was not conducted in a vacuum. Therefore, preferences, power balance, and potential researcher biases may have influenced the data interpretation, preferencing of certain narratives, and the development of the overall themes (Willig, 2013). Consistent with IPA, it was recognised that there were ongoing considerations and negotiation when engaging with the transcripts. Checking back and forth, being submerged in the data, identifying the themes considering 'the relationship between convergence and divergence, exploring commonality and individuality' (Smith et al., 2009:107) were at the forefront of the IPA process throughout.

Table 5.2. Master themes (with sub-themes)

Master theme	**Sub themes**	**Related transcript quotations with line references**	**Superordinate themes informing master theme grouping.** **C&YP participant identified (1-9).**
5.2.1 Knowledge understanding and support. (1-9)	5.2.1.1 Knowledge and information. 5.2.1.2 Understanding and explaining ID, same and difference. 2(2) 5.2.1.3 Family, adapting, care needs. 4(7). 5.2.1.4 Support for families 7(4), 8(3).	*1.242 - 1.246; 1.253 - 1.257; 1.286 - 1.284; 1.286 - 1.288; 1.295 - 1.303; 1.309 - 1.315; 1.317 - 1.320; 1.333 - 1.341; 1.362 - 1.366; 1.391 - 1.398; 1.402 - 1.406; 1.571 - 1.573; 1.929 - 1.937; 1.947 - 1.949; 1.1057 - 1.1063.* *2.222 - 2.223; 2.251 - 2.256; 2.504 - 2.505; 2.507 - 2.515; 2.529 - 2.535; 2.768 - 2.769; 2.771 - 2.775; 2.798 - 2.799; 2.799 – 2.804* *3.270 - 3.272; 3.285 - 3.288; 3.515 - 3.517; 3.657 - 3.662; 3.676 - 3.679 3.802; 3.816 - 3.821 3.827 - 3.829; 3.872 - 3.878.* *4.205 - 4.209; 4.218 - 4.220; 4.321 - 4.327; 4.337 - 4.344; 4.414 - 4.419; 4.424 - 4.426; 4.468 - 4.473; 4.537 - 4.540; 4.731 - 4.735* *5.248 - 5.249; 5.349 - 5.350; 5.696; 5.704 - 5.707; 5.791 - 5.792; 5.819; 5.259 - 5.262; 5.727 - 5.728; 5.268 - 5.272* *5.230 - 5.231* *6.315; 6.685; 6.278 - 6.280; 6.263 - 6.265; 6.634 - 6.639; 6.246*	Valuing knowledge and information (1) Understanding, same and difference (2) Knowledge (2) Knowledge (3) Family, adapting, knowledge, care needs and support (4) Understanding and explaining ID (4) Family impact and coping strategies. Knowledge, power, vulnerability, loss of agency (5) Family impact, roles, responses, risks and coping strategies (6) Knowledge, support and future ambitions (7) Knowledge/support for families (8) Knowledge/Information (9)

		7.347 - 7.349; 7.899 -7.900; 7.905 - 7.909; 7.1034 - 7.1038; 7.434 -7.438; 7.290 – 7.313 *8.95 - 8.99; 8.223 - 8.225; 8.558 - 8.560; 8.573 - 8.575; 8.585 - 8.589; 8.592; 8.186 - 8.190; 8.374 - 8.377; 8.157 - 8.159; 8.561 - 8.564; 8.648 - 8.650; 8.249 - 8.252* *9.189 - 9.190; 9.195 - 9.204; 9.210 - 9.214; 9.535; 9.578 - 9.579; 9.597 - 9.599; 9.481; 9.576*	
5.2.2 Valuing sibling relationships. (1,2.3.4.5.7 & 9)	5.2.2.1 Celebrating being a sibling. 5.2.2.2 Mutual value of the sibling relationship, sharing experiences together. 5.2.2.3 Care and affection, reciprocity of sibling relationships. 5.2.2.4 Valuing uniqueness, skills and attributes of a brother or sister with ID. 5.2.2.5 Sibling responsibility and advocacy.	*1.106 - 1.109; 1.118; 1.340; 1.357 - 1.360; 1.404 - 1.406; 1.428 - 1.432; 1.493 - 1.498; 1.502 - 1.506; 1.547 - 1.552; 1.625 - 1.630; 1.654 – 1.657; 1.662 - 1.669; 1.794 - 1.799; 1.859 - 1.862* *2.308 - 2.311; 2.325 - 2.330; 2.357 - 2.359; 2.361 - 2.369; 2.424 - 2.43; 2.513 - 2.516; 2.554 - 2.563; 2.596 -2.592; 2.601 - 2.607; 2.714 -2.722; 2.513 - 2.516; 2.626 - 2.635* *3.217 - 3.218; 3.373 - 3.381; 3.391 3.393; 3.348 - 3.349; 3.506 - 3.511; 3.575 - 3.582; 3.596 - 3.612; 3.776 - 3.779; 3.783 - 3.794* *4.299 - 4.304; 4.358 - 4.370; 4.402 - 4.408; 4.588 - 4.600; 4.749 - 4.759*	Valuing the sibling relationship, positive accounts (1) Positive accounts of being a sibling. Maturity and Awareness (2) Valuing sibling relationships and insight (3) Valuing the Sibling relationship, positive accounts alongside vulnerability (4) Maturity, awareness of difference. Protecting sibling with ID and family, sense of social justice (5) Knowledge, support and future ambitions (7) Normalising and difference, valuing sibling, acceptance, care and compassion (8)

		5.354 - 5.355; 5.360 - 5.363; 5.430 - 5.436; 5.500 - 5.506 *7.515* *8.196 - 8.200; 8.345 - 8.349; 8.161 - 8.162; 8.165 - 8.168; 8.530 - 8.534; 8.352 - 8.353; 8.361*	
5.2.3 Context outside the family. (1-9)	5.2.3.1 Valuing friendships. 5.2.3.2 Escapism and support through interaction with friends. 5.2.3.3 Opportunities to make friends and engage in shared activities. 5.2.3.4 Valuing hobbies, interests and achievements.	*1.56; 1.57; 1.79 - 1.81; 1.449 - 1.458* *2.47 - 2.64; 2.88 - 2.90; 2.120 - 2.121; 2.508 - 2.516* *3.22 - 3.24; 3.29 - 3.30; 3.41 - 3.42; 3.58 - 3.62* *3.96 - 3.98; 3.329 - 3.338 3.360 - 3.363; 3.373 - 3.381; 3.540 - 3.545* *4.154 - 4.157; 4.177 - 4.180; 4.403 - 4.408* *5.75 - 5.84* *5.123 - 5.125; 5.193 - 5.196; 5.199 - 5.201; 5.54 - 5.542 5.550 - 5.552* *6.210 - 6.217; 6.76 – 6.78; 6.87; 6.132 - 6.134; 6.174 - 6.179* *7.78 - 7.83; 7.145; 7.184 – 7.192; 7.397 - 7.398*	Valuing the sibling relationship, positive accounts (1) Sibling self-identity and expression (1) Sibling context outside the family. Family impact and support (2) Siblings value friendships/other experience outside family (3) Siblings value friendships (4) Importance of sibling context outside the family, (support, enjoyment, potential escapism) (5) Sibling awareness and understanding of norms and difference from peers and others' (5) Change and divergence of experience for siblings (5) External relationships, social outlets, pride and future ambition (6) Sibling context outside the family, shared interests, (support, enjoyment coping strategy) (7) Context outside the family, friendships, hobbies, pride (8) Valued relationships, networks, hobbies and interests (9)

		8.520 - 8.521; 8.63 - 8.64 8.75 - 8.77 8.80 - 8.82; 8.110 - 8.114; 8.117 - 8.118 *9.65 - 9.71; 9.70; 9.83 - 9.84; 9.167 - 9.168*	
5.2.4 Becoming aware of ID, age, birth order and growing maturity. (1,3,4,5 & 7)	5.2.4.1 Birth order/age/life stage. 5.2.4.2 Becoming aware of having a sibling with ID. 5.2.4.3 Being a twin. 5.2.4.4 Growing awareness of ID and maturity.	*1.25 - 1.31; 1.280 -1.284; 1.327 - 1.341; 1.719 -1.728; 1.777 - 1.78;6 1.803 - 1.812* *3.155 - 3.161; 3.172 - 3.175; 3.285 – 3.290; 3.252 - 3.262; 3.506 – 3.515; 3.575 – 3.582* *4.204 - 4.210; 4.233 - 4.244; 4.266 - 4.285; 4.292 - 4.304; 4.321 – 4.332; 4.337 - 4.349; 4.355 – 4.361; 4.364 – 4.371 4.569* *5.230 - 5.238; 5.252 - 5.256; 5.762 - 5.764; 5.787 - 5.789* *7.280 - 7.286; 7.318 – 7.322; 7.899 – 7.900*	Sibling age, life stage and experience impacts experiences (1) Age/life stage, conflicts between self-acceptance of ID and social acceptance (3) Age/Life Stage, birth order. Self-expression, support, pride in self (4) Age, awareness, life changes and future ambitions (5) Age, sibling awareness, maturity, loss and sense of social justice (7)
5.2.5 Sense of agency; compromise; power, and loss. (1,2,3,6,7,8 & 9)	5.2.5.1 Children and young people's sense and use of agency; compromise and containment. 5.2.5.2 Power.	*1.124 - 1.130; 1.195 - 1.198; 1.349 - 1.360; 1.363 - 1.366; 1.391 - 1.398; 1.411 - 1.421; 1.428 - 1.432; 1.470 - 1.485; 1.591 - 1.601; 1.596 - 1.603; 1.777 – 1.782; 1.831 – 1.832* *2.472 - 2.480; 2.662 - 2.666; 2.744 - 2.751*	Sibling 'agency' (1) Sibling self-identity and expression (1) Power, agency', and identity in the family (2) Responsibilities of being a sibling (2) Communication complexities and challenge(s) (3)

	5.2.5.3 Prioritisation, and loss. 5.2.5.4 Risk and vulnerability (physical, psychological, emotional).	*3.140 - 3.146; 3.155 - 3.158; 3.160 - 3.167; 3.172 - 3.175; 3.192; 3.200 - 3.201; 3.294 - 3.296; 3.457 - 3.462; 3.472 - 3.478; 3.487 - 3.495; 3.490 - 3.545; 3.543 - 3.545 3.629 - 3.634; 3.771 – 3.779; 3.790 - 3.794; 3.848 - 3.858* *6.941 - 6.952; 6.564 - 6.569; 6.653 - 6.655; 6.656 - 6.660; 6.518 - 6.519; 6.395 - 6.399; 6.700 - 6.710* *7.318 -7.322; 7.359 - 7.364; 7.470 -7.479* *8.290 - 8.293; 8.356 - 8.359; 8.192; 8.626 - 8.628; 8.629 - 8.631; 8.632; 8.323 - 8.324* *9.270 - 9.272; 9.367 - 9.370* *9.371 - 9.373; 9.374 - 9.375; 9.220 - 9.221; 9.517 – 9.522*	Family dynamics/roles, relationships and responsibilities (3) Maturity, loss, agency and emotional impact (3) Managing personal environment, use and loss of agency (6) Age, sibling awareness, maturity, loss and sense of social justice (7) Family dynamics and impact, coping strategies, knowledge, power, loss of agency (7) Coping, maturity, agency, loss and power (8) Care, compromise, loss, agency, risks and vulnerability (9)
5.2.6 Family impact and coping strategies. (1-9)	5.2.6.1 Impact on C&YP. 5.2.6.2 Impact on parents. 5.2.6.3 Shared responsibilities and pseudo-parenting role for siblings. 5.2.6.4 Wider considerations and the family, working together.	*1.401 - 1.406; 1.158 - 1.162; 1.170 - 1.175; 1.611 - 1.619; 1.650 - 1.656; 1.738 - 1.743; 1.744 -1.751; 1.973 - 1.981; 1.876 - 1.883; 1.855 - 1.862; 1.886 - 1.894; 1.56 -1.59; 1.311 - 1.312; 1.343 - 1.360; 1.180 - 1.185; 1.703 -1.713; 1.719 - 1.728* *2.251 - 2.254; 2.301 - 2.305; 2.626 - 2.632; 2.423 - 2.432; 2.492 -2.497*	Coping strategies and managing sibling with ID relationships in the family (1) Family dynamics and behaviours influence/impact sibling experience (1) Coping strategies; the narrative of normal and of ID; impact on siblings and the family (2) Family dynamics/roles, relationships and responsibilities (3) Family, adapting, knowledge, care needs and support (4) Understanding and explaining ID (4) Maturity, loss, compromise and emotional experience (4)

	5.2.6.5 Importance of the extended family. 5.2.6.6 Coping strategies.	*3.106 - 3.109; 3.115 - 3.120; 3.421 - 3.430; 3.451 - 3.462; 3.472 – 3.478; 3.507 - 3.515; 3.638 - 3.644* *4.135 - 4.139; 4.424 - 4.427; 4.435 - 4.443; 4.466 - 4.469; 4.476 - 4.483; 4.484 - 4.491; 4.498 - 4.502* *5.222 - 5.224; 5.240 - 5.243; 5.265 - 5.276; 5.370 - 5.371; 5.396 - 5.403; 5.416 - 5.419; 5.656 - 5.660; 5.762 - 5.768; 5.787 – 5.789; 5.626 – 5.636; 5.770 - 5.771* *6.502 - 6.512; 6.353 – 6.356; 6.564 - 6.569; 6.685 - 6.686; 6.691 - 6.693; 6.921 – 6.928; 6.365 - 6.368* *7.452 - 7.454; 7.463 -7.473; 7.862 - 7.867; 7.408 - 7.413; 7.252 - 7.253; 7.419 - 7.431; 7.558* *8.255 - 8.262; 8.300 - 8.302; 8.530 - 8.534; 8.590 - 8.591* *9.277 - 9.288; 9.220 - 9.221; 9.367 - 9.370; 9.371 - 9.375; 9.220 - 9.223; 9.283 - 9.286*	Family impact and coping strategies. Knowledge, power, vulnerability, loss of agency (5) Maturity, awareness of difference. Protecting sibling with ID and family, sense of social justice (5) Family impact, roles, responses, risks and coping strategies (6) Family dynamics and impact, coping strategies, knowledge, power, loss of agency (7) Normalising and difference, valuing sibling, acceptance, care and compassion (8) Knowledge/support for families (8) Care, compromise, loss, agency, risks and vulnerability (9) Coping strategies, support, containment (9)
5.2.7 Insight, vulnerability, loss of childhood, changed family relationships. (1,3,4,5,6,7 & 9)	5.2.7.1 Sustained experiences, impact, vulnerability and the need for support.	*1.470 - 1.474; 1.625 – 1.630* *3.125 - 3.131; 3.140 - 3.146; 3.155 - 3.158; 3.165 - 3.175; 3.160 - 3.161; 3.192 - 3.197; 3.200 - 3.201; 3.210 - 3.213; 3.288 - 3.290; 3.348 - 3.352; 3.407 - 3.410; 3.490 – 3.495;*	Family dynamics and impact, coping strategies, knowledge, power, loss of agency (1) Communication complexities and challenge (3) Maturity, loss, agency and emotional Impact (3) Maturity, loss, compromise and emotional experience (4) Having a faith and social justice (4)

	5.2.7.2 Loss of childhood, expectation and changed roles as siblings. 5.2.7.3 Risk of isolation. 5.2.7.4 Survivor guilt. 5.2.7.5 Exposure to judgment of external others.	*3.629 - 3.775; 3.771 - 3.775; 3.783 - 3.794; 3.790 - 3.794; 3.848 - 3.858* *4.269 - 4.275; 4.289 - 4.291; 4.525 - 4.540; 4.514 - 4.517; 4.566 - 4.575* *5.269 - 5.272; 5.635 - 5.639; 5.627 - 5.631; 5.273; 5.774 - 5.779* *6.395 - 6.399; 6.704 - 6 710; 6.409 - 6.413; 6.653 - 6.655* *7.318 – 7.319; 7.320 - 7.322; 7.359 - 7.341; 7.325 -7.331; 7.947 - 7.949* *9.145 – 9.149; 9.213 – 9.214; 9.278*	Maturity, awareness of difference. Protecting sibling with ID and family, sense of social justice (5) Maturity, insight, risk and vulnerability; loss of agency (6) Age, sibling awareness, maturity, loss and sense of social justice (7) Care, compromise, loss, agency, risks and vulnerability (9)
5.2.8 The future. (1-9)	5.2.8.1 C&YP future career and life ambitions. 5.2.8.2 C&YP thoughts on becoming parents in the future. 5.2.8.3 Future ambitions of sibling with ID, choice, equality and support needs. 5.2.8.4 C&YP's future care responsibilities for their sibling with ID.	*1.434 - 1.435; 1.763 - 1.765; 1.777 - 1.786; 1.839 - 1.844; 1.794 - 1.799; 1.805. 1.812; 1.828 - 1.835* *2.662 - 2.666; 2.748 -2.751* *3.720 - 3.727; 3.689 - 3.393; 3.724 - 3.727; 3.734 - 3.738; 3.745 - 3.751; 3.755 - 3.759; 3.874 - 3.875* *4.699 - 4.718; 4.685 - 4.692; 4.699 - 4.704; 4.616 - 4.629; 4.638 - 4.646; 4.647 - 4.652; 4.670 - 4.676; 4.699 - 4.709 4.713 - 4.718; 4.719 - 4.722*	Imagining the future, growing up and responsibilities (1) Pride, ambition and success (2) Age/life stage, conflicts between self-acceptance of ID and social acceptance (3) Siblings value friendships/other experience outside family (3) Valuing sibling relationships and insight (3) Imagining the future (4) Change and divergence of experience for siblings (5) Age, awareness, life changes and future ambitions (5) Family impact, roles, responses, risks and coping strategies (6) Maturity, insight, risk and vulnerability; loss of agency (6)

		5.568 - 5.521; 5.583 - 5.587 *6.820 - 6.822; 6.852 – 6.853; 6.840 - 6.843* *7.221 - 7.226; 7.794 – 7.795; 7.818; 7.833 - 7.836* *8.469 - 8.485; 8.499 - 8.503; 8.515 - 8.518; 8.524 – 8.525* *9.440 - 9.447; 9.483 - 9.490; 9.491 – 9.493*	External relationships, social outlets, pride and future ambition (6) Knowledge, support and future ambitions (7) Future (8) Future ambitions, pride, uncertainty (9)
5.2.9 Culture and having a faith. (1,4 & 7)		*1.703 - 1.713; 1.746 - 1.751; 1.738 - 1.743* *4.598 - 4.600; 4.582 - 4.587* *7.596 - 7.599*	Family dynamics and behaviours influence/impact sibling experience (1) Having a faith and social justice (4) Family dynamics and impact, coping strategies, knowledge, power, loss of agency (7)

5.2.1 Knowledge understanding and support

Knowledge and understanding emerged as a recurring theme from discussion about the C&YP's awareness of their siblings' needs, and of ID. Several C&YP identified their parents as gatekeepers of knowledge and information, and this was imparted more often by their mothers. In all the interviews, the C&YP demonstrated considerable contextualised knowledge and insight into the uniqueness of their sibling's needs. There was recognition of the diversity of ID, associated conditions and diagnoses. Having knowledge was expressed as being helpful and valuable. This enabled greater understanding and supported their coping mechanisms. Alongside their parents, professionals and wider media were identified as sources of knowledge and information. C&YP also valued themselves as sources of knowledge and in some cases, they also recognised the unique knowledge and perspectives offered by their siblings with ID.

5.2.1.1 Knowledge and information

C&YP's personal knowledge and understanding of ID was evident, framed within their experience of living with their brother or sister and supporting their specific needs. Given the age range of the participants, C&YP between 11 and 16 years old, they demonstrated a considerable level of maturity, with the ability to articulate complex information to others. One of the C&YP provided insightful and detailed knowledge of ID:

> *"Well I'd say autism is a learning difficul… erm disability that you get when you are like you're very young or you're diagnosed with it when you're born, and what it is it makes it hard, it makes it difficult for you to process things and it makes it harder for you to learn. And it gives you other things like hearing gets very sensitive and an autistic person, there's erm I know there's something called the autistic spectrum, so I remember going up and learning about Zahra's, where Zahra was and I think I remember seeing like a diagram of some semicircle or something like that with autism*

in the middle and OCD and stuff like that. I'd say erm for someone with autism it's err quite a severe part on the autistic spectrum. We might be all on the autistic spectrum, but my sister or Zahra is quite severe on that." (1.253 - 1.257).

All nine C&YP demonstrated some level of knowledge about ID and provided insightful descriptions of their understanding of ID and the impact on their sibling and their family. Three of the participants articulated their understanding firstly, in how they might explain this to others; by what might be observed in the day to day life of their sibling with ID, or observed by someone outside the family:

"…and people like sometimes do ask me 'oh what does your sister have' and I'm saying 'well she has triple x chromosome and something else I can't pronounce but I know what it is', which is like a missing, like she's got like a missing like end of chromosome 6 but I've no idea what that's called…." (3.515 - 3.517).

"he just seems to want to be on his own a lot right now and that is something which could have been the case even if he wasn't autistic but I think if he wasn't autistic he would maybe when you did see him he would talk more but because he's autistic he doesn't really say much." (4.537 - 4.540).

"He takes tablets every day and it's he doesn't get up. And like most people like at least shower like every two days but he showers like once a week, and he smells really bad and spits and all that sort of disgusting stuff." (5.259 - 5.262).

Other C&YP demonstrated their knowledge by describing the ways in which their sibling needed extra help, and the role siblings and family members played in supporting them:

"You've got to basically show him the routine, for instance if I was to say "can you please put your shoes on or your socks on", he'd go, he wouldn't know how to do it so you need to teach him how to do it before. It's like with everyone but like stuff like putting your socks on, your shoes on becomes naturally doesn't it?" 2.251 - 2.256

5.2.1.2 Understanding and explaining intellectual disabilities, same and difference

The C&YP demonstrated a perceptive ability to break down complex information. One (6) Olivia, used a metaphor to explain to her friends the experience of ID and differences for her sibling and their associated needs:

"Well I would explain the condition like with eyes. Like you could focus on one thing but she can't focus on one thing, she has to look at everything else at the same time, and so I explain it like that." (6.246).

"I would just say that she's got a problem, like condition and she's got an anger problem or something like that. Because if I say "oh she's got APD" they'll be like "what?" So I just say, "oh she's got anger issues", just to like simple it down and stuff. Yeah because like I'm pretty sure my friends wouldn't know what a neurological condition is, yeah." (6.634 - 6.639).

Another identified the value of courses and training, for example, in Makaton Sign Language, and used the knowledge and experience gained, sharing this with their peers to provide insight into ID. They highlighted the value of knowledge and suggested this helped others to understand and supported greater acceptance of their sibling with ID:

"I did a LAMDA examination talk and I did it about Makaton." (2.504 - 2.505).

"So I said all about my brother and Mr Tumble, how he uses Makaton and stuff like that. So while I was practising everybody heard it and then it was a small group but they told the whole year and everyone, as soon as the next day like everybody was asking me questions so I just said the truth and I said "oh my brother has additional needs but he's the same as everyone else, he's just a bit slower." And then they all heard my speech and they said "oh that's very good" and now people take interest in my brother rather than making fun of him,..." (2.507 - 2.515).

Most C&YP found out about their brother or sister having ID, often termed as 'special needs' from their parents, more often from their mother, even where both parents were present in the family home:

"That's when I really found out, when my Mum told me or when she actually got diagnosed. I never noticed it before that." (1.286 - 1.288).

"So I had a lot of questions, I just want.. needed to find out what it was first. So obviously my Mum explained that to me and she kind of taught me a bit, kind of taught me about what autism was and what learning difficulties are, like er the autistic spectrum. And obviously when Zahra grew up a little bit she went to meetings and stuff like that. And I've been to a few of her like, um, oh what's it called um? Parent evenings and stuff like that with my Mum." (1.333 - 1.341).

"I normally say that he like is, I normally explain like what my mum explained to me, that he has like special needs and that sort of stuff." (5.349 - 5.350).

"Well I would explain the condition like with eyes. Like you could focus on one thing but she can't focus on one thing, and so I explain it like that…" (Olivia (6) providing a description of how she explains sister's ID*) (6.246 – 6.249)*

(When Olivia (6) was asked who explained this or answered her questions about ID she replied)*"My mum. Yeah, my mum." (6.280).*

Two of the C&YP (4) Lucy and (9) Ryan, had other typically developing siblings, in both families their siblings with ID were older. The role that older siblings played in supporting and sharing information differed from their experiences. (4) Lucy reported that she did not really talk much to her older brother (Evan) particularly about their sibling with ID. While (9) Ryan found his older sister (Elisabeth) to be a valued source of knowledge. Discussing information and concerns with another sibling helped (9) Ryan to take in information about their sibling's ID. Information received from parents about their brother's diagnosis of and needs related to intellectual disabilities was difficult to absorb, this was described as a '*shock*'. Being supported by an older typically developing sibling appeared to be linked to and dependent on their broader existing sibling connections and relationships, given (4) Lucy reported less of a connection to her older brother:

"It's kind of much the same. I think we get along kind of better. We're more amicable and stuff but we still don't talk for very long periods of time because Evan and I don't really, well, we have some things in common but not that much because he really likes Maths and things and I don't and he doesn't really like any things that I like much." (4.294 - 4.298).

In these two families, the older typically developing siblings were opposite gender, with (Elisabeth) a sister potentially taking on or mirroring a pseudo-parenting role in supporting their brother's understanding of ID:

> *"Well I got told apparently, there was a massive conversation but I didn't take that in and a few days after I finally got told."* *(9.189 - 9.190).*

> *"No, it was when he was 5. I just... It was a shock to me because...*
> ***…**It still is.* ***…**I don't know, we were just in a conversation about needs and that and then she just suddenly said, Julian has a need and then I was like, wait, what? And I was just shocked."* *(9.195 - 9.204).*

> *"Yeah, it was helpful because I didn't know and if I didn't know things probably could have gone out of hand."* *(9.213 - 9.214).*

Several of the C&YP discussed acceptance of their sibling with ID as just being their brother or sister, they described not being overtly aware of ID or difference, particularly at a younger age:

> *"I think I was about 3 or 4, maybe 5, and I never noticed anything because I was so young but when my Mum told me I learnt about what it was and then I realised and understood it."* *(1.286 - 1.284).*

> *"I never like knew. I thought that was just like what everyone's brother was like."* *(5.230 - 5.231).*

"To be honest I think I just grew-up with it, like it was normal to me so I didn't really like think about it as having a sister with special needs, I just thought about it as having a sister, so I didn't really understand it, and then I don't really remember like when someone told me she had Down's Syndrome, I think it was just somehow I don't know….." (8.186 - 8.190).

(2) Aayan, referenced his awareness of ID, support needs and considerations for his brother, and cited himself as his comparator, seeing difference in a "*mirror*" image. He identified that he experienced life somewhat differently from his younger brother:

"… because I've never had a brother that has like non additional needs so, and I don't know, I'm not like, I don't have like, I don't know how to, I don't see myself in the mirror like when I'm growing up because I don't have special needs, so I'd say you'd need to consider him a bit more.."(2.231 - 2.305).

Two of the participants (3) Isy and (4) Lucy, demonstrated awareness of the spectrum of ID:

"Yeah, because like I feel like everybody with disabilities has probably got it a little bit differently and would react differently, so yeah.." (3.321 - 3.32).

(4). Lucy highlighted the value of her brother with ID' capabilities, alongside his areas of need:

"parents of some children with learning difficulties and things it's, I don't think it's been as hard as it could have been, at least Thomas is mobile and he can talk and stuff and he's not too severely autistic but it's always hard for my parents to just sort of get him to tell them things, he never really wants to talk about stuff, it's always very hard to try to make him speak about any event that's happened or whatever." (4.468 - 4.47).

Five C&YP reported that they developed greater awareness of ID as they grew older. They absorbed and responded to more information as this became accessible to them. Several reported "*noticing"* difference, or described a gradual recognition over time of the need to adapt to support their sibling with ID:

> *"So I mean I guess, I think I was probably told that she had autism when I was about 5. So at first obviously I was like "what's autism?" because I had no idea but once I, explained to it as a family we kind of learnt more about it, all of us learnt more about it because all of us needed to learn more about it and we learnt how to kind of help her in a way. So we all learnt how to, what we should do to help her, so as I grew up and as my Mum, family raised me." (1.295 - 1.303).*

> *"Yeah. It was more when he was born I was asking a lot of questions "oh is this usual? Is this not usual?" Stuff like that. And then I realised he had a special need." (2.333 - 2.335).*

> *"... I think I, like I started to realise once we got told that she had a disability. I'm not sure like what age I was at...." (3.270 - 3.272).*

> *"Not really. When I was little I didn't really, because I didn't really ask anything because I didn't, I still accepted it, I didn't really want to know why or anything, I just thought that he was very strange and not like other people and I can't really think of a time when I actually had learned that he had learning difficulties but I think I kind of learned it just by my parents talking about it and stuff and also because as I got older I learned more about these things...." (4.321 - 4.327).*

"I know what neurological disorders he has, that's kind of how I think of them, the ADHD, Epilepsy, learning difficulties and Autism and when I was very young I didn't really, I mean I knew he was different obviously but I didn't know what it was that was actually the matter with him." (4.205 - 4.209).

"I think I said to my mum "why is Kevin like really different?" and then I think she told me." (5.248 - 5.249).

One of the C&YP (3) Isy, recognised with a degree of pride the uniqueness of her sibling with ID, being the only person known to have their condition:

"Well like I know there's like a different forms of like, of like the disability, like I don't really know like, it's your sister really, is it your sibling's really after all and they're always going to be a sibling and like I think my sister, she's so far the only one that we know in the world that has got like her disability, so it's quite special and just like take it in, see.." (3.872 - 3.878).

5.2.1.3 Family, adapting, care needs

The C&YP were knowledgeable about the impact of ID on their sibling, and their family. Several C&YP recognised the need for everyone to adapt in order to support a child with ID in their family. Parents were identified as the gatekeepers; they researched and sought out knowledge and information and this provided support for the family as they adapted to meet the needs of their child/sibling with ID:

"Yeah definitely, so my Mum learnt about it, she did a lot of research about it and found out what we should do to help her. And she, we had a lot of talks as a family and we also ordered a lot of like guides and books and like leaflets and things like that to read

and learn. And I guess obviously I was so young I didn't read these books and things." (1.309 - 1.315).

The C&YP actively applied their knowledge and experience and were attuned to the impact of ID on their wider family, this is discussed further in theme 5.2.6 (Family impact and coping strategies). Several C&YP demonstrated their knowledge by providing examples of how they adapted, supported, and responded to the needs of their sibling with ID, such as offering reassurance and engaging in shared activities. They also described times when they were required to read cues and step away:

"…like reassurance I think is key, especially with like an autistic person, they look for reassurance. So if you tell them it's all going to be okay they'll know like "oh he said it's going to be okay like." I think that helped her." (1.402 - 1.406).

"She likes the feeling of being involved, which I know I need to include her in things so that's perfectly fine." (1.571 - 1.57).

"She lies on the sofa and she goes (sigh) I don't want to do any more, I want to watch TV, and then I'm like are you sure, and she's like, yes, I'm like even if we make the den even bigger, she's like yes, so she's very like, <u>once she says something there's no changing her mind</u>." (8.374 - 8.377).

C&YP were also knowledgeable about the physiological needs of their brother or sister with ID, two siblings recognised the impact of this on their sibling, but also more broadly they recognised the impact on their parents and the wider family:

"Well, I mean, I suppose the thing that affected us most was when he was having quite a lot of seizures, that was obviously very upsetting for my parents and quite upsetting for everyone." (4.424 - 4.426).

"But I don't think it's a headache, because he's got, he finds it hard to sleep, I don't know if it's erm insomnia, I don't know, I think it's like a mixture." (7.347 - 7.349).

5.2.1.4 Support for families

All the C&YP identified that having someone to talk to was important for them. Parents were identified as their primary source of knowledge, information and support. There was a recognition that professionals, doctors, teachers and others also provided valuable knowledge and insight for siblings and their families:

"Yeah. But it was a good insight from specialists and stuff. And like I learned, I've noticed as I'm growing-up as well like her vocal and her speech is improving quite a lot and we kind of like helped her with that but also her teachers helped her with that." (1.362 - 1.366).

"And if you for instance a speech therapy or something like that. Erm, but I think the school, if you go to a special needs school, especially a severe special needs school, they'll have all the equipment and stuff and that will just straightaway give you clues on how to handle children and stuff like that." (2.771 - 2.775).

C&YP valued knowledge and were aware of varied sources of information. (3) Isy, grounded her understanding in scientific knowledge, others advocated the use of social media, the internet, books, leaflets and films. Media sources reflected the times, i.e., the growing

availability of information on the internet. They welcomed and acknowledged wider avenues of obtaining information that helped them to gain greater understanding of their sibling's needs. This supported their adaptation and sense making of their own day to day experiences.

"...science so that's got me quite far. But like also, I don't know, it's given me like a little bit of even better understanding of the world, like watching like quite a lot of documentaries and stuff like that. So yeah." (3.676 - 3.679).

"I find quite a lot of information on the internet." (3.802).

"I would go on the internet or a leaflet probably." (5.696).

"Probably them or maybe even their mum....So that they, because yeah, probably, or someone who knows a lot about it. So like you or someone like you, yeah." (5.704 - 5.707).

"We went to see this speaker about autism and so that was interesting so that helped me quite a bit, and, oh, and there's a film called X+Y, have you seen that film? Because it just explains what is going on in their brains that makes them perform the actions that they do, like aggressiveness and things like that." (7.290 - 7.313).

"Um, books, just so I can get more information on how I could help him more often, um (pauses)...." (9.578 - 9.579).

One of the participants (2) Aayan, had plans to engage with work experience in his brother's specialist ID school, as a means of increasing his knowledge:

"I'm going to do some work experience there in the summer." (2.222 - 2.223).

Groups and networks were identified as valued sources of support for C&YP, their sibling with ID and their whole family. (8) Helene articulated the value of access to specific specialist expert knowledge and groups, as a supportive opportunity and network for her sibling with ID:

"I think it's like an organisation for people with Down's Syndrome and it's like it's mainly for kids who're like 4 or 5 and it teaches them shapes and the basic things, like that, and she met lots of her friends there." (8.573 - 8.575).

"I think it's good because it helped us a lot because it taught her like the basic things before school because in nursery, she went to two nurseries and they didn't really teach her that much, so I think at that point we went there to (names special needs/Down's Syndrome group) and then they really helped her learn a lot of things." (8.585 - 8.589).

(8) Helene, described reaching out to other families with similar experiences as an avenue of information and support mechanism, to build social networks, for siblings, their brother or sister with ID and their parents:

"I know there's one boy in the Year below who my parents know their parents so we're like friends, and sometimes we meet up and then Ellie and his name's Thomas, they play together." (8.223 - 8.225).

When asked about where they sourced helpful information about ID, C&YP also recognised the value of their own lived experience and knowledge as a resource for other C&YP with siblings with ID. For all nine of the C&YP, participation in the research itself represented an opportunity to share their knowledge. (8) Helene identified the need for a broader spectrum of

information to inform siblings' experience over time. She expressed the value of drawing on the experience of families and siblings at a later developmental life stage, anticipating that there would be more to know later in life:

> *"Other families who've like gone through it, preferably like families who have someone with Down's Syndrome but who's grown-up so they experience the whole package, and obviously it's not going to be the same for everyone but at least they'll have some experience." (8.561 - 8.564).*

(2) Aayan also recognised the value of his own and his parents lived experience, as well as the potential of drawing from specialist resources:

> *"I think asking people like me or people like my mum or my dad who have a person with special needs, like for instance, or there's this theatre called the (names county) Inclusive Theatre and they came in to do a play and they had, and there were people, adults and young people who got on the play but they all have special needs." (2.799 - 2.804).*

(5) Anna welcomed the idea of drawing on the experience of C&YP themselves to inform others and recognised that they may have questions. She suggested they may have concerns or be scared, hence she considered that speaking to others who have a sibling with ID would be helpful:

> *"I can't think of anything you could add but definitely what, like what might scare you and all that sort of stuff." (5.819).*

Several C&YP discussed the importance of sharing their subjective views as C&YP. They recognised value in their own lived experience as siblings as well as the knowledge and

expertise available within their families. When asked their views on groups that enable siblings to share their insights, they acknowledged the individual nature of their experiences. However, they also considered that there were benefits in sharing their unique knowledge and perspectives with others, particularly with siblings who may have a brother or sister with ID, in order to support them and their families in the future:

> *"Because no-one's ever really done research on what it's like to be a sibling. Like when I was younger I never found anything on how to be sibling. I just learnt how to be like a family, have someone with autism, just like my Mum did. So I mean I think it's good that this research is going on because it kind of gives a bit of insight into, you know, people that have young autistic children on how to act and how to act if you're a sibling. Because I think it's a bit more on a personal level, like I learnt through how to live with an autistic person but I think if there's actually information on how to be a sibling I think that's a bit more personal and it's a bit more easy to understand." (1.947 - 1.949).*

> *"...I think asking people like me or people like my mum or my dad who have a person with special needs, like for instance,...." (2.798 - 2.799).*

> *"Probably, that'd be quite helpful, because you can learn from people." (7.1037 - 7.103).*

5.2.2 Valuing sibling relationships

This theme emerged from the positive narratives and reflections shared by several of the C&YP. Five C&YP particularly identified and discussed what they gained from being a brother or sister. Two of the C&YP described examples of celebration on the arrival of their sibling. C&YP emphasised their brother or sister with ID talents and shared examples of times enjoyed

together. All the C&YP described their awareness of potential misunderstanding and judgements made by others about their sibling and about ID. They also recognised the potential for misperceptions of their experience as a sibling. The C&YP contextualised this emphasising the importance of understanding the individual nature of ID, the uniqueness of their brother or sister, and every individual with intellectual disabilities.

5.2.2.1 Celebrating being a sibling

Five of the C&YP (1) Shafeeq, (2) Aayan, (3) Isy, (4) Lucy and (8) Helene outlined ways in which they gained from, valued and enjoyed being a sibling. They emphasised the importance of acknowledging their brother or sister as an individual, they valued being a sibling first and foremost, as well as being a sibling to someone with ID. (1) Shafeeq described being a sibling to someone with ID as unique, different, he reflected this as being normal for him, his sister and family:

> *"I think it's kind of unique and a bit different because not many people can say "I've got an autistic brother or sister." So I mean it's quite different, like I've seen how my other friends act with their brothers and sisters but I mean I'm so used to having an autistic sister that it's kind of standard for me and like normal." (1.625 - 1.630).*

Two of the C&YP described the anticipation of becoming a sibling and the celebration that surrounded the arrival of their brother and sister respectively. (2) Aayan valued having a brother against being an only child, and was proud of his role in teaching his younger brother:

> *"Well first of all I'm not an only, I'm not an only child. That's why I said to my mum "oh can I have a brother?" and she said yeah." (2.357 - 2.359).*

"Yeah. I did say to my mum "oh please can I have a brother? I'm a bit lonely" and she said "okay." So… So I, the things we like to do together are games, for instance if it's like identifying which one's which so, I don't know, say there's the word that says red, you've got to find the colour red. So it's like pretty much games and high-fiving and fist pumping. I've taught him how to say "alright mate, what's up mate" and high-five and fist pump and stuff like that because I'm a brother, brothers teach younger brothers that." (2.361 - 2.369).

(8) Helene, described with emotion, the moment she saw her new baby sister:

"Ellie was born here, I remember that, and I went in one night and then I saw mummy lying on the mattress and then I went downstairs with grandma and then I came up and there was this little baby cuddling into daddy…So cute!" (8.124 - 8.129).

5.2.2.2 Mutual value of the sibling relationship, sharing experiences together

Several C&YP presented examples of time enjoyed together with their sibling with ID in shared activities and experiences. This was particularly evident where they were the older sibling with a younger brother or sister with ID. They reflected on positive aspects of their relationship and the impact they had on their brother or sister and vice versa, and expressed a shared mutual value derived from their sibling relationships:

"… And then Zahra, I enjoy it as well, Zahra really enjoys err this place called Mega Jump, like a trampoline park indoors. So she really loves that so I enjoy going there with her." (1.106 - 1.109).

" And just fun doing it together as well." (1.118).

"Fun because like we have two of these beanbags so we just, on the weekends we like get them out and then pile them on top of each other and then I jump on and then she jumps on me, so that's like, yeah." (8.361 - 8.363).

(2) Aayan described how his brother sought him out, valuing him as his big brother and their time together:

"Well he's very happy all the time. I think he just feels happy. He's very, I think bottom line I think he's very happy about me because, I don't know, he'll drag me to, first of all he's sometimes a bit annoying but either way like for instance if he's dragging me, I don't know, all the way upstairs to the TV room to put on Peppa Pig, that's a bit annoying. But then stuff like playing games with him, that's a bit more, that's, he's happy and stuff like that. So yeah." (2.601 - 2.607).

(3) Isy similarly expressed valuing time together and described an example of her sister with ID seeking out her company. They engaged in a shared activity, enjoying trampolining together, with both siblings gaining positively from their time together. It was described as a release back into younger childhood years, both having fun together. It suggested these might be quite precious times, valued but intermittent or short lived:

"Most of the time she's like quite tuned into her phone and like watching her YouTube, but like, and she always, sometimes asks me, it's like 'oh yeah, do you want to go on the trampoline' I'm like 'yeah sure, I'll go on the trampoline and I'll play with you for a little bit', because like I feel like if I play with her I can like go back into like my childhood and that's quite a fun experience,"(gentle laughter). (3.575 - 3.582).

5.2.2.3 Care and affection, reciprocity of sibling relationships

Several of the C&YP expressed positive aspects of their relationships and experiences where their sibling with ID showed affection and thoughtfulness towards them. (1) Shafeeq described a circumstance where he became very unwell, and his sister's response had overwhelmed him. He contextualised this in a realisation of how important he was to Zahra, given the concern she had shown:

> *"...something, you'll see her like laughing, playing very, in a happy good mood because she enjoys going out. She enjoys spending time with me. Like I was ill, I was like really ill last week from school." (1.654 - 1657).*

> *"... Like I was in so much pain and like really ill, I was lying down on the bed and Zahra saw me like that and she started crying and like was so upset because I was upset. So I kind of, I didn't know what to do really to be honest because I've never experienced that like. And then when I told her I'm staying home on Monday the first thing she said is "will you play with me?" (1.662 - 1.669).*

> *"I think she looks up to me quite a lot and she like cares about, because I've cared about her, she cares about me." (1.915 - 1.917).*

(8) Helene described how her sister demonstrated open affection towards her, hugging her. This was depicted as a closeness of the sibling relationship, a familiarity openly expressed when meeting other people. It seemed to suggest trust and pride in one another as well as offering as a sense of security for her sibling with ID:

> *"She hugs me a lot, when like we're around either her friends or my friends, she comes like she's like Helene and she squeezes me really tight, which is really cute, and she's*

also like quite shy in front of other people, but in a good way, so she's not like doesn't want to talk, she like smiles and then…" (8.345 - 8.349).

One of the C&YP (5) Anna shared quite a challenged narrative of her sibling experience with her brother, and articulated difficulties in their relationship, yet also identified times when her brother did nice things for her:

"Sometimes Kevin is quite nice. Like Kevin's one of those people who if you say "ooh please, oh I really want a pack of crisps", he'll volunteer to get you a packet and like get a packet. But then sometimes he's "oh well go get your own." (5.360 - 5.363).

In response to a question of what might be important for C&YP to understand about being a sibling of someone with ID, (3) Isy described siblings with ID still loving their brothers and sisters. She recognised that even though it can be difficult sometimes for siblings with ID to show affection, she considered it important for C&YP to be assured that they are still loved by their brother or sister. Care and affection were interpreted from small acts of kindness, through receiving drawings and small gifts. Like (5) Anna, (3) Isy referenced several experiences throughout her interview, that were less positive and identified circumstances where she faced risk of physical hitting or harm, of being hurt physically and emotionally, or feeling like giving up. Despite this, she still appreciated the gestures of care and affection shown by her sister with ID:

"Because like, I don't know, like different children like me could like take it different ways, like they might not be able to see that like their brother and sister do still love them, like they can't really like show it and stuff like that, so yeah, Evie does sometimes show it, like she draws like little pictures and stuff like that and she like brings stuff back from school which is quite sweet, but yeah, it's just to like let people know that like

even though they do like sometimes like hurt you and like it just might seem like you just have to give up and stuff like that, but like you still, they still like love you and stuff like that, so yeah." (3.783 - 3.794).

5.2.2.4 Valuing uniqueness, skills and attributes of a brother or sister with intellectual disabilities

Five of the C&YP discussed the uniqueness of their sibling with ID. They demonstrated their acceptance of them as people first, and recognised their special needs were an integral part of their brother or sister with ID. (4) Lucy described this eloquently emphasising her experience of being a twin and sibling as an individual thing, as normal, advocating for others to appreciate and value C&YP's lived experience as siblings. She promoted a narrative of acceptance of a brother or sister, with acceptance of their ID, and highlighted that as a sibling they would not want anything to change:

"I think people maybe should know that its mostly an individual thing, I think and everybody's experiences of somebody with special needs is different but I think maybe people should also remember that, and this might sound kind of inconsiderate or something but I think people should remember that I imagine for most people whose siblings have these sort of neurological disorders or special needs that for them it's just kind of normal because it's the way they've always been. I think that's maybe something people should remember a bit just because I think that's the case for most people. So, it's kind of like they wouldn't really want anything to change. That's the way it's always been and that's the way their siblings are to them." (4.749 - 4.759).

The C&YP shared examples of things their brother or sister enjoyed. They emphasised their siblings' skills and talents and demonstrated a sense of pride in their attributes. (1) Shafeeq expressed his sister's (Zahra) open welcome and confidence when meeting his friend:

> *"Yeah. So my friend stayed the night once and she was very excited, very happy to meet him and she's shaking his hand saying "hello, what's your name? My name's Zahra." Very, you know, confident and very excited that there's a new person here." (1.502 - 1506).*

(8) Helene celebrated her sister:

> *"Everything! Like I said she's creative and she's very cute and kind." (8.353).*

The ability to establish friendships was highlighted by the C&YP as an important aspect of their experiences. All the C&YP and their siblings were in their pre-teen or teenage years, and they outlined their ability and opportunity to make friends as being an asset for them and their siblings with ID. (3) Isy emphasised positively that friends see her sister (Evie) and not her ID. She recognised her sister's attributes and personality as enablers, allowing her to make friends easily:

> *"No, not really, like Evie, she can make friends quite easy because I realise that kids around her age don't like particularly realise that she has a disability, like they just realise like she's just fun like this fun like excited, energetic like girl, and they don't like realise it." (3.506 - 3.51).*

(8) Ryan acknowledged the importance of friendships to ensure his brother was not alone:

> *"He has quite a few friends already which is good. I don't want him to be alone." (9.167 - 9.168).*

5.2.2.5 Sibling responsibility and advocacy

Several of the C&YP discussed experiences of adjustment. They outlined an awareness that being a sibling was a significant responsibility. They presented a considered perspective of their experiences, often emphasising their willingness to take on responsibility, alongside an awareness of the value they bring individually to their sibling relationships, and when acting as role models.

Two of the C&YP protected the narratives of their sibling with ID, several spoke about situations where they advocated for their sibling with ID. They emphasised the importance of a non-judgemental approach from others and demonstrated a strong sense of fairness and social justice, discussed further in theme 5.2.7 (Insight, vulnerability, loss of childhood, changed family relationships). Two of the C&YP described their role as big brothers, they demonstrated both a willingness to take on responsibilities and acknowledged adjustments needed. There was a sense of their responsibility as siblings to be a good influence and support their brother or sister with ID:

> *"like this must be like right." So I kind of like obviously need to be careful what I do and make sure like I'm setting a good influence on her because she's going to copy what I do, so I just kind of make sure I'm showing her the right things to do…."I mean quite responsible and like, um, I know I can do it <u>but I just feel like it's a big responsibility</u>." (1.428 - 1.435).*

> *"It's a big responsibility. You have to, it's a big responsibility and it's more, you have to be more careful with your brother because as I say he doesn't, he's slow understanding and you also feel, there's a disadvantage and an advantage to having, as I said there's an advantage as in like you get a free pass and stuff like that, but there's also a disadvantage*

as in like before, when people who would go, if I was to give my brother directions and go "right, you've got to do this, you've got to do that to put your socks on", he wouldn't do it, I have to physically show him rather than, for instance there's a person called Matthew and he's got a sister called Sarah and if we give directions to Sarah how to put her socks on she would do it, well that's the disadvantage I'd say of being a brother and having a brother who has a sibling but then there's a big advantage anyway so it balances out." (2.424 - 2.437).

"You have to put a bit more consideration into the fact that he can't like, uh, what's the word? He can't, he's a bit more, he's slower with his understanding." (2.308 - 2.311).

(1) Shafeeq at 15 years was one of the oldest C&YP interviewed, he shared his awareness of the potential longevity of his responsibilities for his sister. He described his role in later life potentially in loco parentis. He accepted and integrated this as a given factor in his life for now, and outlined his responsibility to factor care and support for his sister into his future plans:

"I kind of just realised really and like saw how much my Mum looks after her and how much she relies on us. I'm just thinking when I'm grown up my Mum might not be around so I have to be the person there that she can like 100% rely on. And I know I can do it, I just need to make sure I get a good job and stuff like that." (1.794 - 1.799).

(2) Aayan described the normal experiences of being a sibling akin to the experience of his friends, noting that all siblings fight or squabble. Alongside this, there was an awareness of the need to take things slower, to explain things differently to support his brother with ID:

"Well first of all he's not, my brother with special needs, my brother with special needs he's more like a normal person as in like we sometimes fight over stuff, we're normal

people, we don't do stuff differently. He's not severely got a disability, he's just mildly, that's why he goes to a mild disability school. So like Matthew and Sarah they squabble over a lot of things, we squabble over a lot of things, so we do have similarities but there are also differences that you have to take him slowly and you've got to explain stuff to him but I think the school are doing that, are covering that quite nicely." (2.554 - 2.563).

Two of the C&YP described being protective of their sibling's story and emphasised the importance of not sharing information about their sibling with ID with others. They also linked this to protecting themselves from having to engage in explanations to others. However, they firmly purported a position of fairness in protecting their siblings' confidentiality and story:

"Yeah. I don't tell them everything because I wouldn't like for my brother to say everything about me to his friends because…" (5.354 - 5.355).

"I tell them like I have a brother and things but it's not really my stuff to tell, is it?" (7.515).

Protecting their story and family narrative was linked to potential judgments made by others. C&YP emphasised the need for awareness and tolerance of difference and social justice. They acknowledged that everyone has positive attributes, including their siblings with ID more specifically. However, they also identified that there might be a requirement for different levels of support:

"Yes, I do. One of my friends is just judges people. She goes "urgh, why is" but she's really nice but she always goes "ew, like he's disgusting", all that sort of stuff." (5.430-5432).

"Mm, I don't really like it that much. I'm thinking "mm, that's a bit rude to say that out loud", like maybe you could think that but to say that out loud is just a bit, I don't think that's right really." (5.434 - 5.436).

(4) Lucy aligned this to her interpretation of the teachings in Catholicism, and emphasised people with ID are unique and gifted in themselves. She advocated a view of everyone being equal:

"Catechism annoys me slightly because it says a child with a learning disability and a highly gifted child they've been given what they've been given by God and they should be treated equally and <u>it annoys me slightly because it makes a distinction between somebody with learning difficulties and somebody who's gifted</u> and that annoys me because if you have learning difficulties you can still be a highly gifted child in different ways but I think Thomas is gifted with things which other people don't have. Things which people who don't have learning difficulties could still have but which not all of them do so it's just kind of like just because he has special needs it doesn't mean he isn't gifted in any way but I know it kind of helps me to remember that everybody is equal and everything and that's what I believe as a Catholic and what other Catholics are supposed to believe." (4.588 - 4.600).

<u>5.2.3 Context outside the family</u>

This theme emerged from conversations within the interviews focused on getting to know the C&YP, their families and their wider context. All the C&YP discussed the value of their context outside the family; their school, favoured subjects, hobbies and activities outside the home. The participants identified that friendships were important to them, but they also

expressed a sense of protectiveness over their story, as well as valuing the opportunity to step away sometimes from the focus on being a sibling.

5.2.3.1 Valuing friendships

All C&YP identified friendships as being particularly important to them. Three of the C&YP (1) Shafeeq, (3) Isy, (4) Lucy, described valuing friends who understood their sibling, or ID, either by being a part of their family over time or through other wider experiences:

> *"...have, I've never really explained it to my best friend but she knows kind of what it means and everything because she's coming here for long enough so I kind of have explained it a bit now, now that were older and we can understand it but she's always kind of accepted Thomas for who he is because she knows him very well because she's been coming to this house for a long time." (4.403 - 4.408).*

(3) Isy described not talking much about having a sister with ID. She highlighted an occasion when younger siblings came to her school as part of their transition taster day. As her sister was attending a special needs school, she did not attend the taster day, and this was queried by her peers. Her close friends, one in particular, made this easier to explain, as he brought prior insight to their friendship through his mother who worked in a special needs school:

> *"No, not really, like some people, I think we had like the people in Year 6 come up to our school for like two days and everyone's having siblings and it was like 'oh yeah, you have a sibling don't you' and I was just like 'well, well anyway she wouldn't come up this year but she, because of her disability she's in the other school', and like my close friends understand that, and I also have a friend that his Mum works in the school, so he understands about my sister, so yeah I don't really talk about it though." (3.329 - 3.338).*

(1) Shafeeq described shared values as being important in his choice of friends. He highlighted that, people can make disparaging remarks and be '*rude*' to, or about people with ID. He positioned himself as wanting to challenge such behaviour if this was directed to his sister or others with ID. He valued friends who shared his beliefs and adopted a similar respectful approach:

> *"Yeah. I mean I'd never accept anyone being rude about my sister or rude about someone with autism. And I think my friends are very like nice people and respectful people, for example if we saw like an autistic person at school being made fun of, we'd definitely step in to defend him or something like that. And even if I wasn't there, it's not like I influence my friends, they also have that view." (1.591 - 1.601).*

(6) Olivia highlighted the importance of friends having knowledge and shared values. She described a situation where her sister kicked one of her friends, reinforcing the need for understanding from others and acknowledged a potential impact and vulnerability in friendships:

> *"And then I was like "no, no, no" and then she started kicking me and the older, the, um, my other friend, like both of us, yeah, because the other friend tried to split it up because she was like actually hurting me, yeah, and then she got kicked at as well." (6.409 - 6.41)*

Two C&YP further reinforced the importance of building friendships for their sibling with ID:

> *"She has got a lovely friend called Amelia and she's got like, it's quite weird though because Evie she can like talk and talk and talk for like ever, but her friend Amelia's got like speech like problems, so she can't really talk but it's just, it's actually really like weird just to see how like two people like quite different like getting along like that, and*

they do some, yes, they do like go over each other's houses, so yeah, it's quite cool, to see that happen." (3.373 - 3.381).

(9) Ryan highlighted the importance of friendships in establishing social connections. He shared insight of care and concern, wanting his brother to have his own friends to avoid isolation:

"He has quite a few friends already which is good. I don't want him to be alone." (9.167 - 9.168).

5.2.3.2 Escapism and support through interaction with friends

Several of the C&YP spoke about a need to get away from the family pressures. (3) Isy valued her time with her friends as a means of getting away from problems:

"No not really, I feel like when we meet each other and go out it's kind of like we get away from like, all like the family like problems and stuff like that and you can just stay focussed by ourselves." (3.360 - 3.363).

Similarly, (7) Iain referred to sibling activity and support groups,. He expressed the view that it was *"nice"* to be with other people who shared similar experiences. This highlighted a need to have opportunities to take his mind off things in the home environment:

"Yeah, sometimes it's nice to see other people and sort of take your mind off it." (7.397 - 7.398).

(5) Anna described being with her friends as an outlet for shared experience, an opportunity to discuss their experiences as brother and sisters:

"Mostly annoying siblings because I have an annoying sibling, most of my friends do, and we just like exchange stories." (5.200 - 5.201).

5.2.3.3 Opportunities to make friends and engage in shared activities

Several of the C&YP outlined their enjoyment of sports and other varied social activities. They highlighted the importance of their school environment as a venue that provides opportunities to engage in extracurricular activities of interest, to try new things and build friendships:

*"Well normally my friend will take us all around, out roller-skating and stuff like that. I want to take some of my friends to a pottery class like or painting pottery, I want to do that, yeah….Yeah. One of them, my friend *******, she really likes doing painting as well…Well there's a club on Thursday during lunch and we can go to that together, yeah. We just draw all the time together really." (6.210 - 6.217).*

"Yeah, we actually like run a club together on Tuesday lunchtimes which is fun." (8.63 - 8.64).

"Well there are actually quite a lot of Year 7s girls who play football, we have about 10 who come and then about 13 Year 8s, which is pretty good." (8.75 - 8.77).
Um, well there's loads of friends at school and there's also some here." (9.70)

5.2.3.4 Valuing hobbies, interests and achievements

Perhaps unsurprisingly, given the age and diversity of the participants, the C&YP outlined varied interests in school subjects, as well as in their choice of hobbies. All of them spoke with enthusiasm about school subjects, hobbies and interests they particularly enjoyed, these were

often described as an outlet for self-expression and the C&YP were proud of their own skills and achievements:

"Well, I enjoy well lots of sports I used to do gymnastics in Year 2 and I also used to do horse riding but I had to stop that because horse riding got a little bit too expensive." (3.22 - 3.24).

"I really enjoy art and music and maths because I like my maths teacher, and science, I like science as well. That's pretty much it. And history. History is a good subject." (6.76 - 6.78).

"I like science, I like chemistry and biology. I used to like physics but I don't really like my teacher this year…So, I like history as well, and I like learning about the war and things like that. I quite like sport a lot, I like erm wrestling and I like football and I know a lot about wrestling and football." (7.78 - 7.84).

"I like dance and PE, so I'm on the sporty side. The main like topic in PE I like is football, I really like football." (8.51 - 8.52).

"Yeah, I like football. I like chess as well, I haven't mentioned that." (9.83 - 9.84).

(1) Shafeeq spoke about being part of a team and made connections to this as a benefit in his broader life:

"I guess I enjoy being part of like a team so obviously football and sports really encourages that, <u>being like a team player. It also builds your like team building skills which helps in life</u> and I kind of erm, school I enjoy more subjects this year than I did

last year. I find like this year I've been like trying to concentrate a bit more and I've actually been enjoying the subjects." (1.56 - 1.59).

The C&YP were proud of their talents and achievements both academically and through enjoyment of their hobbies:

"Maths I… I (laughs), um, maths I'm not, like I like maths, I just find it fun. And English I love comprehensions so yeah, and then French I'm very good at it." (2.88 - 2.90).

"Well, I'm good at most of them but I like English but I'm good at all of them. I like English because, especially English Literature, because I like all the different texts that you can study from all the different time periods and things and I like learning about the context of different texts and stuff and I like Biology because I like Science generally but the thing is I don't like Maths and other sciences are more related to Maths but I prefer Biology because it doesn't really have much to do with Maths in it and I quite like the whole idea that it's to do with the study of living things and I like French because I like the language and I like kind of, I like learning the language, I'm quite interested in languages and stuff and I also like it because it's the subject I'm best at."(4.30 - 4.40).

(8) Helene proudly described taking a leadership role as captain of the football team:

"So on the, in Year 8 I'm the captain of the football team so, and then there's a vice-captain, so me and the vice-captain we like run a like club for it, which is good." (8.66 - 8.68).

Several siblings described having creative hobbies, and shared interests with their friends:

*"Well, I like cooking things, I cook things quite often with my friend who goes to ********** School so she lives down the road so we cook things quite often when she comes here. I also sometimes like to act out Fawlty Towers so I have a copy of that." (4.177 - 4.180).*

(6) Olivia proudly showed off several pieces of artwork on display that she had created, while (8) Helene also described herself as creative:

"I painted that." (6.87).

"I like like socialising and like I said, playing sports. Probably my favourite academic subject would probably be English because I'm quite creative, I like poetry and things like that, yeah," (8.80 - 8.82).

5.2.4 Becoming aware of intellectual disabilities, age, birth order and growing maturity

This theme emerged from the descriptions presented by the C&YP of becoming aware of their sibling having ID and connected with the earlier sub theme of C&YP accepting their sibling as an individual. This was evident in their descriptions of how their understanding of ID developed over time, with awareness often from a young age. As they got older, differences between them and their sibling with ID appeared more evident. C&YP described becoming more aware of ID, identifying differences in their awareness, experiences and in their relationships with their sibling with ID. This was informed from their own observations and through others. They identified a need for greater tolerance and understanding of their siblings' needs. They outlined circumstances where they delivered care and provided support roles, this was described through a sense of growing maturity.

5.2.4.1 Birth order/age/life stage

(5) Anna as a younger sibling described seeing comparisons with brothers of her friends, bringing a realisation that her brother might have different needs:

> *"I never like knew. I thought that was just like what everyone's brother was like. And then I started to realise. I can't really remember what, how like I was told but…"Because I saw other people's brothers and like "mm, my brother's nothing like that." (5.230 - 5.238).*

For (5) Anna it was her mother who explained about ID, reinforcing mothers as the gatekeepers of information. This suggested that parents assessed the right time to share information with their children, judging information at a level they could access:

> *"I think she said he has special needs. I think that's about it. And then obviously I didn't know what that meant so I asked because I was about 6 or 7, and then she like explained to me like what it was, like it means like he's annoying and, she didn't say it means that he's annoying but, mm..." (5.252 - 5.256).*

(7) Iain, also a younger sibling, identified becoming aware of his brother having ID when he was 7 or 8 years old, and his brother about 11 years old:

> *"Well, I think it was when he was in Year 7, so I would have been in Years 3 or 4, I think, because I know he was diagnosed in Year 6 with autism I think or ADHD or dyslexia, one of those, and yeah, so I think it was about Year 3 or 4 but I don't think I understood about it then, I don't think I really understood it till like end of Year 5 probably, end of Year 5's when I understood it." (7.280 - 7.28).*

(7) Iain explained he was aware of his brother having some special needs, but it was later when he understood more about the diagnosis, when aged 10 or 11 years old.

> *"I don't know, I didn't know when he was diagnosed, I didn't know about it when he was diagnosed." (7.899 - 7.900).*

Both (5) Anna and (7) Iain, were younger than their sibling with ID, and described difficulties. They struggled at times to cope with the needs of their siblings with intellectual disabilities. (5) Anna described dealing with challenging needs, and shared feelings of vulnerability. She described being reassured over time by exposure to varied situations, as she learned more about her brother Kevin's expressed behaviours, his responses, and through seeking out parental support:

> *"It doesn't happen quite as often anymore when he just kicks off because now I've kind of learnt that he doesn't, that he won't actually hurt anybody. He's harmless but just scary…." (5.762 - 5.764).*

> *"Definitely. Because when, sometimes when you do feel like really scared you do just need to talk to someone that you know isn't then going to like say, go to them and say 'oh you're scaring your sister'." (5.787 - 5.789).*

(7) Iain outlined that a degree of compromise was required, as a younger brother, having to *"put up with things",* and suggested his brother Christopher's needs were prioritised. He described the impact on him, missing out on outings or opportunities, and especially having less time with his mum, which he found difficult:

> *"Sometimes <u>when I sort of have to erm, not like take one for the team</u> but, erm, it's hard to explain, like be…" Just sort of erm put up with things kind of like…" (7.318 - 7.322).*

One of the youngest siblings (2) Aayan, who was 11 years old described his acceptance that his brother Isma'il had special needs. He was optimistic and positive about his brother's potential, expressing a view that his brother will mature, and things will be ok as he gets older. This suggested a potential limitation in his understanding of ID, and the potential for a degree of lifelong impact for his brother:

> *"So I think it's really when he gets to a certain age that he'll grow-up and he'll mature and he'll like get all his speech right and stuff like that. And once he's done that he can probably find his interest." (2.718 - 2.721).*

5.2.4.2 Becoming aware of having a sibling with intellectual disabilities

Five of the C&YP, (1) Shafeeq, (3) Isy, (4) Lucy, (5) Anna and (7) Iain, spoke about when they became aware of their brother or sister having ID. Several outlined being quite young when they began to see differences, yet they still did not quite understand ID or their siblings' needs. All the C&YP suggested their awareness evolved as they grew older, suggesting age as an important consideration in siblings' experience and understanding of ID:

> *"Oh obviously when, she was diagnosed very young and I think I was about 3 or 4, maybe 5, and I never noticed anything because I was so young but when my Mum told me I learnt about what it was and then I realised and understood it." (1.280 - 1.284).*

(3) Isy who was 13 years of age, spoke about her growing awareness of ID and her sister's needs. Yet this co-existed alongside a sense of unpredictability. Despite her emerging understanding, she was still surprised by some of her sisters responses in their day to day interactions:

> *"No, because I think I was old enough when we found out Evie had her disability, I could, like I could understand, but I still don't really understand it, like yet, but*

sometimes I joke about things that I think she might get but she doesn't and then she, then she gets a little bit angry, yeah." (3.285 - 3.290).

5.2.4.3 Being a twin

For (4) Lucy in having a twin brother, there is the opportunity for immediate comparisons to be made with herself. While they are different genders, they are inevitably at the same life stage. (4) Lucy discussed not wanting to know anything about ID when she was younger. She described recognising some differences for her brother, when compared to other people, and getting information from her parents. As she got older, she learned more, coming to realise her twin brother had ID, and subsequently being aware of some of the additional difficulties he might face:

"Not really. When I was little I didn't really, because I didn't really ask anything because I didn't, I still accepted it, I didn't really want to know why or anything, I just thought that he was very strange and not like other people and I can't really think of a time when I actually had learned that he had learning difficulties but I think I kind of learned it just by my parents talking about it and stuff and also because as I got older I learned more about these things and I think maybe people, people at school didn't really mention it but I just kind of, I sort of knew that it wasn't, that Thomas had problems with learning and things in school and also when he got the sort of helper, at that stage I kind of, I knew what everything was and I think I knew that the correct term for it was learning difficulties." (4.321 - 4.332).

Developmental age, support needs and schooling heralded a time of separation, change and differentiated experiences for these twins. This was apparent in their schooling, with Thomas having additional input and support in his early years, and thereafter moving away from (4)

Lucy's school to a special needs school which separated the twins in their school life from the age of 10 or 11 years:

> *"Yeah, we went to the same primary school and most of the school time he didn't really, obviously he was treated differently but now that I think of it he wasn't really treated that differently throughout most of school but in Years 5 and 6 or perhaps 4, 5 and 6 he got a kind of like a helper like a woman to sort of support him through everything and I think that helped but he couldn't go to my secondary school mainly because of the Maths, that's what he struggles with above all else, just doing Maths and stuff, he can count but he can't really, he's just very bad at calculating things, and calculating sort of everything, his Maths is at a very low sort of level and my school said they couldn't, like even the Maths they had in the bottom set would be too hard for him so that's why he moved to the special school he goes to, ***** **** School." (4.233 - 4.244).*

(4) Lucy and Thomas have an older typically developing brother (Evan); a sense of distance was described between her and her twin, a potential loss in her relationship with a greater closeness to her older typically developing brother as they grow older, at 16 years old and (Evan) being 19 years:

> *"Well, I sometimes wonder if he's closer to Evan but then, I think maybe he is but I'm not too sure. It's just kind of, I feel mainly in recent years we've grown apart a bit because it seems harder to talk to him than it was kind of in the past, he just doesn't really kind of a bit, he sort of seems to want to distance himself from other people a bit more than he used to and it's just kind of hard to talk to him because of the Autism and stuff. It's like I've never really been able to have a proper conversation with him and when we were young you could just sort of like play and stuff but now we're too old for*

that, its kind if like, I find it hard to think of things to do with him these days and because I sometimes get annoyed, I don't always want to be alone with him because then he just sort of asks, when he tries to talk to people he doesn't really listen to what they're saying, he just asks lots and lots of really bizarre questions and it gets quite annoying and if you're on your own with him there's nobody else to talk to and nobody else to answer the questions and then it just gets quite dull sometimes and also, sometimes if he wants to go for a walk which normally I go with him but he often wants to go to strange places like he likes to walk in alleyways around the area which I don't much like so I don't always want to do that." (4.266 - 4.285).

5.2.4.4 Growing awareness of intellectual disabilities and maturity

Several siblings described taking on more responsibility and demonstrated a growing awareness of the support needs for their sibling with ID, more so they reached their later teens, this was particularly evident for older siblings. (1) Shafeeq described an evolution of his understanding, he had started to ask more questions and it was his mother who provided information. He outlined becoming more engaged in taking on co-parenting responsibilities, for example, going to parent evenings. Of note, (1) Shafeeq was an older sibling but his mother was also a widow and a single parent. (1) Shafeeq outlined a closeness in their relationship in supporting Zahra:

"Well to be honest… when I was first being told about autism and stuff obviously I was still getting my head around it and I was still trying to understand what autism actually was and what a, to be honest what a learning difficulty was. Because when I was really young I had no idea what a learning difficulty was. I just never knew anyone with a learning difficulty. So I had a lot of questions, I just want.. needed to find out what it was first. So obviously my Mum explained that to me and she kind of taught me a bit,

kind of taught me about what autism was and what learning difficulties are, like er the autistic spectrum. And obviously when Zahra grew up a little bit she went to meetings and stuff like that. And I've been to a few of her like, um, oh what's it called um? Parent evenings and stuff like that with my Mum." (1.327 - 1.341).

Two of the C&YP (3) Isy and (4) Lucy, described a growing awareness and maturity in their understanding of ID. This was accompanied by a desire to challenge others' to inform their understanding and perceptions of their sibling, and of ID. Yet they also outlined a sense of their own vulnerability and did not always feel confident to challenge others:

"Well, I was like, because I think I just learnt about it as I was growing up into secondary school, and like there was people, there were people there that like I've kind of grown up with it and there's people that were just like, they were, there's like people as well that have got disabilities at our school and they always make fun of it and they'll make me a little bit sad because my sister, because my sister's almost got the same problems as them, and I'm just like, and I don't really have the courage to like go up and like say 'well you can't do that' and stuff like that. But yeah.." (3.252 - 3.262).

"it's different,' and sometimes I kind of get annoyed when I hear people talking about, because people at my school, I sometimes wonder if I ought to tell people at my school more or if I should have done because obviously people at my school still kind of use the term autistic as an insult or whatever and they talk about things like that and I always find that quite hurtful and I feel if I told them my brother was like that they wouldn't do it anymore but I don't usually have the courage to say that sort of thing."(4.364 - 4.371).

5.2.5 Sense of agency; compromise; power, and loss

This theme emerged from questions and conversations about day-to-day experience of living with a brother or sister with ID. From the C&YP's examples and further exploratory questions, sub-themes related to C&YP's agency, their experience of control and compromise were evident. Participants gave examples of containing their emotions or diffusing situations; the issues of power and the potential impact on self-efficacy also emerged.

5.2.5.1 Children and young people's sense and use of agency; compromise and containment

Several of the C&YP described a sense of agency, as well as the lack of agency over their lives. They shared circumstances where they had compromised, taken control of situations, e.g., deescalating disagreements or managing situations of conflict. They also described times where this was more difficult, where they felt less in control, or where their siblings' needs or perspectives were prioritised. C&YP highlighted strategies they had developed to manage difficult interactions, identifying a need to control their feelings and responses. They further suggested how this helped their sibling with ID, and their family, in developing shared coping strategies.

Two of the C&YP (1) Shafeeq and (2) Aayan, spoke of keeping their sibling "*happy*", they shared this almost as a priority. This elicited a sense of containment, suggesting circumstances where they deprioritised themselves, their needs, and self-expression in pursuit of keeping their sibling "*happy*." For (1) Shafeeq, his future life plans were framed around his responsibility for his sister. He readily accepted that he would have a role in caring for her (Zahra) for the rest of his life. He presented a sense of active agency, of compromise, and used his knowledge and insight to acknowledge the needs of his sibling with ID as a reality, now and for the future.

He connected his responses to the positive impact that being happy would have for his sibling and the collective experience of the family:

> *"Well I mean for Zahra I think keeping her happy and I just kind of need to try hard and go to a good university, get a good job so I can provide for her and look after her. I know I'm going to have to care for her for all my life but I'm completely fine with that. I just know that I need to kind of work my way so I can provide for her and keep her happy." (1.777 - 1.782).*

> *"So I mean I, for me I just want her to be happy so whatever makes her happy,…."(1.831 - 1.832)*

For Aayan, there was also a sense of keeping his brother "*happy*" he saw his role bringing a positive impact in that regard:

> *"Well he's very happy all the time. I think he just feels happy. He's very, I think bottom line I think he's very happy about me because, I don't know, he'll drag me to, first of all he's sometimes a bit annoying but either way like for instance if he's dragging me, I don't know, all the way upstairs to the TV room to put on Peppa Pig, that's a bit annoying. But then stuff like playing games with him, that's a bit more, that's, he's happy and stuff like that. So yeah." (2.600 - 2.607).*

Three of the siblings (6) Olivia, (7) Iain and (9) Ryan, described strategies they use to manage their emotions, particularly in difficult situations or episodes of conflict with their sibling with ID. For example, they actively removed themselves when they might be at risk of harm. These were often situations outside their control. There was a strong narrative of holding back, they often contained their responses and thus avoided conflict. They expressed an awareness of the

need to deescalate difficult circumstances, to minimise risk of harm for themselves, and for their sibling with ID. Risk and vulnerability for C&YP was explored in theme 5.2.7 (Insight, vulnerability, loss of childhood, changed family relationships). It is notable here, that in applying self-efficacy to these challenging situations, the C&YP demonstrated an awareness of the need to regulate their responses, particularly when they felt angry. While they recognised a degree of inequity in their sibling relationship, namely an awareness of their own vulnerabilities, they also acknowledged the potential vulnerability of their brother or sister with ID should they express adverse or negative reactions towards them:

> *"Squeezing a pillow, just urr, yeah…Pretty much just that, just like urr, just yeah."(6.729 - 6.731).*

(3) Isy described a similar approach in managing her emotions in situations of difficult interactions:

> *"Yeah, I used to go like bite a cushion or something, and like I think I like stopped in Year 3.""I think something, so like if I asked for something like I didn't get it, I would just like, or like if someone, you know, like wounded me up and like started teasing me, I'd get quite angry at that, so yeah." (3.160 - 3.167).*

For (7) Iain, this was described as "*taking one for the team*". This enabled his parents to prioritise his brother's needs and supported their coping strategies as a family, but it also exposed a sense of loss for Iain in his parental and sibling relationships:

> *"Sometimes <u>when I sort of have to erm, not like take one for the team</u> but, erm, it's hard to explain, like be…Just sort of erm put up with things kind of like…" (7.318 - 7.322.)*

(9) Ryan elicited a sense of containment of emotions for him and his family, to avoid a "*meltdown*" for Julian:

> *"Um, we've got to think about him... Um (pauses) we've got to think about him a bit more because he's got needs and we don't want to him to have a meltdown or like not like where we're going or what activity we're doing." (9.367 - 9.370).*

5.2.5.2 Power

The siblings' responses to questions concerning challenging interactions with their brother or sister with ID highlighted issues of power and made evident their own sense powerlessness. Two C&YP (6) Olivia and (9) Ryan, described containing their emotions. (6) Olivia described conflicted feelings about her relationship with her sister and how she felt towards her:

> *"Just very (sighs), like I can't really explain it. It's just… I feel sorry for her but then I also feel really angry at her, like yeah." (6.518 - 6.519).*

(6) Olivia shared a sense of care. On one hand she sought support for her sister in times of high expressed emotion. On the other there was a sense of her own powerlessness, seeing unfairness in judgements or assumptions made by others. She expressed a desire to disprove situations where she was perhaps unfairly blamed, and believed this was justly her sister's (Frances') fault. When asked what might be helpful in such circumstances, she wanted to both perspectives of support and fairness to be addressed:

> *"Um, somebody to just calm Frances down properly. Like just like "oh Frances, it's alright" or like cameras to show when, when my mum's not looking and Frances does hit me and then Frances will like slap herself and then start crying "oh my God, Olivia hit me, Olivia hit me, Olivia hit me" and I'll get told off even though I'm telling my mum like "oh no, it wasn't me, it wasn't me, it wasn't me." Or Frances will be sitting*

on the sofa and I'd be sitting over here and like Frances will just go "Olivia stop it, you're really hurting me" and then like (sighs), and then, and then I would get the blame, like yeah." (6.941 - 6.952).

(9) Ryan described similar situations of powerlessness and a sense of injustice. He described deploying a strategy of walking away. He was aware of the need to contain his reactions e.g., when being hit by his brother, thus protecting them both:

"Okay, if he hits me or something I react back but my mum's told me that I've got to just breathe in, tell her and then it's dealt with." (9.270 - 9.272).

5.2.5.3 Prioritisation and loss

Building on the earlier sub-theme of power, several C&YP shared examples of experiences where the needs and support of their sibling with ID were prioritised. Some experienced this positively; however, others expressed a sense of loss and described such circumstances as being out of their control. Where this was attributed positively, it was connected to a supportive narrative that contributed to greater family harmony:

"Yeah. I'd definitely say the first thing that's absolutely key if you have an autistic brother or sister is to be patient and understanding. Like you have to be kind and patient and understanding with the autistic person. You have to kind of suit their needs and try and help them and encourage them in doing things, and not rush them, not force them, kind of let them go at their own pace and keep them happy, definitely. That's absolutely key. Keep them happy." (1.596 - 1.603).

In contrast, where this was framed more as a loss, such circumstances were described as life interruptions. Examples included planned family outings being cancelled, where the needs of

siblings with ID impacted the families' choices and priorities. Consequently, this involved loss for the C&YP, in terms of support. The resulting experience of reduced time with their parents was particularly difficult for siblings. Yet this was also framed more positively in a narrative of their emerging independence:

> *"… Sometimes for instance if there was maybe something I wanted to do or something, but then Christopher was having a really tough day, we wouldn't be able to do it, so it's annoying but I understand it, and sometimes when he has like a difficult night and things, I have to erm get the train in the morning which I don't really like doing, and erm just things like that…Become sort of, (pauses), be less like kind of needy, like being a bit more independent." (7.325 - 7.321).*

While (7) Iain above, appreciated his brother's higher level of need, he saw himself as being more independent given his insight and through the conscious compromises that he makes:

> *"Because he needs a bit more support so I have to sort of take a more backseat role kind of, I don't know if that's the right analogy at all?" (7.359 - 7.364).*

5.2.5.4 Risk and vulnerability (physical, psychological, emotional)

When asked what C&YP as siblings needed to know about being a brother or sister to someone with ID, several C&YP identified risk as important to highlight, both for their sibling with ID, as well as for themselves. Examples of risk involved being physical hurt, being hit, kicked or spat at, potential psychological risks and emotional vulnerabilities, as well as dangers in the environment and outside of the family. (1) Shafeeq described his sister's vulnerabilities, highlighting the risk of 'stranger danger', alongside this identifying his role in teaching and protecting her:

"I think she's very naïve which is why I think I need to look after her a lot, especially in the future because I mean things could happen and she's very trusting. So if someone says "oh I'll take you here, I'll take you home" or something, she's going to believe him. She's going to believe that person. So we've taught her as she's grown up to like, you know, not believe strangers, not listen to these people but, you know, trust her family and trust these people. But I know like it's just she trusts me and like believes that I say, so I just kind of need to be careful that…" (1.411 - 1.421).

(3) Isy described the potential risk of physical harm for C&YP and outlined examples of potential limitations of personal resilience at times, and how siblings' responses might manifest in the wider context of life, at home or at school:

"I just like want them to know it can sometimes be difficult sometimes, like they will get angry, they might, you might get like a little bit like hurt in the process and they might like punch you or something like that…" (3.771 - 3.775).

"I think like some people might get like in different times you do get quite effected like quite a biggie like I think sometimes like I've just got so fed up I've just like, and I've just let it out, all like tears and like and stuff like that, and it's just like a, and also like a build-up of things, it's quite big, so like if stuff has happened at home and then like you come, like you get to school and you just find like a test or like someone just like accidentally hits you, you're just like, yeah, can't hold it in any more really, it's like, yeah, little things so it's like they could like set you off, so yeah.(trails of)." (3.848 - 3.858).

Four of the C&YP (3) Isy, (5) Anna, (6) Olivia and (9) Ryan, outlined examples where they or their sibling were at risk of being hit or physically hurt in their interactions. Two of the C&YP (3) Isy and (6) Olivia gave specific examples of how they adapted to unpredictability, yet in the same scenarios, described being vulnerable and at risk of potential psychological and emotional impact having to cope with physical and or emotional harm. (3) Isy adopted a strategy of dividing her personality to respond to different people and circumstances:

> *"Like I feel like I have, like different people, like I'm like, I've got like different people because I've got like person like how to act, my personality of like how to act round Evie, then I've got like my personality how to act round like my friends and like how to act round my Mum and then how to act round like teachers and stuff like that, yeah." (3.472 - 3.478).*

(6) Olivia highlighted situations of high expressed emotion and the risk of hitting out in response to being hit herself, she suggested this posed a risk to both her and her sister (Frances):

> *"Well I try to walk away but sometimes my brain doesn't work and I just hit her back, yeah. So, but normally I will just be like "oh that's not nice" and I'd go tell my mum, so yeah….. Well it doesn't really work because then she'll follow me so (laughs), so then I'll just have to go in my room and just hold the door." (6.653 - 6.655).*

(6) Olivia illustrated how these highly charged moments might be misinterpreted by others, posing a risk to C&YP of being misunderstood, isolated or resentful where they perhaps viewed an injustice:

> *"No. She'll just, because my nan treats her a bit differently to me. Like the other day I was watching TV and Frances came down because my mum was on a conference call and my mum sent her down here, and then she put her iPad on full blast and this sort*

of like opera singing, like screaming so, and then I asked her perfectly politely "oh Frances, can you be quiet? I'm trying to watch my programme" and then Frances started like yelling and shouting, just like "no, this is England, I have right of speech", I was just like "yes I know that." Then my nan turned round and was like "Olivia, get upstairs." I was like "what?" Like because my nan doesn't know really, like she knows but yeah, she doesn't understand when it has on me, yeah" (6.700 - 6.710).

5.2.6 Family impact and coping strategies

All nine of the C&YP gave examples of the impact of having a family member with ID, for them directly, for their sibling with ID, their parents, and the wider family. They identified coping strategies and discussed strategies used by their parents to manage the broader family dynamics and day to day experiences for the whole family. The following sub-themes explored this further.

5.2.6.1 Impact on children and young people

While there was a sense of pride in being a sibling, as explored in the sub-theme 5.2.2.3 (Care and affection, reciprocity of sibling relationships), C&YP also identified less favourable practical, physical, psychological and emotional impacts of having a sibling with ID. They identified their need for personal space to help them cope with difficult situations, to remove themselves in times of high emotion or when at risk of harm from their siblings' violent or harmful expressed behaviours. They also highlighted their sense of responsibility and a mature awareness of the impact of having a child with ID for their parents and the wider family. (1) Shafeeq, described his sense of responsibility and reinforced the need for him to ensure he does not add any additional burden for the family:

"Well obviously my main priority with like my relationship with my family is to never do anything that would make them upset or ashamed. It's like keeping their interests, best interests basically and making sure I don't upset them or do anything bad." (1.158 - 1.162).

(2) Aayan identified the need to have time on his own, but acknowledged this was difficult given the demands from his brother:

"Um, like for instance I'm in the process of tidying my room, for instance my loom bands are all over the place and I do them in colour order, so it's a very big process so he's, (pauses) he kind of, I tell him to go away but I can't have time on my own basically. But sometimes he helps for instance with the loom bands but when I'm doing Lego for instance or playing with Lego that he's trampled all over, he can't really help with that." (2.626 - 2.632).

Four C&YP (3) Isy, (5) Anna, (6) Olivia and (9) Ryan described circumstances where they had been hit or hurt by their sibling, and challenges faced in managing this:

"Um, when like she'll hit me and then my mum will be like "no Frances, that's not nice, stop it, I'm going to take your phone away now" and then Frances will just like scream and shout and kick and fight for her phone back. And then my mum will eventually turn the Wi-Fi off so she can't use it and then or put her on kids lock which is like an app where you can take all the like the YouTube and Safari away. And then she'll just kick, scream, like try to take my mum's iPad away, like try, like break it and like turn everything back on and stuff, like trying to figure out how to use the Wi-Fi box and stuff, like trying to turn it all back on, yeah….Yeah, it's when she hits me multiple times and it hurts, (exhales)." (6.502 - 6.512).

Two C&YP described the psychological impact of having a sibling with ID. (7) Iain described feeling neglected although he also recognised his brother's essential need for his parents time and support:

> *"I think sometimes on occasions it makes you feel a bit neglected kind of, but not like (pauses), purposefully neglected not like, but like sort of no one's thinking of you……you've sort of been forgotten a bit." (7.452 - 7.454).*

(3) Isy highlighted an example of psychological impact, providing an analogy of dividing her personality in order to meet the expectations of people in different contexts, for her family, her friends, her teachers, as already seen, *(sub section 5.2.5.4)* Isy noted:

> *"Like I feel like I have, like different people, like I'm like, I've got like different people because I've got like person like how to act, my personality of like how to act round Evie, then I've got like my personality how to act round like my friends and like how to act round my Mum and then how to act round like teachers and stuff like that, yeah." (3.472 - 3.478).*

(4) Lucy recognised a broader impact of her brother's engagement and communication issues, recognising the impact for her parents and the potential isolation of her brother, separating their family experiences as twins.

> *"It's a bit saddening I suppose but I'm quite used to it really. It's just kind of what always happens, and I sometimes think it's a bit of a waste of time for my parents to try because he never really says anything, he never really talks the way other people would perhaps talk, he's not really able to just open up and just talk freely about something that's happened or he never really tries to." (4.485 - 4.491).*

"Well, there's not really that many things which we all will do. If we go for a walk then mum's usually not there because of her, she's not very good at walking and stuff but there's me and my dad and my brothers and that's something that we enjoy, and Thomas seems to like that and I think it does him good usually." (4.498 - 4.502).

5.2.6.2 Impact on parents

All the C&YP spoke of the importance of their parents in their lives, and in supporting the wider family. Seven C&YP highlighted the broader impact of having a child with ID for their parents. They described the impact on parental relationships, on careers and in day-to-day family interactions. C&YP demonstrated a level of maturity and care, presenting examples of trying to support their parents, aiming to ease the demand on them and their perceived burden:

"I think it's quite hard on them sometimes, like they both work and I think sometimes it's a bit stressful…"But they're quite good at that, I help them sometimes by just taking myself away if need be or sometimes I do like the little jobs just to save time you know, like erm the dishwasher." (7.465 - 7.473).

"… and at the moment there's more things to remember. At the time, we also had to remember that the heat makes the Epilepsy worse so at the time my parents had to be more careful about Thomas not wearing too much clothing and drinking more water and stuff which is quite hard for them to do because Thomas doesn't like wearing T-shirts much and he doesn't really, he doesn't usually like to wear what people tell him to wear and he just usually dresses quite inappropriately for the weather and so then those have been hard for my parents to deal with, harder than it is for most parents I think and there's more things to remember…" (4.435 - 4.443).

(2) Aayan described the impact on his mother's career being deferred for an extended period to ensure she was available to support his brother as his main carer:

> *"Yeah. Whereas now she can get on with her business because she, for seven years she had to stay like at home but now she can get on with her business. She's set up a skincare business so…" (4.435 - 4.443).*

(3) Isy referred to potential pressures for her parents, now divorced, and outlined a changed dynamic for the family, with the sisters now engaged in their parental relationships across two homes:

> *"Yeah, I don't think he, like I think it was OK but like that happened before like we found out about Evie… Because then they obviously still like, they still like lingers over me that like my, my Dad doesn't live in the same house as me anymore, but I still get to see him quite a lot, I think I get to see him a lot more than I did because he used to work quite late hours, so yeah, I think I kind of prefer it, him living in two houses, and it's cool because like I have two houses to like..." (3.421 - 3.430).*

(5) Anna acknowledged there were pressures on her parents. She recognised situations elicited different responses from each of her parents, and impacted wider family interactions and relationships:

> *"I noticed that it makes my dad really like mad and then he's then, that kind of like, you know when someone just gets like really angry with someone and then you ask them a simple question like "what time is it?" and then they like yell it back to you because they've just told someone off so they're still kind of mad at that and…?But that doesn't really happen because whenever he is like shouting I normally just leave the room and go into my room and just try and ignore it.." (5.266 - 5.276).*

"Well my mum just like does the count to 10 and calm him down. My dad does stuff like that and as he gets madder my dad gets a little bit madder, then he gets a little bit madder, it just all gets, and then it just all explodes. And then my dad just walks away and then he strops. My dad strops quite a lot. He doesn't just, he just strops." (5.656 - 5.660).

(6) Olivia highlighted the impact and potential for parental stress to be directed at C&YP themselves, as parents tried to cope:

"My mums really stressed and when she, she got both frozen shoulders, and the doctor said that was because of stress. And like she would take it out on other people sometimes, like me and stuff." (6.353 - 6.356).

(4) Lucy identified the impact of having a child with ID for her parents, contextualised positively within the broader spectrum of ID and support needs:

"... So, I think there are more responsibilities for my parents but it's not, I mean I can't really speak for them but I think compared to the parents of some children with learning difficulties and things it's, I don't think it's been as hard as it could have been,.." (4.466 - 4.469)

5.2.6.3 Shared responsibilities and pseudo-parenting role for siblings

Two C&YP demonstrated an overt willingness to share responsibility and support their parents. (1) Shafeeq, described the closeness of his relationship with his widowed mother. He outlined an almost 'pseudo parenting' role as he accompanied his mother to school meetings for his sister:

"Her new school (named removed) she started in September, she had a parent's evening and I went with my Mum to talk to her teachers and her specialists and stuff, to get a bit more insight on how she's doing at mm like how she's been so… Well the most recent one, yeah. I went and we, yeah, just me and my Mum, my sister didn't go, and we went, and we talked to each teacher like individually. We talked to her form tutor and like it was kind of like the first time I've seen Zahra at school really, because it's a big change for her going to this new school, so I'd never 1really experienced like the first part of her big change before. So, it was really like different for me because I erm, when we were talking to these teachers, we realised that she was struggling and stuff like that and like finding it hard and getting frustrated because it was a massive change and..." (1.343 - 1.360).

(1) Shafeeq described his relationship with his mother as a friendship, working together as a unit to support his sister with ID:

"Me and my Mum have quite a good like friendship relationship kind of so we get along together as friends and mother and son. And I know she works hard so I try to make sure I don't, well I try hard in my school and stuff like that because she's sending me to a good school so I need to try and like, you know, not let her down basically." (1.170 - 1.175).

When asked what might be helpful for other C&YP to consider, (7) Iain advocated the importance of helping and supporting parents in the broader context of their parental responsibilities:

"Help your parents, because I think it's hard for the child with special needs and it's hard for the sibling of the child with special needs, but I think it's very hard for the

parents because they've got to work and come home and deal with this child, or maybe come and pick them up at school, like take them out early from school." (7.862 - 7.867).

5.2.6.4 Wider considerations and the family, working together

C&YP shared examples of the whole family providing collective support around the needs of the C&YP with ID in their family. The family worked together as a team described by (1) Shafeeq:

"I mean I use that phrase as a family because we have to work as a team and work together. But I mean we all kind of see it as whoever's here, whoever's with Zahra, whoever's looking after Zahra has to keep her happy and has to ensure she's living a happy life. And just look after her and take care of her, not let her get in dangerous situations, not let her be in danger and just, hopefully just give her a very happy life." (1.855 - 1.862).

(1) Shafeeq spoke further of a whole family approach to finding and navigating information in the development of their knowledge and coping strategies as a family:

"…to help her. And she, we had a lot of talks as a family and we also ordered a lot of like guides and books and like leaflets and things like that to read and learn." (1.311 - 1.312).

Four C&YP reported whole family considerations, in terms of working together to pre-empt responses from their sibling with ID, to given situations. They described how the pace and their manner of approach was important. Families adapted, changed collective plans, and ensured they involved and supported the person with ID in family events. However, compromise was required to mitigate or avoid situations that might challenge everyone involved, thus wider

impact on the whole family's experience was indicated. An overall need for due consideration and compromise was evident. The focus for the family was often framed in the context of how the person with ID might react, the priority narrative being to support them and avoid situations where this might manifest a challenging response:

> *"Yeah. I'd definitely say the first thing that's absolutely key if you have an autistic brother or sister is to be patient and understanding. Like you have to be kind and patient and understanding with the autistic person. You have to kind of suit their needs and try and help them and encourage them in doing things, and not rush them, not force them, kind of let them go at their own pace and keep them happy, definitely. That's absolutely key. Keep them happy." (1.611 - 1.619).*

> *"He, mm, I don't really know. He likes watching TV, that's about it. He likes Emmerdale and Coronation Street and all that sort of stuff…Yeah. And he loves, and if there's one day, he records them all so we have every single one from like 2010 recorded and that uses up all the space. But if, like it's kind of like a little routine for him, if we don't get home by like 8:30 to watch them or if we don't watch them he'll like kick off." (5.396 - 5.403).*

> *"Well, I mean, I suppose the thing that affected us most was when he was having quite a lot of seizures, that was obviously very upsetting for my parents and quite upsetting for everyone and it did mean that we had to go somewhere else for our holiday" (4.424 - 4.427).*

"Um, we've got to think about him... Um (pauses) we've got to think about him a bit more because he's got needs and we don't want to him to have a meltdown or like not like where we're going or what activity we're doing." (9.367 - 9.370).

5.2.6.5 Importance of the extended family

Several of the C&YP identified the important role of their extended family. Three of the C&YP described grandparents sharing and supporting caring responsibilities:

"Yeah, I do. Especially when growing-up as well. She, because my Mum was at work my grandmother used to like look after me all day. So I'm quite close to my grandmother and like my auntie as well because I spent so much time with them at home. Like they, we all care for each other, one another, one and the same." (1.180 - 1.185).

"Because my Mum's usually working so I usually just stay with my Grandparents, but when we do have a chance we like just like have days out or something like that, so yeah, it's quite nice, yeah." (3.106 - 3.109).

"Yeah. Because my mum's like finding it really difficult at like this moment and so my nan's just here just to like help her a bit… "When Frances does kick-off instead of actually like being like all feisty and hitting us all, she'd go to my nan and like cry a bit," (6.685 - 6.692).

(3) Isy recognised her grandmother as a line of support, yet also identified a potential generational gap in knowledge, with her grandparents possibly misunderstanding her sister's needs related to intellectual disabilities:

"Yeah, yeah I have… my Grandparents are alright, I don't think they understand Evie as much as we do, but I'm not sure because they're the older generation of course, it's like quite a lot of new things and stuff like that so they don't like understand Evie but, erm yeah, I think they're alright though." (3.115 - 3.120).

(4) Lucy articulated the importance of extended family networks and relationships, namely her maternal grandmother and aunts, the family valued the connections and spending time with their extended family:

*"Well, my grandmother is quite important. She is the only grandparent I have left, my ****** grandmother and so are my aunts quite important, especially I think, I think I'm closer perhaps to my ****** aunts than my ******* ones. I'm closest particularly to one of my ****** aunts because I usually see her in the summer when we go to visit my grandmother." (4.135 - 4.139).*

5.2.6.6 Coping strategies

C&YP's resilience, self-awareness and ability to adopt innovative approaches to challenging situations was evident. They described strategies employed to manage interactions with their sibling with ID and to cope with family life. Three of the C&YP described removing themselves from potentially volatile circumstances, keeping out of the way as a strategy to deescalate situations of high expressed emotions, safeguarding themselves, their sibling with ID and to support their parents' coping strategies:

"Yeah. I just stay in my room. Sometimes I do just hide in the bathroom because that has a lock on it but I don't do that as often anymore." (5.770 - 5.771).

(3) Isy described needing to be able to get out of the way. giving her parents space to manage more difficult situations for her sister. (6) Oliva reinforced the need for personal space, to get away from more challenging situations at home:

> *"Well she's usually really happy when we go and see our Dad so she doesn't usually get like quite angry and stuff like that. But then like she gets, I don't know, I think she gets more grumpy when she's in like the normal house, and she like knows she can like act like that in front of my Mum, but, but yeah, they deal with it quite well which is quite surprising, like they usually, they like tell her to like calm down and like go like sit somewhere and do something. Like usually like I'm out of the way by then so I don't actually know what they do, because I like, I feel like I'm going to get in the way so I might just go and like sit somewhere, so yeah." (3.451 - 3.462).*

> *"Uh, like my friend, she has a little hut at the back of her house, like a summer hut, like a sofa, a sofa bed in there, I'd love just one of those where I could just go in there and just like let everything happen in here. That would be so helpful. Or like move my whole entire bedroom into there, just like that would be my own little space, like nobody's allowed in there unless I like grant them permission. Like yeah, but there's a bush and guinea pigs there so we can't really put that there." (6.921 - 6.928).*

(6) Olivia acknowledged her sister's efforts in containing her expressed emotions and reinforced the importance of home as a safe personal space not only for herself, but for her sister too:

> *"Yeah. Because she doesn't get it. Like she tries to be really good in school so when, at school so she's trying her best not to cry and scream, then when she comes home she just takes it out on everybody else, yeah." (6.365 - 6.368).*

(6) Olivia described using colloquial references, humour and deflection techniques as a means of deescalating potential arguments with her sister:

> *"No. She called me pregnant today. I was like "okay." And then I turned around and was like "oh yeah but being pregnant is a wonderful thing because you're giving life" and she was like, and she was, and she used to call me big butt and I'd be like "oh yeah but isn't Nicki Minaj and Kim Kardashian like all the trend right now?" and she was like "oh"." (6.564 - 6.569).*

(5) Anna described what C&YP might need to be aware of to minimise their risk of being hit or hurt, highlighting the need to be alert to and manage their environment, protecting themselves and keeping out of the way to enable their parents to manage more difficult situations:

> *"Important for them just, if they had one just to keep out the way because keeping out of the way is just the best thing to do. Because otherwise if you try and get involved you end up with a broken nose or something because when he gets, when he, what happens with him is he doesn't really stop. If he says something he'll then carry on and carry on and carry on, then he'll just get so mad and then he'll just kick off." (5.626 – 5.631).*

(7) Iain described needing to get away and engaged in self-directed activities as a means of coping with challenges at home, as a way of managing potential concerns or anxieties. He described this as a supportive approach to help the family, yet highlighted his potential isolation:

> *"I might watch TV or I might read a book or I might get along with one of the models, like we've usually got one out that we're working on so I can just pick that up." (7.409 - 7.413).*

5.2.7 Insight, vulnerability, loss of childhood, changed family relationships

This theme emerged from the C&YP describing how they navigated day to day interactions with their sibling with ID, their parents and other family members. This theme was also informed from the C&YP's responses when asked what might be helpful in the future for siblings who have a brother or sister with ID to be informed and aware of. There were connections to the earlier themes 5.2.5 (sense of agency; compromise; power, and loss) and 5.2.6 (family impact and coping strategies). C&YP gave examples of their exposure to violence and risk, they further highlighted potential vulnerabilities due to the sustained nature of some more challenging circumstances. C&YP experienced a sense of loss at times, in their family relationships, reduced time with their parents was particularly difficult. They exhibited mature insight, accompanied by a desire to support their parents, and demonstrated resilience. Yet they also described a sense of a differentiated childhood one that required adaptation and an ability to navigate challenges in their relationships with their brother of sister with ID, and in the family.

5.2.7.1 Sustained experiences, impact, vulnerability and the need for support

Several of the C&YP described situations of being exposed to physical hurt, being hit, kicked, or spat at, as explored in the sub theme 5.2.5.4 (Risk and vulnerability, physical, psychological, emotional). While insight and tolerance from C&YP was evident in these earlier themes, C&YP also expressed fear, frustration or anger, in circumstances where they were exposed to more challenging circumstances and risks of being hurt. (3) Isy, (6) Olivia and (9) Ryan, described their reactions to sustained experience of being exposed to physical hurt, where they might retaliate and hit out in response. This represented a risk to the C&YP themselves and their sibling with ID:

"Well I try to walk away but sometimes my brain doesn't work and I just hit her back, yeah. So, but normally I will just be like "oh that's not nice" and I'd go tell my mum, so yeah." (6.653 - 6.655).

"Okay, if he hits me or something I react back but my mum's told me that I've got to just breathe in, tell her and then it's dealt with." (6.653 - 6.655).

"I don't know, I feel like, because like sometimes like I accidentally do something she gets angry at me, so like I accidentally might hit her or something and she just like completely overreacts and like shouts at me, and so I feel like angry that I take all the blame for it even though I didn't do anything. So I try and just ignore it." (3.192 - 3.197).

When asked what was important for C&YP to know about being a sibling to someone with ID (6) Olivia described sustained challenging experience and emotional impact as important factors to be aware of:

"That it's very, very hard…Very hard. And, um (sighs)… Very just like hard like I said and stressful as I've already said, emotionally toiling, like yeah." (6.896 - 6.899).

5.2.7.2 Loss of childhood, expectation and changed roles as siblings

C&YP described protecting and supporting their parents, as discussed in sub-theme 5.2.6.2 (Impact on parents). These examples highlighted C&YP's insight into the demands placed on their parents, as well as their understanding of the needs of their siblings with ID. The participants demonstrated maturity and tolerance, yet also identified a sense of loss regarding their expected childhood experiences. C&YP outlined a change in their roles and relationships

with their parents and, as siblings. They described examples of missing out on parental time and support. C&YP highlighted risks and identified where their support needs might be missed, as they try to limit their demands on their parents, and in their efforts to support their sibling and the wider family:

> *"Because he needs a bit more support, so I have to sort of take a more backseat role kind of, I don't know if that's the right analogy at all?" (7.359 - 7.340).*

(1) Shafeeq, described the responsibility of being a sibling, as an integral part of his childhood. He explained his role as a big brother, illustrating how he has adapted his approach and actions to support his sister and the family, recognising his responsibilities from an early age:

> *"Yeah. My Mum taught me from a very young age as I'm growing-up that with an autistic person or with an autistic sibling you have to be very patient and very understanding, so as a family we try to be really understanding and patient with Zahra." (1.470 - 1.474).*

> *"I mean quite responsible and like, um, I know I can do it but I just feel like it's a big responsibility." (1.433 - 1.435).*

Seven of the C&YP participants, (1) Shafeeq, (2) Aayan, (3) Isy, (5) Anna, (6) Olivia, (7) Iain and (8) Helene, were a sibling dyad, with a brother of sister with ID, they had no comparator in terms of what their role as a sibling might otherwise have been. They discussed their known reality as a sibling, they recognised differences from the experiences of others. (3) Isy, described comparing her experience as a sibling with that of her friends to check out differences:

"No, because all my friends, they've got like siblings but they're like, they don't have a disability, Yes so I would usually ask them like 'is this the normal things that siblings do or is it just because of my sister' like, and yeah." (3.348 - 3.352).

"I always used to think before we knew that I just had a normal sister, like everybody did this, but now like I have like she does, I don't actually know what it's really like to have like a broth... a normal brother or sister." (3.541 - 3.545).

Shafeeq, described being unique, he recognised differences in his experience of having a sister with ID:

"I think it's kind of unique and a bit different because not many people can say "I've got an autistic brother or sister." So I mean it's quite different, like I've seen how my other friends act with their brothers and sisters but I mean I'm so used to having an autistic sister that it's kind of standard for me and like normal." (1.625 - 1.630).

5.2.7.3 Risk of isolation

Two of the C&YP (6) Olivia, and (3) Isy described the potential risk of isolation, from containing emotions, or removing themselves at times of high expressed emotions or violent outbursts:

"No. My mum normally says, "go to your bedroom and just hide under the covers." That's what I normally do, yeah. Because my mum knows that I'll probably get hurt because I'll be like "Frances calm down, calm down" and then Frances will come at me and like slap me or something so…" (6.395 - 6.399).

"…so I feel like angry that I take all the blame for it even though I didn't do anything. So I try and just ignore it… " I usually just like come and sit on the sofa or go up in my bedroom and just like leave her to like calm down." (3.196 - 3.201).

5.2.7.4 Survivor guilt

As noted, several of the C&YP described examples of deprioritising their needs to support their sibling and their parents. (1) Shafeeq and (2) Aayan outlined their efforts to keep their sibling happy. (3) Isy, (6) Olivia, and (4) Iain described needing to remove themselves from difficult and risk of harm situations. There was a potential vulnerability for the C&YP of a 'survivor guilt'. Siblings' acknowledged opportunities they might have in their lives that their siblings with ID potentially may not have. They described examples of striving to be better, more successful. The expressed a desire to be less of a burden, potentially compensating in some way for the demands placed on their parents in supporting their sibling with ID. (4) Lucy articulated this sense of vulnerability in striving to be "*a better person*", linked to sub-theme 5.2.4.3 (Being a twin). (4) Lucy had a direct life stage comparator in her relationship with her twin brother. She described praying about the problems Thomas may have, and being sorry for things she may have done or not done:

"Well, I try to use it to help me be a better person and I quite often pray about like if Thomas is struggling with something in particular. In the past, I've prayed about problems he's had and stuff and it kind of, I just sort of use it and because I read the Bible and the Catechism regularly and I just try to use things from it to help me to be a good person and to help me to believe in stuff and I suppose I try to use it to, like if I say sorry to God for things that I have done to Thomas or things that I've not done, if I've not been patient enough or something then that kind of helps me just to think about

my actions and what I should be doing and how I can change for the future and things." (4.566 - 4.575).

5.2.7.5 Exposure to judgement of external others

Other aspects of C&YP's vulnerabilities were expressed in their exposure to the perceived judgement of others. All the C&YP were acutely aware of and influenced by the reactions and opinions of others. (3) Isy described this in an example of being embarrassed by her sister's behaviour in public:

"Yeah, it's like, yeah because like sometimes like she just gets annoyed and it's a little bit embarrassing if she gets like annoyed in like public and stuff like that." (3.629 - 3.775).

(5) Anna described her awareness of the judgements made by her friend:

"Yes, I do. One of my friends is just judges people. She goes "urgh, why is" but she's really nice but she always goes "ew, like he's disgusting", all that sort of stuff." (5.430 - 5.432).

Two of the C&YP (4) Lucy and (6) Olivia, described situations where their sibling and the family were open to misunderstanding and potential judgement of others. C&YP expressed a desire to ensure they, their sibling and the family's actions and reactions are not misunderstood:

"...really knows the whole ins and outs of everything but I mean, when I've told people they've sometimes seemed quite sympathetic and they've not really said anything more but it seems to make some of them feel sorry for me at least in that moment and once a boy kind of he didn't really seem to understand what I said when I told him that he had special needs and he sort of seemed to think that I meant something to do with mental

illness or whatever…it's different,' and sometimes I kind of get annoyed when I hear people talking about, because people at my school, I sometimes wonder if I ought to tell people at my school more or if I should have done because obviously people at my school still kind of use the term autistic as an insult or whatever and they talk about things like that and I always find that quite hurtful and I feel if I told them my brother was like that they wouldn't do it anymore but I don't usually have the courage to say that sort of thing." (4.355 - 4.371).

"I can't remember but she didn't want to leave the hotel and like we, and then she walked all the way back to the hotel, like I can't even believe she remembered it, like we walked for a good 10 minutes and she walked all the way back to the hotel. And then because it was in the London and my uncle worked at the hotel, my mum called him and was like "oh well Frances's like storming off, she's really upset and like crying and stuff", so then she was fighting my uncle like trying to get into the hotel. And then like three guys came up because like all this kidnapping going on in London." (6.965 - 6.974).

5.2.8 The future

This theme emerged from discussion with all nine C&YP about their ambitions and dreams for the future. C&YP discussed potential career opportunities, or a place and way they would like to live. Three of the C&YP spoke about potentially becoming parents. The participants expressed a desire for a positive future for their sibling with ID, one that exploited their interests and talents. They described potential differences in their futures, recognising their sibling with ID' potential future needs for enhanced support. One of the C&YP (1) Shafeeq, contextualised

his future alongside his expected role as a carer for his sibling. Within this theme, the following four sub-themes emerged.

5.2.8.1 C&YP future career and life ambitions

All nine of the C&YP described their ideas and dreams for their future and framed this around growing a career from areas of interest or talents:

> *"Yeah, I would love to be a zookeeper, like it's been my dream like ever since I was little to be a zookeeper and yeah, I'm trying to work towards that, I was like just looking after animals, I don't know why, it's just like I love them, I just love animals like quite a lot." (3.689 - 3.393).*

> *"I'd like to do engineering at GCSE because we had this STEM day the other day which is Science, Technology, Engineering and Maths and we had this *** come in for one of the periods and he talked about bridges and physics and it was in engineering and it was really, really interesting." (7.221 - 7.226).*

Several C&YP described being uncertain of their future careers. (3) Isy described not being ready to grow up yet, anticipating a greater level of responsibility in the future:

> *"Like I feel like this year's gone pretty quickly so far and like I have to, I've almost finished like a year of my GCSE's already, which is quite scary because like I want to leave school because it's just getting boring, it's getting a little bit boring now, but I also don't want to leave school because I don't want to grow up and like I just want to stay like the same age, but like you can't really do that, it's like yeah.(trails off)" (3.720 - 3.727).*

(1) Shafeeq framed his future ambitions alongside his role in caring for and supporting his sister. He identified his responsibility for his sister alongside the need to be successful to provide that support:

> *"Well I mean for Zahra I think keeping her happy and I just kind of need to try hard and go to a good university, get a good job so I can provide for her and look after her. I know I'm going to have to care for her for all my life but I'm completely fine with that. I just know that I need to kind of work my way so I can provide for her and keep her happy. And personally I don't know what I want to do yet to be honest. I haven't really given much thought about it. I think in the summer we have a careers talk, so yeah." (1.777 - 1.786).*

(2) Aayan suggested his parents were not so focused on his future:

> *"They think, they're not really bothered. They first of all, yeah, they're not really bothered about my future so I think I want to get into a Formula 3 or 4 team and I'll hopefully go to Formula 1 or Indianapolis." (2.748 - 2.751).*

(4) Lucy described her parents' avoiding conversations about her future suggesting this might be related to different expectations for the twins and the potential upset or uncertainty that discussing this openly this might bring, for them and her brother:

> *"We've never really spoken, we don't talk about my future as a whole family usually. Thomas has never really been spoken to about the future I think because it would kind of, I think my parents maybe try not to or perhaps they don't but maybe they try not to talk about my future when Thomas is there because it would kind of, it might not upset him but it would kind of make him wonder about himself and stuff.." (4.699 - 4.704).*

5.2.8.2 C&YP thoughts on becoming parents in the future

Five C&YP (4) Lucy, (5) Anna, (6) Olivia, (7) Iain and (8) Helene, discussed becoming parents:

> *"I'd like children, I think that'd be fun (smiles). I'd like, I think a cool name to have for a child would be (****)." (7.794 - 7.795).*

Two C&YP (4) Lucy and (6) Olivia, described being concerned about giving birth, both suggested they would consider adopting a child instead.

> *"I would hope that I would have kids but obviously the birth bit, errr, mm hm." (winces face)…Yeah. Just adopt." (6.840 - 6.843).*

(4) Lucy who was not adopted herself, suggested she might consider adoption. In describing becoming a parent Lucy connected this to supporting someone that might otherwise have a difficult life. Yet she also questioned her own ability to cope with motherhood.

> *"Well I don't really have any kind of, I'm not really bothered about getting married or having children. I don't actually want to give birth because I think it would be too painful unless I maybe had an epidural or something. I've thought about adoption. I might do that because I quite like the idea of adopting somebody from a really horrible place and then I can give them a better life but I'm not really, I don't really think I'd be a very good mother myself. I just don't really, I'm just not very fussed about marriage or having a family or anything. I'm not against it but I just…Just because I've never really liked children and I'm not very patient so I get the feeling that if I had a baby which was screaming at me all the time I would just, I wouldn't really be able to cope." (4.638 - 4.646).*

(5) Anna considered the possibility of having one child. Like (4) Lucy she questioned the challenge of a future experience of parenthood and her coping strategies:

> *"I don't know. And I don't really think about it that often. I mean like I don't really want like a massive house when I'm older and I don't, I do want children when I'm older but I only want like one because babies can be very annoying in my opinion, when they like start to cry and you don't know what to do. It's like, mm, apart from that I don't really know." (5.568 - 5.572).*

One of the C&YP (8) Helene, connected her considerations of parenthood to the potential risk of having a child with Down's syndrome, and reflected a degree of uncertainty. This was also expressed with an awareness of the unique and uncertain experience of parenthood per se:

> *".. obviously, it's quite rare to have someone with Down's Syndrome so I don't really think it would be, so it'll be quite different because I don't really know how to like handle it, but eventually I would be but I wouldn't know at first, but that's all parents." (8.489 - 8.492).*

5.2.8.3 Future ambitions of sibling with intellectual disabilities, choice, equality and support needs

All nine C&YP had ambitions for their siblings' future:

> *"I don't really talk about that much, like Ellie says every day she wants to be something different and then at the end of the day she's like oh no, I'm going to be a hairdresser, so Ellie wants to be a hairdresser. I don't really know, like I don't know." (8.515 - 8.518).*

"She, I think she wants to open a pet shop or like a grooming pet shop or like a guinea pig sanctuary.. (6.852 - 6.853).

(9) Ryan emphasised his desire for equitable opportunities for his brother (Julian):

"Like its equality, I want him to have the same amount of chances I do." (9.489 - 9.490).

Reflective perhaps of the age of the C&YP and of their siblings with ID, the participants highlighted the potential to change their mind. This uncertainty about the future is not unusual for C&YP people at this life stage. The siblings were also positive about the future for the brothers and sisters with ID, and did not necessarily set boundaries for their siblings:

"I mean she can change her mind, yeah. So she was obsessed with purple and now she's obsessed with pink, or she said she wanted to be a teacher, now she's so keen on being a movie director. And I mean her mind is going to change but I think whatever she wants to do she can do really." (1.839 - 1.844).

Two C&YP did share a sense of uncertainty regarding their sibling's capabilities and consequently the opportunities they might have for the future. They recognised the potential impact of their ongoing needs for additional support:

"I don't really know what Thomas's future is going to be because it's not something we ever really discuss and it's not something we discuss with him because obviously there are limits to what he can do but I don't think my parents want him to know about that yet but I don't think he thinks a lot about the future either." (4.713 - 4.718).

"Well, I want to become a chef...I love my cooking and because Julian's got needs I want Julian to have as good as job rather than because he's got needs he has a slightly easier job." (9.440 - 9.447).

5.2.8.4 C&YP's future caring responsibilities for their sibling with intellectual disabilities

(1) Shafeeq described taking on future responsibility for the care of his sister, as discussed in sub-theme 5.2.6.3 (Shared responsibilities and pseudo-parenting role for siblings). This was particularly poignant for (1) Shafeeq, given his father was deceased and his mum their sole parent. He outlined significant future responsibilities, needing to be successful and therefore able to take on a life enduring caring role to support his sister:

"I kind of just realised really and like saw how much my Mum looks after her and how much she relies on us. I'm just thinking when I'm grown up my Mum might not be around so I have to be the person there that she can like 100% rely on. And I know I can do it, I just need to make sure I get a good job and stuff like that." (1.794 - 1.799).

(1) Shafeeq reflected this positively, seeing himself as a responsible person, with a transferability of his experience in caring for his sister to his wider life. The caring role was accepted as part of his shared future with his sister:

"...that's what I need to be like. If Zahra wasn't around then I probably wouldn't be as responsible I think because I wouldn't have to care this much about anybody, I wouldn't have to like look after and attend to people as much. I think having to look after Zahra and care for her and care about her needs has made me a more responsible person because I know I have that responsibility." (1.805 - 1.812).

5.2.9 Culture and having a faith

This theme emerged from discussions about faith, culture and beliefs in the families. Several C&YP described faith and religious belief as not particularly important for them or their family. Two C&YP (6) Olivia, (7) Iain, described having a defined religion but as non-practicing. Their faith was not presented as a strong influence in their family narrative:

> *"I think I'm, I think we're, Christopher's an atheist, but I think the rest of us are Roman Catholic but we're not very strong, like we don't go to church much, we used to but we don't anymore." (7.596 - 7.599).*

Two of the C&YP (1) Shafeeq, and (4) Lucy, spoke specifically about having a faith and described the impact of their faith on their lives, as trying to live a "good" life:

> *"Well we're all Muslims so we follow Islam and there's lots of rules in Islam and stuff like that. But personally I think Islam's quite a peaceful religion and the main thing I stress is about, in Islam is about being a good person being a good human. So I try and like just base my life on being a good person and not trying to wrong people." (1.746 - 1.751).*

Shafeeq and his family are Muslim, and he described their culture as being Asian in origin. Both culture and religious beliefs presented guiding principles impacting life and influencing their life philosophy of a respectful and caring approach:

> *"... we're mainly I think an Asian family. So I think in Pakistan and Asia elderly people are so highly respected, like you'd never do anything to wrong an elderly person. So I think as a family we care for each other quite a lot, and especially with Zahra." (1.738 - 1.743).*

"Well I think our culture especially is all about respect, especially respect for elders. And our religion as well, it's mainly about being a good person, being a good human to other people. So I think we've just kind of integrated that into Zahra and like focused our attention on Zahra a bit to like, you know, care for her a bit more. And like, you know, make sure she's not in danger, make sure she's happy, just we as a family like I say we've all kind of come together to, you know, focus a bit on her, to make sure she grows up and, you know, improves a little bit." (1.703 - 1.713).

(4) Lucy described her faith as presenting principles to live by, associated with equity and fairness:

".I haven't really met any other Christian family with somebody who has learning difficulties or anything but I know that Catholics and Christians certainly are supposed to treat everybody equally, we view everybody equally and the Catechism is very clear on this point and how everybody has equal human dignity and stuff." (4.582 - 4.587)

"...but I know it kind of helps me to remember that everybody is equal and everything and that's what I believe as a Catholic and what other Catholics are supposed to believe." (4.598 - 4.600).

5.3 Diaries as a data collection tool

The inclusion of diaries as an additional data collection tool for this study was explored in chapter four (section 4.6). The idea was to enable the C&YP to have an opportunity to record their thoughts, feelings and experiences in real time as events occurred, without my direct presence and intervention ,as the researcher and interviewer. Willig (2013) identified diaries as a valuable tool for data collection, though noted this tool is not widely used in qualitative

research. ‘Phenomenology centres on first-person accounts of phenomena. First-person accounts are readily accessible through diaries although these are analysed from a second person’s (researcher) point of view’ (Cudjoe, 2022:3). For this study diaries were not considered the primary source of data collection, but it was hoped they would provide additional information as an alternate means for the C&YP to engage with the study and share their experiences of ID.

The use of diaries in qualitative research requires a high level of self-motivation from participants to maintain their diary records, which can be a limiting factor and may contribute to high dropout rates. The age of C&YP as research participants is also cited as a potential limiting factor impacting their commitment and motivation to complete diaries (Cudjoe, 2022). While prompts were provided via monthly email contact directed to the C&YP via their parents, completion of the diaries was quite low, reinforcing the challenges that others have reported in using this method of data collection (Cudjoe, 2022; Willig, 2013). Finlay (2011) recognised the valuable insights diaries can offer as a data collection tool; however, this is not explicitly in relation to the use of diaries with C&YP as participants. Given the age of the participants in the study, this was likely a factor influencing their motivation to complete the dairies. It may have been perceived by the C&YP as a task or a chore, particularly over what might have seemed to them a long period of time. The participants were invited to complete the diary or blog entry for a six month period, minimally making one or two entries a month.

Four participants completed the diaries, each provided between six to twelve entries, (see appendix 16). Although the diary data was limited, and not interpreted following the IPA process, their inclusion reflects the value and importance of participatory research with C&YP as discussed in chapter four, (section 4.4). Accordingly, each diary and it’s entries were

reviewed individually to identify potential correspondence or connections with the findings from the interviews. The following section outlines suggested connections linking the diary entries of the four C&YP who completed them, with the resulting findings and themes that emerged from the IPA of the interviews.

5.3.1 Diary entries, connection to IPA themes and findings

The C&YP recognised the importance of their family who supporting their access to knowledge. Information was often gained from their mothers, who provided guidance and support. The C&YP who completed the diaries often opted to provide vignettes of their day, sharing insights from a birthday celebration, a sports day or other family event. The collaborative family approach to the development of their knowledge was evident from their entries (8) Helene illustrated an example of this, noting observations of her sister's interaction with her own friends. She reflected on a first 'sleepover' opportunity for her sister, and in her diary noted that:

> *"me and mum are predicting that she may need to come home",* (see appendix 16).

This was expressed as a shared concern with her mum, they didn't think the sleepover would go well, however, she diarised this as a positive celebration and surprise when it did:

> *"so she did it. She stayed overnight and didn't even get up. "We underestimate her but this has taught us not to",* (see appendix 16).

She reflected a sense of protecting her sister, suggesting the potential to underestimate her capabilities. This entry provided an example of the experiential evolution of siblings' knowledge over time evident from the emerging themes and results of this study, in the context of the family's shared learning experience. It also pointed to the importance of experiential

learning for her sister Ellie, and the value of offering her opportunities to test her capabilities, and build a degree of independence outside the security of the family.

Recognising siblings' experience from the results suggested positive and less positive experiences of having a brother or sister with ID. In their diaries (1) Shafeeq, (8) Helene and (3) Isy provided entries that were both positive reflections of a family event or an encounter with their sibling, alongside examples of less favourable circumstances. (3) Isy described a family outing that did not go well she described her sister moaning and disrupting the day:

> *"we spent the day with our dad. We went over to **** **** it was a lovely sunny day but after we walk up the ***** Evie started to mone a lot…. When we went home she started moning because we had 1 hour on the x -box but she started getting angry so I turned it off any way so she stomped off to watch youtube...she moned about her pizza and bit her arm",* (see appendix 16).

The example highlighted (3) Isy adapting to accommodate her sibling with ID' needs having to turn off the x-box. In contrast, (3) Isy provided a further example of feeling sad and being looked after and comforted by Evie:

> "*..Evie has like a super power.. she can pick up a persons feelings like today I was feeling sad and she made me feel better by showing me her new toy",* (see appendix 16).

These entries reinforce the diversity of siblings' experience being both positive, and less so. Adjustment, capability and resilience for C&YP and their families was identified, related to the adjustments needed in supporting someone with ID, but equally reflective of the normative experience of being a sibling and in everyday life.

In the findings, the C&YP identified circumstances where they took a back seat, as in (7) Iain's example:

> *"....I have to take a more back seat role kind of..." (7.360).*

The C&YP experienced times where their needs were less of a priority, with the focus being on the needs of their siblings with intellectual disabilities. The potential for misunderstanding siblings' experience emerged, where they are not given the opportunity to voice their views and opinions, and when their capacity, capabilities, and agency are not recognised. The results highlighted the potential vulnerabilities experienced by siblings with a brother or sister with ID. Isy provided a diary entry that illustrated this, describing a school day articulating a particular situation where her lunch tray was knocked over. She described this as a catalyst:

> *"... then I had lunch every went to s*** all the stress and everyelse going on in my head just got let out someone nocked my food on the floor and everything just came out and only two people understood and helped me",* (see appendix 16).

This resonated with the vulnerability of C&YP as siblings identified in the IPA of the interviews, where they described actions used to deescalate potentially difficult outbursts.

The findings highlighted a strong sense of value of being a sibling. There was a mature recognition of the differences in some of their experiences from their peers, yet siblings celebrated being a sibling and were proud of their brother or sister with ID, their uniqueness and achievements. (8) Helene made diary entries about her sister's sports day and being proud not only of her achievements but also proud of seeing how others responded supportively:

> *"Today was Ellie's sports day and because.....she came 4th out of fith both times and it is really sweet because all the kids and adults on the sideline all cheer for her and it is*

really nice as it shows the kindness and respect that people have for her", (see appendix 16).

(1) Shafeeq, made entries about his connection with his sister. He had changed his hairstyle and shared his sister's interest and curiosity, highlighting their strong connection and interrelationship as a sibling dyad:

"I died my hair blonde for a bet and Zahra had an amazed face on when I got home she wanted to touch it all the time which was funny", (see appendix 16).

These findings highlighted an openness from the C&YP; in participating in the study, they had a strong desire to share their experience as siblings of a brother or sister with ID, for the benefit of other C&YP.

For (4) Lucy, her entries were brief (five in total), she described noticing changes in her brother's interaction with others:

"I notice when Thomas is angry, he becomes more annoyed when people touch him he never used to be like this", (see appendix 16).

Lucy's entries appeared to be more descriptive observations of Thomas, rather than talking about their connections. The findings suggested emerging differences in the twins' life experiences and highlighted potential overshadowing of Lucy's experiences by the day to day needs of her brother. A sense of loss of their sibling relationship emerged, with divergence being evident as they got older, this resonated with findings in the descriptive diary entries.

The findings from the analysis identified that C&YP value friendships outside their family. They value friendships, and yet they are selective when choosing their relationships, seeking people in their lives who connect with their values. Indeed, from the results, the C&YP described this as a potential escape valve, particularly for those who experienced challenges or were at risk of being hit or hurt related to the expressed behaviour of their sibling with ID. As with her interview, (3) Isy's diary entries reinforced the need for independent space and time outside the family:

> *"I went for a school trip to ****** and it was the most amazing trip I've ever been on when I came back my mum told me my sister spent most of her time…in my room which was lovely but I wish I was there longer because it was beautiful",* (see appendix 16).

This demonstrated their connection as siblings, as she was missed by her sister. Yet this also highlighted that siblings' value time spent away from one another. This further reinforced the findings of the importance of independence and friendships for siblings outside their role as a brother or sister.

Culture and having a faith were recognised as an underrepresented lens through which sibling experience was explored from the literature (Kao et al., 2011). Culture, and values as well as religion for some of the C&YP, were important themes that emerged from the findings for several of the C&YP, theme 5.2.9 (culture and having a faith). While the diary entries did not refer to cultural context specifically, several of the siblings' chose to write about events and circumstances related to holidays, trips out and shared experience with their family. This reinforced the connection of day-to-day life as siblings, experienced in the context of their families, shared norms, cultural context and beliefs.

While there were clear limitations, the diaries provided an additional lens into siblings' experience of ID and were included to support the broader themes that emerged from the IPA of the larger data collection engaged through conducting semi-structured interviews.

CHAPTER SIX: DISCUSSION

6.0 Overview

This chapter discusses the main findings of the study. Areas of insight are identified, informed by conducting an interpretative phenomenological analysis (IPA) of the unique perspectives of the participants who were children and young people (C&YP) with a brother or sister with intellectual disabilities (ID). The discussion references reviewed literature, highlighting where findings appear to corroborate or differ from previous work. Theories underpinning the study, namely family systems theory and Bronfenbrenner's bioecological model of human development, are referred to throughout (Bronfenbrenner & Morris, 2006; Hayes et al., 2017, 2022).

A new term, "assumptive overshadowing", is introduced, emerging from the siblings' interpreted experiences. This interpretation led to the development of an enhanced three-dimensional model designed to guide professionals in specifically considering siblings' perspectives and experiences of ID when assessing both their needs and those of their families. A new 'droplet model' also emerged from the findings and is presented as an explanative and explorative frame to guide holistic, pro-active engagement with, and representation of, siblings' experiences informed by an enhanced understanding of their unique perspectives. The discussion will illuminate how I came to identify this guidance model, synthesising the C&YP's experiences, the themes from the literature, and my interpretation of both. Consideration of testing the findings is presented. Methodological issues of conducting the research are discussed. Potential gaps and indicators for future research are highlighted. Finally, a concluding summary of the discussion chapter is offered.

6.1 Discussion of findings

The section presents a dialogue between the emergent themes identified in chapter five and the literature reviewed in chapter three. It highlights connections, areas of affirmation and notable differences, in order to address the central research question: What are siblings' experiences of having a brother or sister with intellectual disabilities? This section is presented under seven pertinent headings to frame the discussion.

6.1.1 Being in and knowing the world of intellectual disabilities as a sibling

Findings from this study indicate that access to knowledge was important to the C&YP. Supporting their experiences, by enabling understanding, fostering resilience and promoting greater tolerance is essential in helping them manage the day-to-day reality of having a brother or sister with ID. From their accounts, it emerged that when, how, and by whom information about ID was communicated was important. This connected with previous studies that identified the potential for more positive sibling experiences where C&YP have early access to knowledge (Hames, 2008), particularly where there are complex diagnoses and co-morbidities alongside ID (Correia & Seabra-Santos, 2022; Luijkx et al., 2016). All the siblings looked to their parents and valued information being made available and shared with them in an accessible way. The literature supports this finding, suggesting that most C&YP gain initial knowledge about the term intellectual disabilities appropriately from their parents (Aksoy & Bercin Yildirim, 2008; Mandleco, et al., 2003; Graff et al., 2012; Petalas et al., 2009a; Ross & Cuskelly, 2006; Seligman & Darling, 2007).

The CY&P positioned their parents as gatekeepers of information and providers of primary support for their children, consistent with other findings (Christensen & James, 2008). Indeed, their parents were the primary contact engaging the participants in the research and expressing

a desire to support their C&YP towards enhanced understanding by participating in this research.

While most of the C&YP participating in the study appeared to be able to discuss ID openly with their parents, this may not always be the case. However, this open approach affirmed findings from previous studies, that parents' knowledge, response and coping has a direct correlation with siblings' understanding, this enhances their day to day experiences and relationships (Hayden et al., 2023; Mascha & Boucher, 2006). In developing their knowledge and understanding of ID, the majority of the C&YP did not recall a specific time that they were told that their sibling had intellectual disabilities. Hames (2008) longitudinal study of siblings' experience of ID, identified differences in understanding at key stages of C&YP's development, and this was supported from the findings in the current study. Knowledge acquisition was described by the C&YP as evolutionary, access to knowledge was important, but equally C&YP's developmental age and their ability to engage with this information at different stages of their lives was evident.

Early identification and diagnosis of intellectual disabilities positively impacted siblings' experiences. This was highlighted by one participant whose sibling had a diagnosis of Down's Syndrome (DS). DS offered a body of knowledge and language to draw from, to explain and understand their sister's needs. Having a diagnosis, evident soon after birth, did not mean she necessarily understood all about DS, but collectively, her family understood from the outset that her sister with Down's Syndrome had additional needs. The literature explored differing diagnoses and their impact on sibling outcomes, suggesting, for example, that siblings of C&YP with DS may experience more positive outcomes than those of individuals with Prader-Willi Syndrome, as the latter condition can have a greater potential impact on day to day life

and the home environment (Kaminsky & Dewey, 2002; Mazaheri et al., 2013; Pollard et al., 2013). While this was supported from the findings in this study, specific diagnoses appeared to be less important than knowledge and information sharing, i.e., early, and accessible information, accompanied by parental support and openness. This enabled a shared understanding of ID, with parents able to contextualise this for their specific family's needs. While only one participant had a sibling with DS, thee positive outlook of their experiences of ID, and positivity towards the quality of their relationship with their sibling was evident, consistent with other findings (Pollard et al., 2013).

Having a common terminology and a formal diagnosis presented the opportunity to engage with established familial support networks for all the family. This enabled immediate access and connection to wider systemic resources, such as through the Down's Syndrome Association. This was reported as having a positive family impact. The literature points to the value of support groups for siblings and families, given the potential isolation for families as they grapple with diagnoses, health issues and adapt to change that ID brings to their lives (Correia & Seabra-Santos, 2022; Giallo & Gavidia-Payne, 2006; Kaminsky & Dewey, 2002; Petalas et al., 2009a). Findings in the literature point to the value of connecting with a cohort of people who share a relatable context, a theme that was consistent with the experiences of the C&YP in this study.

What also emerged, was an emphasis on the timing of when support is offered; the earlier it is offered, the greater the positive impact on siblings and the whole family's insight. Collective acceptance and shared understanding positively impacts siblings' experiences, enhancing resilience and supporting collective coping strategies. The findings highlighted both individual and whole family experiences of ID, demonstrating that the sharing of knowledge and the

pursuit of support yields benefits for individuals as well as for the family unit collectively. Sibling support groups were identified as being particularly beneficial by two of the C&YP. They highlighted this as an opportunity to make friends with others who have siblings with ID, who share similar experiences to their own. This resonated with Bronfenbrenner's idea of proximal processes and the progressive evolution of experience over time. He termed this the reciprocal interaction; in this case of the C&YP engaging with those around them who have a shared understanding, drawing on support from within the family but also benefiting from engagement with wider networks (Hayes et al., 2022).

The findings suggest that early diagnosis of ID provides the opportunity for helpful access to support for all the family, connecting with similar findings in the literature (Benderix & Sivberg, 2007). What resonated from the siblings' accounts was not only the value of sibling support networks, but also the importance of engaging in shared networks with their family. When interpreted from a systems perspective the opportunity to engage with support as a family facilitated more positive outcomes for the whole family (Benderix & Sivberg, 2007; Correia & Seabra-Santos, 2022). This also connects with Bronfenbrenner's bioecological theory of human development (Hayes, O'Toole & Halpenny, 2022). In the example of the family with a child with Down's Syndrome, Bronfenbrenner's theory helps to explain how the immediate family environment, (the microsystem), interacts with wider support networks such as the Down's Syndrome Association community, (the exosystem), all within the influence of broader cultural and societal environment 'macrosystem space', shaping the development and well-being of the individuals and the family members collectively. The diagnosis of DS enables the family to draw on a shared narrative, which provides further informed insight, strengthens their resilience, contributing to understanding and support not only within the family but similarly for others outside their family. This resonates with one aspect of 'disability by

association' identified in the literature (Burke, 2010), acknowledging the positive aspects of identity as a community of families with a shared experience of ID, with such connections being viewed as enabling, supportive and empowering.

As noted in chapter three, research of siblings' experiences is more often reported by parents, usually by mothers given their continued primary caring role (Hayes et al., 2022). The findings from this study align with the literature that suggests parents potentially perceive a greater level of impact and challenge for their C&YP in having a sibling with ID, than that reflected by C&YP's direct and comparative reports (Kao et al., 2011; Lobato et al., 2011). It might reasonably be interpreted that parents' reluctance to share knowledge and information, could be related to their own transition, as they themselves come to terms with having a child with ID and explore and develop their own coping strategies.

Applying Bronfenbrenner's bioecological theory, parents serve as the primary source of knowledge and support within the 'microsystem' (family) of the siblings' experience (Hayes et al., 2017). There was a sense that they may be protective of their children, perhaps concerned regarding siblings ability to absorb and understand information. They therefore endeavour to manage the impact on their wellbeing and to support the emerging relationship between siblings, while being less forthcoming with information, as they perceive that greater openness may have a less positive impact (Turnbull et al., 2006, as cited in Seligman & Darling, 2007). Where parents limit conversations about, or explanation of intellectual disabilities and associated needs, potentially to protect their C&YP, they may inadvertently stifle the open discussions that were so valued by the participants in this study. Such an approach carries the risk of underestimating siblings' capacity to process and engage with the information provided,

limiting shared opportunities to inform the wider family's narrative and enhance their collective understanding.

The findings from the study therefore suggest there can be counterintuitive unintentional consequences of withholding information. One of the C&YP described the 'shock' of learning their brother had special needs and the difficulty of comprehending the implications for themselves and their sibling with intellectual disabilities. This resonated with the literature that identified potential vulnerabilities for siblings as they adapt to having a sibling with ID and the associated impacts, e.g., being exposed to and managing idiosyncratic behaviours (Petalas et al., 2009a). This highlights the importance of adopting an individualised focus when assessing and interpreting support needs. Being mindful of the experiences of ID for other family members, considering how this will impact e.g., parents own coping strategies, and acknowledging interactions with wider systems and the influence of their societal and cultural context, i.e., what is accepted as the norm. Parents may adopt different protective strategies some being open about their experiences, while others protect their C&YP by avoiding talking about ID or difficulties directly. Both approaches can be understood as expressions of parental protection and both are valuable (Hayes et al., 2022; Greene & Hogan, 2005). The findings from this study indicate the importance of sense checking siblings' knowledge, to promote greater awareness of their understanding of ID and their own needs.

Considering this in terms of models of childhood, James and James (2004) discussed the role of parents in providing stability and control, as well as nurturing. As discussed in chapter three, UK social policy relating to support of families with ID, continues to focus on support for parents. While the language and rhetoric of policy promotes greater rights for and recognition

of the contribution and independent views of C&YP, there is still a journey to travel in this regard.

From the findings in this study, parents' ability and willingness to impart knowledge, to explain things in the context of their family experience, as well as their observable reactions to having a child with ID, directly connected to the C&YP's narratives and responses. While parents were not participants themselves, their language, outlook, and approach, as suggested in our initial introductory meetings, was echoed in the language, terminology and explanations offered by the siblings in their interviews.

The C&YP often referred to their parents explanations or observations, reinforcing the interrelated nature of experience from a family systems perspective, consistent with findings from the literature (Aksoy & Bercin Yildirim, 2008; Mandleco et al., 2003; Cooke et al., 2023; Correia & Seabra-Santos, 2022; Freitag et al., 2022; Seligman & Darling, 2007). Participants spoke of learning about ID together, within the family, as a shared endeavour. The approach adopted by their parents to sharing knowledge, acting as role models, directly impacted siblings' experiences as they endeavoured to integrate their own sense making of their experiences of ID within the family. In a similar way, the C&YP demonstrated their own knowledge and interpretations, suggesting parents can learn from, be informed by, and should empower C&YP in their exploration and expression of their unique experiences as siblings. The participants in this study highlighted the importance of enabling the agency of all members of the family. This approaches encourages greater family harmony and fosters resilience for all family members, reinforcing a family systems' perspective of experiences of ID, emphasising the family's interrelationships and interactions therein (Dallos & Draper, 2010; Freitag et al., 2022; Priest, 2023; Seligman & Darling, 2007).

Valuing C&YP as social agents, respecting their rights, enabling access to information to inform their understanding, was important to the C&YP in this study. They validated their capabilities in this regard, demonstrating a rich depth of knowledge, and a willingness to share this with others. By participating in the research, they were actively contributing to enhanced insights, thus informing future practice. All the C&YP reinforced the importance of this study, recognising they had unique insights to bring, and demonstrated maturity, with a heightened sense of social responsibility. The C&YP wanted to impart their knowledge and experience to help other siblings in the future, this resonates with other studies and reinforces the value of research drawing directly from siblings accounts (Correia & Seabra-Santos, 2022; Mandleco & Webb, 2015; Moyson & Roeyers, 2012).

Siblings demonstrated a sense of pride and confidence in their unique knowledge, tested within the security of their family 'microsystem' (Hayes et al., 2022). Opportunities for C&YP to share their knowledge and demonstrate their understanding, in a supportive environment, emerged as a strong finding from this study. Being free to question and learn with the support of their parents, enabled this confidence to grow. One sibling shared knowledge of Makaton a communication system that uses signs, symbols and speech (Walker & Armfield, 1981), which enabled them to positively frame their experience as a sibling, dispel misunderstandings, and sharing knowledge with others. This was a powerful example, given that some of the literature suggests siblings may experience difficulties forming friendships (Benderix & Sivberg, 2007). Opportunity to positively frame their experience, especially within their peer group, as in the Makaton example, was reflected by the participants as empowering. Building this foundation early in their lives provided the C&YP with practical and emotional tools to manage their day-to-day lives as siblings.

Given that the sibling relationship is potentially the longest relationship in one's life, such early understanding can serve to dispel myths, build essential awareness and resilience, and support siblings in navigating their likely shared futures (Pollard et al., 2013; Seligman & Darling, 2007). This resonates with the force characteristics described by Bronfenbrenner and Morris (Hayes et al., 2017), recognising the agency of C&YP and their active ability to contribute to, influence and adapt to their own context and environments (Greene & Hogan, 2005). Siblings' use of their acquired knowledge, sense checked within their family system, demonstrates the empowering potential of informed knowledge of ID, to support siblings' experience.

The findings highlighted the individuality and complexity of siblings' experience of being in, and knowing ID, in their context. Different people in the family responded uniquely to their personal circumstance. The findings emphasise the importance of considering each person individually, and within their wider context, as multiple variables impact experiences.

Two siblings identified circumstances of considerable vulnerability, sharing examples of being subjected to risk of physical hurt, they were at pains to emphasise that there was also love and affection in their sibling relationships. The literature identified where there was more negative day to day experience or exposure to risk of violence and harm such as biting, hitting, or spitting. Through these expressed behaviours of the person with ID, this was more likely to lead to more negative outcomes for siblings (Mascha & Boucher, 2006; Pollard et al., 2013; Seligman & Darling, 2007). While there were evident indicators for greater awareness of the vulnerably of siblings, and a need to protect them and their brothers and sisters with intellectual disabilities, the findings point to maintaining a balanced perspective. This requires understanding of siblings' holistic experience, informed by C&YP and their interpretation of

their sibling relationships, even in contexts where circumstances are reported or appear more difficult.

The findings from this study could encourage parents to be open, to recognise and support their children's need for early access to information, even where this seems difficult. C&YP value their parents' perspectives above all and trust them as their primary source of knowledge and guidance. Siblings themselves also have unique experiences of their own to offer and subsequently bring different insights to inform the wider understanding of their own experiences, but also for their family.

6.1.2 Being the same, and yet different

Several of the C&YP stated they did not see their sibling as 'different'; they accepted them and their ID as an integral part of them (Freitag et al., 2022). This acceptance connected to the hermeneutic position of 'being', a sibling, in a family with a brother or sister with ID, and to Heidegger's existential position, introduced in chapter four (section 4.2.5) that having a sibling with ID is their norm. They acknowledge their sibling's unique place in the world, valuing them as individuals first and foremost. Acceptance was identified in the literature, as a quality-of-life measure impacting siblings experiences, family harmony and positive development (Moyson & Roeyers, 2012). This was more prominent in recent studies, as narratives of ability rather than disability are emerging as a more dominant discourse, alongside greater attention being given to siblings' voices, equity issues, and societal acceptance of ID (Correia & Seabra-Santos, 2022; Moyson & Roeyers, 2012). This concept of acceptance being a positive contributor to siblings' experience was consistent with the expressed experience of the C&YP and supported in the findings from this study.

Several of the C&YP also expressed their sense of difference for them, their sibling and the family. This contrasting perspective was consistent with the divergence of findings represented in the literature (Petalas et al., 2012b; Pollard et al., 2013). Conversations about ID and the 'differences' for their family, often seemed to have occurred around life transitions or milestones. Examples included, questioning the different experiences for them, their siblings and their peers as they changes schools, the inclusion of a new or loss of a family member, or other changes of circumstances.

The findings suggest there is a continual and reciprocal action and reaction, siblings' experiences are not linear. Adaptive understanding is required for and with the C&YP and their family over time. Giving due consideration for example to the unique and particular context of their family, personal attributes, cultural beliefs, and in the historical or temporal context, the 'chronosystem' as described by Bronfenbrenner and Morris, for the family at that time (Hayes et al., 2022). Individuals within, and each family respond differently. Difference co-exists within the family; hence the findings indicate the importance of considering both the individual and the collective experiences of ID for all family members.

C&YP in this study, recognised both similarities and differences in their experiences as siblings, to that of their peers. Several of the C&YP acknowledged that sometimes their experience as siblings was just about being a sibling per se. They considered that siblings bicker and argue and saw similarities in their own relationships, yet they also identified specific differences. This was particularly evident in circumstances where conflict arises in their relationship with their sibling with ID, or where they were at risk of being hit, hurt or harmed. Difficulties were also experienced in circumstances involving engagement with others outside the family, and /or where there was a need to provide explanations for unusual observable

behaviours that created embarrassment or misunderstanding (Mascha & Boucher, 2006). The C&YP struggled with these circumstances, expressing worries and concerns, consistent with others' findings from the literature (Benderix & Sivberg, 2007).

Where the C&YP described incidences of challenge for them in their relationship with their sibling with ID, or for those caring for them, they described their experiences as being conflicted. On the one hand, they understood and wanted to support their siblings' needs, and the wider family experience, especially for their parents. Yet as C&YP themselves, they also experienced a sense of unfairness, a need to be heard, supported, and understood by others. They felt there was a times when less focus was given to their needs by their parents, consistent with findings of others (Moyson & Roeyers, 2012).

There was a potential internal conflict for the C&YP, caring for their sibling and for their family, yet also a recognition of differences in their experiences as brothers and sisters. They combined a sense of pride, and some very practical benefits of having a sibling with ID. One such example given was being able to park close to places using disabled parking. Yet alongside this were frustrations at times, as above, especially where there was risk and direct impact, i.e., being hurt, or having less time with their parents or having to change plans and arrangements around the needs of their sibling. They wanted to understand but found it difficult to always do so. There was perhaps a connection with their age as C&YP in early adolescence going through their own personal changes too, seeking to find their own identity, within their family system. This was consistent with findings by Hames (2008), who described different key stages for C&YP and their evolutionary understanding of ID and their relationships with their sibling with ID.

The findings from this study, highlighted this potential conflicted sense of 'being' a sibling in existential terms, on the one hand loving their sibling, on the other being potentially vulnerable themselves (Freitag et al., 2022). C&YP described containing or checking their emotional responses, feeling resentful for what they perceived as inequitable treatment by parents and others. They experienced of a degree of difference for them and their sibling with ID, e.g., in terms of the consequential outcomes following difficult situations noted above. There was however a sense of genuine investment in their relationship with their siblings. Despite challenges, they still sought to share positive reflections and showed a maturity in their understanding and in how they managed situations of conflict. In this they were clearly not only invested in their relationships with their siblings but equally invested in their wider family relationships.

The findings highlighted the potential sense of loss of the normal sibling relationship. In protecting themselves, their sibling with ID, and consequentially their family, the participants did not always engage in the normative banter of sibling rivalry and relationships. With siblings being identified as important early role models, and their interactions offering opportunities to test out social learning, this was a difference for the CY&P with a sibling with ID. There is potential for them to miss out on these experiences in their early sibling relationships (McHale et al., 2012). This further highlights the integral nature of relationships and supports the value of adopting a systems perspective when considering siblings' experience and needs. This reemphasises the importance of safeguarding the agency of C&YP as co-authors of their lives, attending to their interpreted experience, as well as recognising their vulnerabilities therein.
The value of adopting a systems perspective was also evident given siblings' support not only came from parents, but also through an amalgamation of their wider relationships and integral sources of support. This was highlighted in two families with more than one typically

developing sibling. Having other brothers and sisters provided siblings with the opportunity to sense check their experiences, share information, express concerns, offering different perspectives of their sibling relationships. This is consistent with findings from other authors' who suggest multiple sibling relationships offer opportunities for shared responsibility and contribute to wider family harmony (Kao et al., 2011; Seligman & Darling, 2007).

The C&YP's experience highlighted other potential vulnerabilities, such as the loss of their expected identity as a sibling. The findings suggested siblings moderated their behaviour, to safeguard themselves and their sibling with ID, and to support their family. This inevitably changed their perception of current and future relationships, and their own identity of what it meant to be a sibling. The findings suggested this also shifted the family narrative and expectation of the sibling relationship with more responsibilities being placed on siblings to self-regulate their relationships (Petalas et al., 2012b; Reimers et al., 2023).

The findings identified 'differences' in the experiences of C&YP with a brother or sister with ID, from the siblings' experiences of their peers. At times, siblings were required to absorb a great deal of emotion, to engage in and respond to the sense making of the whole family's experiences of ID. The moderation of their behaviour demonstrated both their emerging maturity and insight, while at the same time pointed to a potential for the suppression of their own needs. This may lead to future difficulties for them personally and in their relationships with others, leading perhaps to possible resentment, internalised emotions and maladjustment from unfulfilled needs and relationships with their siblings. This also relates to the adjustments required in their relationships with their parents and having less time with and attention from their parents (Burke & Montgomery, 2000).

Therefore, recognition of the potential vulnerability for both C&YP with ID and their siblings is indicated as an important consideration when working with families. Being aware of the potential for C&YP to suppress their own needs, consciously or unconsciously, is an important factor to recognise within families and for those supporting them. When assessing and working with families, applying custom and practice approaches may risk siblings' direct needs being overshadowed, given service pressures, practicalities and the emphasis on ensuring direct care and support needs are met for the C&YP with ID and their parents.

Making assumptions or failing to recognise siblings experiences may inadvertently lead to their vulnerabilities being overlooked. This could have a ripple effect on the wider family, in terms of the impact of any maladjustment on their part, such as the emergence of less favourable expressed behaviour, either overtly, or by siblings otherwise suppressing or masking their own concerns or needs. The findings suggest that consideration of siblings' experience within the context of their family system, drawing from their insight, and providing age-appropriate and timely information, while being overtly conscious of process-person-context-time serves to optimise support not only for siblings, but also positively impacts their families (Hayes et al., 2022).

6.1.3 Valuing sibling relationships in different contexts

A heightened degree of warmth and value being attributed to their sibling relationship, was evident from the experience shared by many of the C&YP in this study. Three of the participants who were part of a sibling dyad expressed that they had no other basis of comparison of sibling relationships except with their younger sisters, and brother with ID, respectively. They valued being a sibling, citing this as preferable to being an only child. Recognition of and valuing the sibling relationship, warmth, companionship and enjoying

shared experiences together is evident in the literature (Moyson & Roeyers, 2012; Petalas et al., 2012b). Some studies suggested same sex dyads have greater warmth in their relationships (Begum & Blacher, 2011). From the experience of the C&YP who participated in this study, this was not consistent with their experience of being in a sibling dyad, with their reflections supporting findings in the literature where the gender of siblings was not a significant factor differentiating their experiences (Giallo et al., 2012).

As noted in the discussion, there was a corelation with the literature, whereby the C&YP described conflict in their relationship, with warmth and love for their brother or sister co-existing alongside their experience of aggressive outbursts or physical hurt inflicted by their sibling with ID (Hayden et al., 2019; Petalas et al., 2012b; Shojaee et al., 2020). Two of the siblings expressed a need to protect themselves, and in this circumstance, they identified the importance of having a separate space to 'escape to', identifying some concern for their own safety (Petalas et al., 2012b).

'Forbearance', is defined in the literature as a requirement to suppress one's own emotions, reactions and feelings, related to siblings' experiences and their perception of their quality of life measures, particularly where they experience challenges in their relationship with their brother or sister (Moyson & Roeyers, 2012; Múries-Cantán et al., 2023b). I was struck by the forbearance of these C&YP, despite their emergent narratives of their experiences of aggression, coupled with a sense of injustice at times. This was intertwined with a desire and effort to understand, a sense of care and compassion for their siblings with ID. Such conflicted emotional experiences for the C&YP further highlighted the importance of having access to knowledge and information about ID to draw from, to help contextualise their experiences, embedded in an informed understanding of their siblings' ID and associated communication

and behavioural challenges. Equally, this highlights the need for parental awareness and active curiosity from those supporting siblings and their families, recognising the interactive nature of experiences within the family and the resulting individual as well as shared impacts.

From a family systems perspective, this might be described as an action-reaction response, recognising the mutual connections within interfamilial relationships (Cridland et al., 2014; Dallos & Draper, 2010). The findings also identified the importance of siblings' surroundings, their physical environment, having a space to retreat to, and time to themselves was found to be supportive (Moyson & Roeyers, 2012).

From the literature, birth order was a factor considered in studies exploring siblings' relationship quality. Hayden et al. (2023), suggested a potential binary position, with younger siblings experiencing more intimacy-companionship, alongside more antagonism-quarrelling, in the quality of their relationship with their older sibling with ID. Two of the sibling dyads in the study, were younger than their sibling with ID, suggesting birth order may have a role to play in how siblings perceive, value and manage their relationships with their sibling with ID (Begum & Blacher, 2011; Hames, 2008; Moyson & Roeyers, 2012). All the siblings in the study described experiencing times when having a sibling with ID felt stressful, to a greater or lesser degree, often linking their responses to this with their desire to support their parents. For the two younger sibling participants in this study, the findings suggested a degree of ambivalence at times toward their sibling with ID. They recognised their parents' efforts to provide support for them and their sibling with ID and acknowledged the challenges this presented for them. These two younger siblings described living quite separate lives, with limited shared interests.

As this was a purposive cohort of C&YP with just two of the participants being younger siblings, it is important to adopt a cautious approach to the findings relating to birth order, noting this is one interpretation. However, their experiences also reflected a potential sense of loss of the sibling relationship, combined with reduced time with parents, aligning with previous findings from the literature of siblings' experience of loss, and missing parental time and attention (Burke & Montgomery, 2000; Hastings & Petalas, 2014; Moyson & Roeyers, 2012).

To my knowledge the direct accounts of adopted siblings' experiences of ID has not been explored specifically in the literature. One of the C&YP who participated in the research, along with their sibling with ID, had been adopted and as such provided a unique insight for this study. Acknowledging this is the interpreted experience of one adopted sibling and reflective of their individual existential position and sense making as a adopted child and sibling, further research is indicated. In addition, considering the divergence of experiences evident both from the findings in this study and from the literature, with multiple factors emerging as influencing C&YP's experiences, being an adoptee is not suggested as a solitary factor impacting experience, given that this participant was also, for example, a younger sibling.

For the adopted sibling in this study the findings suggested quite an individualised expressed sense of loss, that both resonated and differed from the wider loss of the expected sibling relationship as suggested in the literature (Petalas et al., 2012b; Reimers et al., 2023). The findings from this study suggested this was potentially an amplified loss, a different experience eliciting a sense of 'separateness' for the adopted siblings. While other findings suggested a balanced perspective of positive and less favourable siblings' experiences this was not so evident from the interpreted experiences of the adopted sibling who participated in this study.

Connecting this to family systems theory, one hypothesis for this heightened sense of loss and degree of disengagement with their sibling relationship, may be connected to the loss of the longed for idealised family, as an adoptee. A close maternal relationship was evident for this sibling, suggesting the potential for a connection between the siblings' sense of loss and that experienced in the wider family. The findings suggested a whole family harmony impact, given additional challenges they faced collectively.

This has resonance with the stages of grief and loss often ascribed to parent and family experience, when they have a child with ID. Parents may experience a sense of mourning the loss of the expected child, as they come to terms with the diagnosis of intellectual disabilities. While loving their child and building their individual and the family's collective capacity and capability to support their emerging needs, there is a recognition that this is different to the experiences of parenthood they may have anticipated, with potential impact on family relationships. (Seligman & Darling, 2007). For families of adopted children, similarly there is a potential sense of loss, a need to adapt, with the impact on family relationships potentially heightened given their conscious investment in one another, in coming together as a reconstituted family.

There is both resonance and difference in the experience of biological and adopted siblings and families as they come to terms with the unexpected additional needs of their child with ID and support their wider family. Bronfenbrenner and Morris provide a helpful means of considering this, describing the varied characteristics of C&YP's development that influences engagement with their environment and phenomena experienced in their lives. In the circumstances of having a sibling with ID, each C&YP's active behavioural disposition, their demand and resource characteristics, will differ (Hayes et al., 2022). Which in turn impacts the way they

interact with their environment and respond to varied situations. This suggests that the sibling's experience, in the case of the adoptee is this study, is as much about their individual as it is about their adoptive circumstance. There is clearly a deficit of research exploring siblings experience in adoptive families, where one or more of the siblings has ID. While there may be a degree of broader application of the findings from this study, given only one of the C&YP was adopted and able to share their interpreted experience as a sibling and an adoptee, further qualitative studies exploring biological and non-biological siblings' experience would add to understanding and insight.

A further perspective emanating from this study was the experience of fraternal twins where one has ID. It is acknowledged that this was the interpreted experience of one sibling who was a twin. However, with the twins' developmental age being the same, their expressed differences in their lives and life experiences are potentially more starkly evident. The findings suggested similar experiences for fraternal twin siblings to other participants, i.e., acceptance, expressing care, seeking to highlight positive attributes, while recognising difficulties, expressing frustration, and acknowledging the impact on them as siblings and their parents. However, the findings also indicated a stronger narrative of a sense of distance emerging in their sibling relationship, with notable changes evident at life transitions, especially during adolescence.

The findings hypothesised that most twins and siblings would have different lives and experiences during adolescence, recognising that experience is influenced by factors beyond simply being fraternal twins. The findings also indicated a potential heightened awareness of differences, and suggested parents may overcompensate, with a tendency to protect the sibling with ID from overt comparisons, thereby compounding a sense of loss and de-prioritisation of the needs and aspirations of the typically developing twin.

To my knowledge, there is no study that has engaged siblings' direct reports of their experiences as fraternal twins where one has ID and the other not (discordant for ID). Studies have explored Autistic Spectrum Disorder, (ASD) with findings suggesting a typically developing twin may also be predisposed to ASD and this may impact their relationship with their sibling (Petalas et al., 2012a). No similar findings were evident for twins with ID from the literature review. For twins, adapting and living quite separate lives may leave both siblings quite isolated, experiencing the loss of the sibling relationship in a not dissimilar way to that noted by other siblings (Petalas et al., 2012b; Reimers et al., 2023).

De Vos et al. (2002) explored mothers' views of coping with twins discordant for ID, they concluded that a mother's coping was positively impacted if they accepted their children as individuals and supported them accordingly. Fraternal twins' experiences as siblings has resonance with mothers' coping as outlined by De Vos et al. (2002). Adopting a positive coping strategy of being an individual, enables twins to be their own person and have their own identity outside of the 'sibling-twin' relationship. This approach lessens the immediate comparison, advocating a position of valuing twins as individuals, co-existing and developing within their family. Given the potential mirror image in which to frame twins' experiences, future studies considering twins both concordant and discordant for ID, would be a valuable addition to research, informing more specifically, the care and support for siblings who are twins, and their families.

Gender impact on sibling relationships was noted in the literature (Giallo et al., 2012; Pollard et al., 2013). Previous findings suggested some impact, more often relating this to caring roles and responsibilities. Recognising that there are socio-cultural and socio-economic factors to consider when interpreting gender roles (Kao et al., 2011; Lobato et al., 2011), however, from

the findings there was no clear correlation to suggest gender make up of a sibling dyad led to more value, positivity or quality of siblings' experience of their relationship. There was some suggestion that sibling age indicated a degree of difference in the quality of their relationships for the two younger siblings, however they also demonstrated maturity and capacity in how they engaged with and supported their families. The findings suggested that the extent to which C&YP are valued, and the quality of their relationships, were closely intertwined with the family context, particularly their parents' narratives, as well as the family's collective capacity, and the availability of support mechanisms. Parental response to having a child with ID in their family was a strong indicator of more positive siblings' experience of ID, and sibling relationships, consistent with other studies (Shivers & Dykens, 2017). The findings pointed to the value of a systems perspective towards a greater understanding of siblings' experience, recognising the mutual and multiple connections in their family relationships (Baum & Lynggaard, 2006).

Specific diagnosis of ID and subsequent needs were found to impact how siblings valued their relationships (Aksoy & Bercin Yildirim, 2008; Hayden et al., 2023). For the C&YP in this study, the dynamic between them and their sibling with ID, how they related to one another and their external environment, was forged in the shared values and experiences developed within their family. There are clear indictors for those supporting C&YP to be attentive to the need for individualised assessment and support, mindful of multiple variables influencing C&YP as they develop, including their behavioural, personal resource and demand characteristics (Hayes et al., 2022).

Experiences of aggression, loss, potential isolation, suppressed needs and vulnerabilities all played a part in how they developed and subsequently how they experienced and responded to

having a sibling with ID. For siblings' relationships, the diversity of individual characteristics for siblings, for their family and in their wider context, also needs to be considered. The age of all siblings, multiple sibling families, concordant and discordant twins, being attentive to non-biological sibling relationships, those in adoptive families, were all indicators for further research.

6.1.4 Sibling agency, compromise, power and loss

Agency for C&YP was highlighted in the literature and embedded in legislation as a principle, recognising the importance of C&YP having a voice, a right to express their agency and to influence their experience of childhood, and the decisions made about them (James & James, 2004; James & Prout, 2015). The C&YP welcomed the opportunity of being asked about their experiences and participating in this study. I was constantly humbled by their honesty and willingness to share their experiences so openly with me. They valued being given recognition for their unique role as siblings. All of the C&YP wanted to impart their experience to inform and positively impact siblings' experiences of ID for the future.

The C&YP demonstrated a degree of agency over their lives, expressed through the examples they shared of their school life, subjects they enjoy, selected hobbies and chosen friendships. Emerging from these conversations was the importance of having relationships and experience both within and outside of the family, consistent with similar findings in the literature (Moyson & Roeyers, 2012). Siblings valued being able to have their own identity, and space to express themselves as individuals. For some, this was also practically about having a physical space, a place where they could retreat to and have time to themselves. This indicated the importance of considering the physical environment for families, taking account of their socio-economic context and the implications and limitations this might present (Kao et al., 2011). Friendships

were important to the C&YP not only for themselves but also for their brother or sister with ID. Seven of the C&YP indicated the importance of similar opportunities being available for their siblings with intellectual disabilities to have independent friendships and social outlets, (see section 6.1.5).

Living with their sibling over time, the C&YP recognised changing and divergent needs for them and their sibling with ID. The C&YP all acknowledged an awareness of difference as a feature of their lives as they grow up, seek their own identity, in their engagement with the wider systems in their lives, such as going to school, in their relationships with peers; seeking greater independence and moving beyond the immediacy of relationships in the family. This resonated with the concept of 'disability by association' described in the literature, with emerging awareness of differences as they are exposed to more experiences outside the family (Burke, 2010). Similarly to findings reported in the literature (Aksoy & Bercin Yildirim, 2008), several of the C&YP expressed this in relation to their caring roles and responsibilities, connecting this to supporting their parents and family.

The development of their knowledge of ID and the sibling role, changed over time, consistent with other studies (Hayden et al., 2023), with findings suggesting older siblings in sibling dyads may take on more of a caring role over time, connecting this to Bronfenbrenner and Morris' concept of 'person-process-context-time' (Hayes et al., 2022). The findings suggested a growing awareness of their support role and positioned this within the interconnected relationship within a sibling dyad, and as part of the parent-child interdependent relationship. The findings suggested the family 'journey' together, growing their knowledge about ID over time, informed by their shared roles from within their family 'microsystem'.

The literature attended to consideration of the caring and pseudo-parenting role for siblings with some studies suggesting this has a potentially more negative impact on siblings' wellbeing, psycho-social adjustment and child-parent relationships, though findings varied. Most studies found older siblings were more likely to take on caring responsibilities, with differentiated more often lesser demands for any caring role for their sibling at a younger age. This was found to be dependent on a number of factors, including the degree of associated conditions, health issues, behavioural challenges and any additional needs (Hayden et al., 2023; Petalas et al., 2009a, 2012b; Reimers et al., 2023).

What was not attended to in the literature, and to my knowledge therefore a unique contribution from this study, is the pseudo-parenting role and a sibling's experience of ID following the death of a parent, creating a single parent family and, as the findings suggested, subsequently a very tight knit and integrated family system. Learning about ID together as a family was an integral part of the experience for all the participants. For one sibling from a single parent family, this connectivity was heightened, due perhaps to the shifted dynamic and nature of their co-dependent relationship with their mother who was a widow.

The findings identified some examples of pseudo-parental roles, however contrary to the literature, for the purposive cohort in this study, birth order and gender were not consistently evident factors, with siblings no more or less likely to take pseudo-parenting roles if their sibling with ID was older or younger (Begum & Blacher, 2011). Previous authors identified that shared caring responsibilities were more self-evident, therefore more readily accepted, where a sibling had more profound ID (Kruithof et al., 2021). This had some resonance with the sibling-dyad from this study within a single parent (widowed parent) family. A heightened level of insight was evident and an acceptance of a shared role in caring, coupled with an

awareness of the demands on a single parent as the sole 'provider' in the family. A level of maturity was expressed by the sibling, not only in their desire to share care responsibilities, but also in terms of working towards their own positive academic and future life achievements (Burke, 2004; Burke & Montgomery, 2000; Hayden et al., 2019).

These findings could be interpreted as representing a degree of loss of childhood, that is, an imposed or necessary expectation within such family circumstances (Kao et al., 2011; Petalas et al., 2012b; Reimers et al., 2023). Certainly, the lifelong interrelationship appears more evident in a single parent (widowed) family, accompanied by a degree of pressure to succeed, go to university, get a good job. Quite a selfless future was envisioned in this circumstance, consistent with the suggestion of siblings' desire to succeed to support their families, from other studies (Hayden et al., 2023). However, from the findings, this was not expressed as a loss by the sibling in this study, but presented as a willingly accepted responsibility, aligned with family culture, faith, shared beliefs and expectation of caring for one another irrespective of having ID. There was recognition of an inevitable lifelong interrelationship between the sibling's life decisions, contextualised in some role of support for their sibling with ID, in a shared future.

The future is revisited later in this discussion chapter, (section 6.1.7). There is caution in the interpretation from these findings. Not every single parent family widowed or otherwise will enable greater acceptance for siblings. Indeed, multiple factors have been suggested by other studies such as socio-economic status, cultural expectations and roles in the family, the latter contributing to a strong sense of 'duty' and expectation, linked to faith, family beliefs and cultural expectations (Dariotis et al., 2023; Kao et al., 2011; Lobato et al., 2011). Socio-economic hardship may also be more of a feature for single parent families than was evident

from the current participant cohort. What was suggested is that single parent families are potentially closer. As such there may be, by necessity, a greater openness and sharing of knowledge over time, supporting siblings' acceptance of their role and responsibilities in the family.

Consideration of the impact of faith, beliefs and different cultural expectations was frequently noted as a deficit in literature exploring siblings experience of ID, and this is discussed later in this chapter (section 6.1.6). Within the literature for single parent families more emphasis was given to socio-economic and psychological pressures (Hayden et al., 2019; Seligman & Darling, 2007), with less emphasis on affection, pride and a sense of duty for siblings. Dariotis et al. (2023), acknowledged the potential for positive outcomes in parentification experience, where this occurs in a supported environment, and C&YP's contribution is acknowledged, supported and valued. The findings corroborated this view, with siblings' child-parent relationships acknowledged in shared and valued endeavours. Cultural beliefs and family constructs may also serve to positively normalise this expectation, leading to greater personal awareness, social competence, resilience and capability for the future, developing a strong sense of social responsibility for siblings (Hayes et al., 2022; Lobato et al., 2011).

The majority of the C&YP identified and embraced additional roles and responsibilities in supporting their sibling, with a clear connection to their recognition of the impact of having a child with ID for their parents and with a subsequent desire to support them. Having a sibling with ID did bring additional responsibilities for all the family, and several of the C&YP articulated a recognition of their differentiated experience as a sibling, alongside a sense of loss and need for compromise (Petalas et al., 2012b; Reimers et al., 2023). The potential for siblings to experience internal conflict was recognised in the literature, being torn between acceptance,

being angry and experiencing a sense of loss of parental attention (Graff et al., 2012; Múries-Cantán et al., 2023a). Such internalised conflict may impede siblings' wellbeing and impact their relationships with their sibling with ID. As discussed earlier in this chapter, this highlights the need for those supporting C&YP who are siblings of a person with ID to be aware of this potential vulnerability when assessing families, attending to siblings' specific context and directing support, based on their needs.

Each of the C&YP in this study brought unique perspectives from their context, in terms of faith, socio-economic and cultural context, with some referencing their beliefs, cultural background and values in their responses. When supporting siblings, professionals should be careful that assumptions are not superimposed based on established cultural contexts, often coming from more western societal constructs that may have informed generalised care, approaches and interventions. Findings from this study indicate that research into siblings' experience of ID needs to include a broader cohort of family circumstances, including cultural considerations, socio-economic status, family background, including single parent families, exploring this in the context of a parent being widowed, contrasting this with separation, divorce or reconstituted families. Such inclusion would enhance the body of knowledge in relation to siblings' caring roles, contributing to understanding and informing the support needs required in these circumstances, with greater inclusion of siblings' own views being essential.

6.1.5 Context outside the family

Bronfenbrenner considered interactions and relationships to be the main mode through which children develop, 'the engines of development' (Hayes et al., 2022:999). The C&YP described forming relationships and friendships with those with whom they have shared interests (Dallos & Draper, 2010). All the C&YP described, in some way, their experience of the value

judgements of others, appearing to have developed a heightened awareness of this, through their interaction with their friends. Shivers and Dykens (2017) suggested that siblings may worry about how their sibling with ID behaviours might impact the views of others, and in turn siblings' own esteem or sense of worth. The C&YP were aware of potential judgements, and as such, many were protective of a separate space for themselves e.g., time with their own friends to forget for a time, about being a sibling.

The C&YP's experience of relationships with others was often expressed in terms of how they perceived their brother or sister was treated, or how 'difference' or acceptance of their brother or sister with ID was expressed, rather than how they themselves were seen. This sense of fairness and justice was consistent with other studies (Petalas et al., 2009a, 2012b). These values-based judgements, alongside their socio-cultural constructs and beliefs influenced their view of others outside the family, and in turn influenced their choice of friends. This connected with Bronfenbrenner's bioecological theory, indicating C&YP develop their sense of self, and of others within their primary family. This is a dynamic process over time, it follows that as they move beyond the family, engage with others and are exposed to wider ideologies and attitudes, they seek contact and interaction with others who emulate similar constructs, values and behavioural dispositions (Hayes et al., 2022).

Siblings demonstrated courage, they challenged judgments and behaviours that did not align with their values. There was a sense of wanting to protect their sibling with ID, even for those who had expressed being quite challenged by or distant from their sibling. They were uncomfortable with judgments made by others, and this 'ethical compass' contributed to their assessment and choice of friends, with similar findings in the literature (Petalas et al., 2009a, 2012b). This aligned with a family systems perspective connecting siblings' experience of ID,

with a desire to connect with and perhaps protect their own narratives, that of their siblings with ID, their parents, and their families (Seligman & Darling, 2007).

Many C&YP described interactions with their own friends as being quite separate from those with their sibling with ID. Several recognised the need for the sibling with ID to have independent experience outside the family and form their own friendships. Seligman and Darling (2007) support this, questioning how 'individuation' might be achieved without access to peers and friendships for all C&YP with and without ID. This can be particularly important in adolescence as one seeks to find one's own identity.

Two of the C&YP articulated the importance of independent friendships for their brother or sister with ID, and three referred to enjoying meeting and spending time with their siblings' friends. Given a variety of factors, including vulnerabilities and potentially higher dependency needs for C&YP with ID, they may have more limited opportunities to socialise and therefore find it more difficult to form friendships independently (DaWalt et al., 2019). Opportunities for their siblings with intellectual disabilities to build friendships appeared to be more heavily dependent on parents' facilitation and connections with established support networks, such as schools or societies, e.g., Down's Syndrome Association, or community support groups. In early adolescence this was not so dissimilar perhaps to their typically developing siblings' experience, with shared reliance on family support in establishing their social networks.

There was a sense of an emerging change in adolescence, acknowledging the age range of the cohort of participants, with the C&YP seeking opportunities to find their own identity at this life stage. It is unsurprising that they were exploring opportunities for greater independence, seeking to manage their own networks and widen their social engagement and experiences

outside the family. Clearly these experiences are not as easily replicated for their siblings with ID.

Private time was identified in several studies, as one of the siblings' quality of life domains (Moyson & Roeyers, 2012; Múries-Cantán et al., 2023b). The C&YP valued having time away from the family outside of their role of being a brother or sister, reflecting positively in terms of having time to themselves and friendships. Bronfenbrenner and Morris, highlighted the importance of established and positive relationships over time, supporting childhood development, and emphasised the 'proximal process', i.e., the quality, frequency and consistency of the relationships as being most important in facilitating best outcomes for individuals (Hayes et al., 2022). All the C&YP identified friendships as very important relationships in their lives.

They did not always want to talk to their friends about their sibling with ID, preferring to protect this as a safe space, a relationship of their own where they were not identified just by their context of having a sibling with ID (Moyson & Roeyers, 2012). Contrary to previous studies, having a sibling with ID did not appear to present significant difficulties for the C&YP in establishing friendships (Benderix & Sivberg, 2007; Moyson & Roeyers, 2012; Shojaee et al., 2020). However, the results suggested the importance of their friends having access to information and opportunity to understand ID and associated needs, especially where expressed challenging behaviours were evident for their sibling. Ease in making friends may have been reflective of their life stage, the C&YP were of school age and therefore have access to peers and friends outside the family. They valued established friendships, with people who already knew their family narrative, so explanations of any idiosyncrasies or circumstances for the family were not required. Findings indicated the primary importance of the family providing a

supportive and secure home environment, facilitating siblings' ability and opportunity to make friends, which in turn builds their resilience.

Having supportive networks outside the family, with people who provide positive reciprocal relationships, helps mitigate some of the challenges of being a sibling to a brother or sister with ID (Moyson & Roeyers, 2012; Yaldiz et al., 2021). This resonated with findings of family focused models of care for C&YP who are recognised as carers, noting a connection with school attendance, building friendships and networks, indicating greater resilience and positive outcomes (Ronicle & Kendall, 2011).

6.1.6 Culture and having a faith

There was limited literature exploring siblings' experience of ID considering diversity of culture, beliefs, values and having a faith. Some authors have explored this, for example, with Latino families in the US Northeast, recognising the socio-cultural impact on families with a child with ID (Kao et al., 2011; Lobato et al., 2011). Findings suggested that Latino siblings with a brother or sister with ID may be more at risk of adverse outcomes. They identified a likelihood of less favourable socio-economic circumstances, challenges with personal adjustments and relationships for Latino families, as factors impacting siblings' experience. This highlighted the impact of familial cultural expectations, such as expected caring roles and responsibilities, suggesting these cultural expectations subsequently impact the C&YP's experience, and potentially their sibling relationships in the here and now, and for the future (Emerson, 2014; Kao et al., 2011; Lobato et al., 2011). The literature widely acknowledges that this aspect of siblings' experiences is underrepresented and advocates the need for future research situated within diverse socio-cultural contexts (Emerson, 2014; Petalas et al., 2012b; Reimers et al., 2023). It was therefore important for this study, therefore, to attempt to enable

the C&YP to express their experience in relation to their cultural identity, values, and faith, being attentive to the influence of these variables on their context and interpreted experiences of ID.

The C&YP all described themselves as British, three specifying their heritage as British/Asian, British/Pakistani and British/Polish. Several of the C&YP described themselves as being Muslim, Christian or Roman Catholic. Others defined their families as mainly Christian though non practising or having no specific faith. For those who identified as formally practicing their faith, their cultural heritage was intertwined with their faith and beliefs.

The C&YP framed their faith and beliefs as a 'moral compass', a barometer influencing how they lived their lives and, especially, how they viewed and treated others. Previous authors' studies have suggested that values grounded in religious belief inform individuals' core beliefs (Correia & Seabra-Santos, 2022). Siblings acknowledged the importance of their beliefs and value-based characteristics in themselves and their families and they related these to the ways in which they assessed and viewed others when engaging with their sibling with ID. Irrespective of their cultural background, faith or beliefs, all the C&YP expressed a strong sense of social justice in terms of the rights and experiences of their siblings with ID. The findings suggested this 'compass', belief system and value base, guided their lives. They all advocated for equity and fairness in one way or another with a desire to protect their sibling with ID. Siblings wanting to protect and advocate for their sibling with ID was similarly expressed in other studies (Correia & Seabra-Santos, 2022).

The findings indicate that siblings and their families experience misunderstanding or unkindness from others. The siblings' narratives of fairness, justice and equality for their

sibling connected with these experiences. This resonates with family systems theory, with the socio-cultural system within which the siblings 'exist', their value base and beliefs, shaping them, and framing their expectations of others, informing their interactions and understanding, both individually and through their interrelationships within their family (Priest, 2023). Having a shared cultural identity, beliefs, shared values or faith connects the whole family. This shared sense of belonging helps to maintain the family system, strengthening bonds between siblings' and within family relationships. This also offers a frame of support for siblings to draw from in their interactions outside the family, establishing and connecting with their cultural norms and expectations (Hayes et al., 2022).

Bronfenbrenner was critical of the idea of a universality of childhood, recognising in the bioecological theory of human development that the developmental nature of childhood over time is influenced by many variables (Hayes et al., 2022). A hypothesis from this study is that family resilience was enhanced within a shared cultural identity, a faith and belief system. Having shared values and expectations, influenced and supported how the individuals within the family viewed and interacted with one another and with those outside their family, framing an expectation of equity for the C&YP, and for their siblings with ID. This highlights the importance, for those working with families with children with ID and their siblings, of considering the families socio-cultural, faith and belief constructs. Professionals should be attentive to siblings' experiences within their unique context, framed by their cultural identity while recognising how this might, in turn, shape their specific support needs. In addition, being mindful as professionals, of their own constructs, beliefs, backgrounds and potential biases that will influence interpretations.

6.1.7 The future

The findings indicate siblings' expressed ambitions for their own future, in their careers, where and how they will live and, for some, their views on having a family of their own. The literature more frequently connects considerations for the future in the context of a sibling's caring role (Aksoy & Bercin Yildirim, 2008; Burke, 2010; Burke & Montgomery, 2000; Correia & Seabra-Santos, 2022; Hastings & Petalas, 2014; Seligman & Darling, 2007; Strohm, 2005). Similarly, policy developed over the last decade in support of families has emphasised a focus of support on those identified as young carers, advocating early pro-active support (Care Act 2014, Section 63).

Concern about future caring responsibilities was not a significant feature of the experiences expressed by the majority of the C&YP in the current study, perhaps reflecting both the life stage of this cohort, and the semi-structured nature of the approach. There were exceptions, such as the single parent family discussed earlier, that suggested a heightened interdependency of the parent-child relationship in this family. Kruithof et al. (2021) suggested siblings anticipated a caring role in the future and most reported no concerns. They do indicate the need for open conversations about caring responsibilities at an earlier life stage to ensure clarity between parents' and siblings' understanding and expectations.

All the siblings in the current study expressed an optimised view and vision of the future, both for themselves and their sibling with ID, with varied perspectives regarding the interconnectivity of their shared futures. Several did not see their future being wholly connected to that of their sibling. In this there was some resonance with the literature, with siblings' perspectives potentially influenced by the diagnosis or descriptor of the sibling's ID and the subsequent impact on the quality of their relationships (Aksoy & Bercin Yildirim, 2008;

Orsmond & Seltzer, 2000). Where siblings with ID were described as having associated ASD alongside ID, or where wider levels of physical disabilities were associated with their siblings' care needs, C&YP were less likely to see a role for themselves in a shared future with their sibling (Burke & Montgomery, 2000; Hayden et al., 2023; Lobato et al., 2011; Petalas et al., 2009a; Reimers et al., 2023).

Three of the C&YP, appeared somewhat dissociated from both their own future ambitions, and that of their siblings. This tended to be the younger participants and again suggests, that consideration of the future and what their roles and responsibilities might be, evolves with knowledge and over time (Petalas et al., 2009a, 2012b).

There was recognition of adjustments and allowances being made in their current experiences. For example, disruption to holiday plans or days out, yet these experiences did not appear overtly connected by the C&YP to their descriptions of their future. Many described their future in relation to a choice of career, having a house/home, for some, they discussed having a family. For the majority of the C&YP there was evidence of a potential idealised expectation, relative to their age and understanding of their siblings' ID. This suggested a lack of awareness regarding the lifelong nature of ID and the consequent enduring needs of their siblings with ID. The findings from this study elicited an empowering narrative from the C&YP reflecting their expressed desire to frame their siblings' positive potential for the future, albeit recognising a degree of difference therein from their own.

The literature suggested parents may be reluctant to discuss the future, particularly in relation to the potential caring roles of siblings for their brothers and sisters with ID. Several of the C&YP were implicitly aware of expectations, though where this was expressed, many were

uncertain about what this might entail (Kruithof et al., 2021; Shivers & Dykens, 2017). Age, family structure, knowledge and insight into ID impacted their reflection of a caring role, with the suggestion for some, of a potential reluctance to ask about or discuss this, to protect themselves and their parents. Perhaps deferring this consideration with some sense of the inevitability of a future caring or guardianship role in their sibling's life, uncertain of the potential impact this might have on them and their futures (Davys et al., 2010; Kruithof et al., 2021; Seligman & Darling, 2007).

Five of the C&YP mentioned potentially having their own children, three of them, all girls, offered more detailed views spontaneously, about potentially becoming parents. One spoke of the potential risk of having a child with Down's Syndrome (DS). In this instance, parenting was contextualised as a unique journey for any parent irrespective of their child having ID and was generally reflected positively. This linked to findings in other studies that suggested better sibling relationships and more warmth in their relationships where a sibling with ID has DS.

An interesting finding was one sibling's consideration of potentially adopting a child. The participant was not an adoptee, and expressed this in terms of their sense of social responsibility, beliefs and values, rather than any suggestion of concern in relation to their risk of having a child with ID. An alternative perspective was a desire to have only one child, reflected by one of the C&YP who was adopted and expressed less favourable experiences of their sibling relationship in their interview. There is potential resonance with siblings' perceived future role as carers, recognising a degree of expectation and demand, and thereby shifting expectations for their potential futures, as well as connecting to the gendered nature of sibling relationships and caring responsibilities for sisters, as suggested in previous studies (Burke & Montgomery, 2000; Orsmond & Seltzer, 2000).

C&YP's considerations of their futures as parents based on self-reported views during adolescence, are not widely covered in the literature. There is a suggestion in the literature, that for adult siblings of those with ID, especially women, they are potentially less likely to marry, may delay marriage or have fewer children (Hodapp et al., 2010). This is under researched and warrants greater exploration of siblings' views and at different life stages, to include any differentiated perspectives of parents and C&YP regarding siblings' future caring roles, with an acute awareness of the interconnectivity and potential for protecting one another, especially between parents and typically developing siblings (Kruithof et al., 2021).

The findings pointed to a need for the provision of information for siblings at an earlier life stage, regarding their potential role in caring or guardianship responsibilities. This should form part of conversations with their parents about their future, in terms of the support that they may be called upon to provide for their siblings with intellectual disabilities. Exploring any connection between perceived future responsibilities, choosing to be a parent and wider life decisions. Alongside this, it is important to consider the normalised experiences of adolescence including the uncertainty of the future, and avoid assumptions being made associated with having a sibling with ID, given that the C&YP were universally positive and ambitious about their future and that of their sibling.

6.2 Contribution to new knowledge

The following section introduces new knowledge that emerged from the interpretation of the findings and exploration of the literature in conducting this study. The descriptive term 'assumptive overshadowing' is introduced, and a 'droplet model' is provided to support and prompt professionals to consider siblings individual needs and interconnected experience of ID in their family and wider systems.

6.2.1 Assumptive overshadowing

The insights from the C&YP's interpretated experiences highlighted potential physical, psychological, and emotional vulnerabilities for siblings within families who have a child with ID. In conducting the analysis and literature review for this study a connection with the term 'diagnostic overshadowing' bias, began to form, and this was reinforced as the data analysis progressed. 'Diagnostic overshadowing' bias, refers to the circumstance for people with ID, where there is an assumption or a predominant emphasis on the person's ID and a failure, therefore, to appropriately consider their presenting health and wellbeing issues. There is a tendency to overlook key aspects of their assessment and diagnosis and assume this relates to their ID. The consequences of this can be life impacting or even life threatening, whether physical or psychological (Jones & Haydon-Laurelut, 2019; Mason & Scior, 2004).

Engaging with the data and the emergent findings of this study led me to define a new term of *'*assumptive overshadowing'. Research not previously explored in the review, conducted by Hanvey et al. (2022) metaphorically describes a 'glass child' experience for siblings, where the needs of their sibling with ID and subsequent demands on parents and other adults in their lives may deprioritise the focus on their typically developing children. This connected with the findings and the sometimes necessary primary emphasis on the needs of their sibling with ID, and or provision of parental support. 'Assumptive overshadowing' provides a collective descriptor for siblings' potential vulnerabilities. It describes the circumstance where siblings' needs or difficulties, as well as their ideas, capabilities and resilience might be missed or overlooked, with their agency thereby ignored or disregarded.

*'*Assumptive overshadowing' also connects with siblings' having unique access to knowledge and inner resources, capacity and resilience, identified from the findings. Siblings navigated

complexity in their relationships with their sibling with ID, and their parents. They managed and adapted to challenges, while remaining invested in their sibling relationships and supporting their wider family even in circumstances where they were exposed to violence and at risk of harm.

'Assumptive overshadowing' describes integrated and at times conflicted experiences for siblings that emerged from the study. It reflects a co-existence of both positive and negative experiences of having a sibling with ID, acknowledging circumstances of personal vulnerability for the C&YP.

The findings suggested siblings' agency, voice and their needs may be deprioritised or suppressed either directly, or consequentially. 'Assumptive overshadowing' emerged as a concept to encapsulate and describe the individualised nature and unique perspectives of siblings' experience. Importantly, this acknowledges the concurrence of both strengths and vulnerabilities for siblings in their experiences of having a brother or sister with ID, recognising the variability and complexity therein. This also resonates with the differing results evident from the literature and that emerging from this study from the interpreted experience of each of the participants.

Considering this concept of 'assumptive overshadowing' a three dimensional model was developed as a tool to support practitioners working with C&YP to co-create a contextual understanding of siblings' experience of ID. The tool is designed to support practitioners working with C&YP who are siblings to recognise and respond to potential 'assumptive overshadowing', this is introduced in the next section below.

6.2.2 The ‘droplet model’

From the findings, siblings’ experience was consistently described as being both individual and inter-relational, influenced by their family and wider systems. As identified above, ‘assumptive overshadowing’ emerged as a term to describe siblings’ potential vulnerabilities but also their strengths, perceptions and capabilities recognising that C&YP have access to unique insight as siblings. Grounding this in the theoretical frameworks of the bioecological model of human development and family systems theory (Hayes et al., 2022; Priest, 2023), an idea emerged of producing a guidance model to describe and support the exploration of this inter-relational concept for professionals working with siblings in families with C&YP with intellectual disabilities. The idea was further developed as a mechanism for professionals to explore, identify and respond to the potential for ‘assumptive overshadowing’ of siblings’ experience of ID. A visual guidance tool is introduced as a new ‘droplet model’ (Figure 6.1) and is explained below.

The ‘droplet model’ depicts the family as a ‘body of water’, existing in and influenced by their ‘wider environment’. The model acknowledges that the family is influenced by changes both from within and from their external environment. The circumstance of having a brother or sister with ID in the family is presented as the ‘phenomena’, depicted by the ‘splash’ in the centre of the water. The ‘phenomena’ causes ‘ripples’ to emanate across the water (within the family), representing change and suggesting potential disruption to family norms and relationships. Each family member is represented by a ‘droplet’, these are presented as different sizes, colours, and positions, and placed in different parts of the body of water, to depict the uniqueness of each person, their role, contribution and relationships within their unique family system. The findings from this study suggested siblings’ experience of ID was both individual, yet concurrently, their responses and behaviours have an inter-relationship with the experiences

of ID for other family members, e.g., parents' responses influence their children and vice versa. Family inter-relational experience can have both positive and challenging impacts and this is not static. The reciprocal nature of experience is continual and might be described as existing as an ongoing 'cause and effect'. The reciprocity of experience is represented in the 'droplet model' by the overlapping 'ripples' across the water (the family), acknowledging an intertwined experience and impact between each 'droplet' (family member). Furthermore the 'ripples' also highlight the potential for 'assumptive overshadowing', i.e., the ripples or impact may represent favourable or less favourable circumstances and experiences for siblings and other family members. The model acknowledges the unpredictable and individualised experience of ID for all family members.

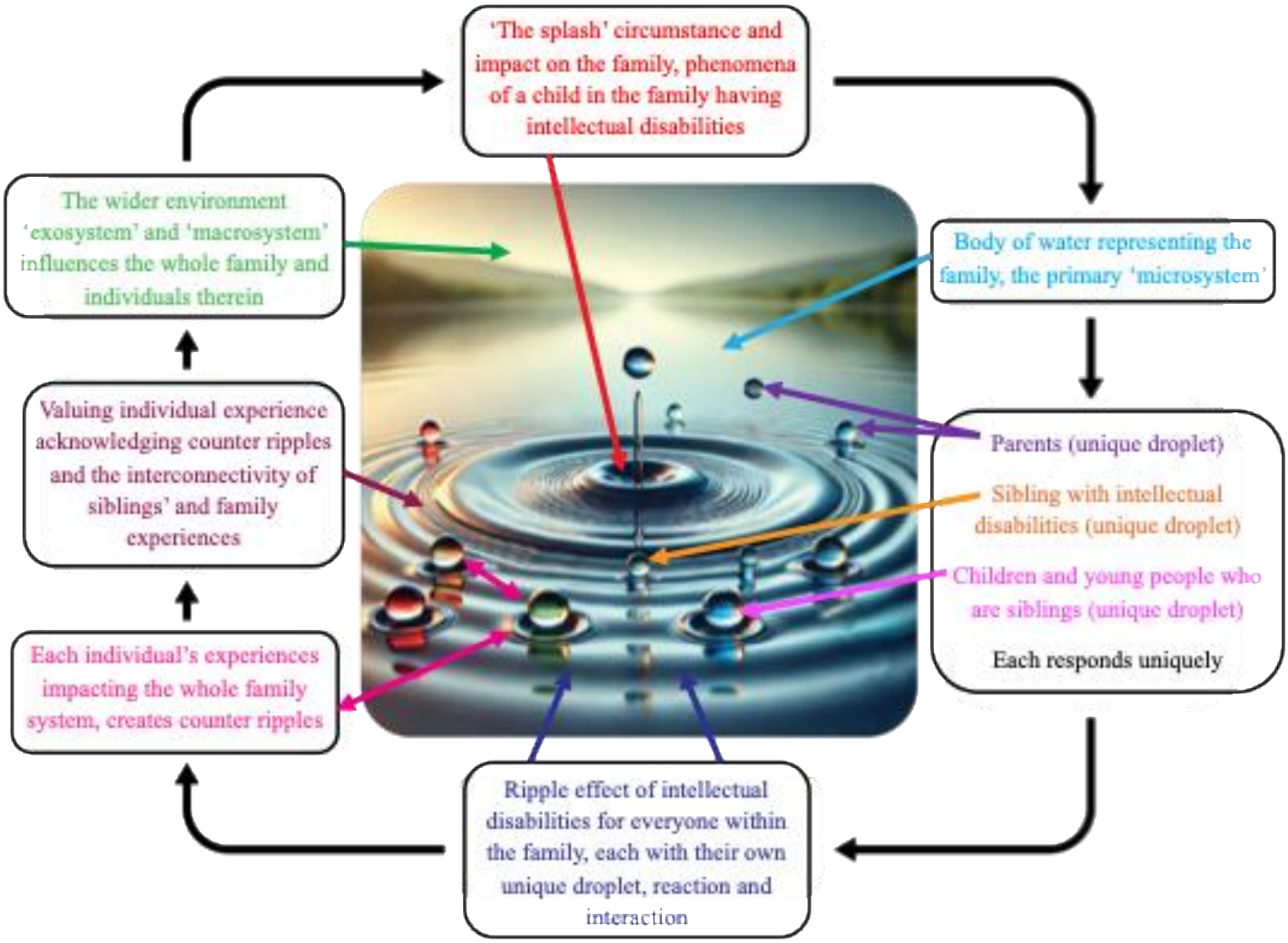
The 'droplet model' is proposed as a guide to support professionals in attending specifically to siblings' individual and unique experience, while considering this relationally, i.e., siblings' experience of ID is experienced in and informed by the context of their family, and through their interactions with their wider context and environment. The model offers an enhancement to whole family approaches to health, care and needs assessments and interventions advocated by recent UK policy, e.g. Supporting Families Programme Guidance, Chapter 3, The National Supporting Families Outcomes Framework (DfE & DLUHC, 2022).

The 'droplet model' therefore provides guidance, to support and reinforce the concept of a more contextualised and holistic approach to engagement with C&YP and their families. This is represented by the arrows depicting the continual flow of discussion and considerations to understand siblings' context and unique experience therein. As a visual model it offers an opportunity to engage C&YP themselves in the co-production of their unique 'droplet model'. It provides a tool to support the exploration of their unique experience as siblings offering

opportunity to explore with the C&YP the potential for ‘assumptive overshadowing’ as applied to their context and experiences. The ‘droplet model’ enables richer descriptions of siblings’ experience to emerge valuing their agency as holders of unique knowledge and offers practitioners the opportunity to attain a more holistic understanding of siblings lived experience of ID, providing tailored support ultimately leading to better outcomes for C&YP and their families. (see figure 6.1)

Figure 6.1. The 'droplet model'

A model for professionals working with families, recognising individuality, reciprocity, attending to the potential for 'assumptive overshadowing', acknowledging the interconnectivity of siblings' experience of ID within their families, and in relation to their wider environment.



'The 'droplet model' – Unique experience: individuality and interconnectivity of siblings' experience of intellectual disabilities.

*Acknowledging reference to terminology from Bronfenbrenner's bioecological model of human development (Bronfenbrenner & Morris, 2006; Hayes et al., 2022).

Note: Figure 6.1 Image prepared using Microsoft Designer (https://designer.microsoft.com/) with the following prompt:

"A single, coloured water droplet falls into a serene body of water, creating large, concentric ripples that spread outward. Five additional droplets fall around the edges, creating multiple overlapping ripples that dance across the surface back towards the centre. The scene is set against a bright and gentle wider landscape, with soft, natural lighting that enhances the tranquillity of the moment. The background features lush greenery and a clear blue sky, adding to the overall sense of peace and calm."

6.3 Testing the findings

While the nature of this study was to conduct an IPA of a purposive cohort of C&YP with a sibling with ID, it is acknowledged that establishing a mechanism to test the findings with the original participants would have enhanced their validity as an interpretative analysis of the lived experience of siblings with ID. I had not factored this into the original 'ask' of the participants but, with hindsight, this is recognised as a deficit. To partly address this and from discussion with my supervisors, having completed the findings and discussion chapters, retrospectively an interview was conducted with an adult sibling identified through a third person contact.

The young woman was 33 years old, with a brother of 28 years old with ID. There was no known connection to any of the C&YP who participated in the study. The young woman is also a health professional and was therefore able to reflect on the potential application of the 'droplet model' and the concept of 'assumptive overshadowing' from the perspective of her lived experience as a sibling, and the potential application to her professional practice as a registered

nurse. What follows is a summary of our discussion having shared the structured interview questions and key findings with her.

I shared the emergent themes and summarised the findings from this study. The findings resonated with her own experience as a sibling. She noted the evolution of her recognition and understanding of the term intellectual disabilities over time. She identified her parents as the gatekeepers of information and primary support and acknowledged that adaptations were needed for her as a sibling, and the family, to meet her brother's changing needs over time. The young woman recognised the concept of interconnection between her individual and the family's experience of ID. She reflected examples of past and more recent situations where compromises were needed, adapted plans or adjustments made in her behaviours, to mitigate her siblings' behaviour, or support their needs. Overwhelmingly she expressed pride in her sibling, in their achievements, and how they continue to overcome barriers experienced by a society described as not always tolerant or enabling. She recognised the commitment of her parents in supporting her sibling with ID and the whole family's life, experiences and opportunities. I shared the emergent themes and summarised the findings from this study. The young woman recognised her own sibling experiences in many of those identified by the C&YP. She too valued her relationship with her brother, yet stated she had experienced frustrations at times, particularly when her sibling's needs disrupted shared family experiences and events.

The sibling reviewed the 'droplet model' and considered that this would be valuable guidance to support her in her work as a healthcare professional. She recognised the potential focus on the patient/service user in her day to day engagement with her patients, suggesting the model would support efforts to consider holistic experience, wider relationships and their impact, not

just for siblings of people with ID, but for any individual with a presenting health issue or 'phenomena in their lives. She advocated the importance of considering siblings' unique perspectives as part of the whole family experience of intellectual disabilities and expressed the value the guidance might bring to a multi-professional context, when considering individual and whole family impact and support needs.

The sibling's reflections above provide a degree of validation of the findings being recognisable and resonating with the reflective experiences of one young woman interviewed. Subsequent testing of the findings would further validate their potential contribution.

6.4 Methodological considerations

As explored in the personal context and method (chapters two & four), considering the qualitative approach to this study, and in adopting interpretive phenomenological analysis (IPA) methodology, a position of self-reflexivity in undertaking this research has been essential throughout. Subjective researcher bias is inevitable given my personal context, motivation and the drivers for wanting to explore the subject, as well as potential preconceived ideas, based on my familial and professional experience. It was important to be explicit about potential biases, adopting an openness from the outset, providing background information of my personal and professional context, using a reflexive diary (see appendix 15) and regular supervision as mechanisms for ongoing sense checking of personal biases. Conducting an IPA of the data, ensured the emergent themes remained connected to the siblings' narratives, considering the double hermeneutic of the siblings' interpretation of their experience, and my subsequent interpretation of their data.

6.4.1 Accessing participants

The recruitment of participants proved to be more difficult than I had anticipated and resulted in an extended recruitment phase for the study. I worried that I would not have an adequate representative cohort to add value, nor be able to extract enough worthwhile data. Having secured nine participants, the reality was the opposite, I found myself grappling with a large amount of data validating the observations of Smith et al. (2015), that IPA offers the opportunity to gain deeper insight into a purposive cohort of participants. IPA research emphasises that the quality of a study is not determined by its sample size. This is more related to the validity of the research question, the quality of the data obtained, the depth and transparency of the subsequent analysis, and this was the reality of the experience of conducting this study.

Appendix one highlighted the transparent process of analysis, connecting the emergent, superordinate and master themes to the narrative of the individual interviews. Thus, the findings from this study make a contextualised and valid contribution to the knowledge base reflecting the experience of the purposive cohort of participants in England, with proposed wider application of the findings through the concept of 'assumptive overshadowing' and application of the 'droplet model'. While opportunities were missed to feedback the findings to the original cohort of participants, future research with the inclusion of a similar participant group, as well as cohorts with differing characteristics would add valuable insight to the validity and application of the emergent contributions.

6.4.2 Reflections: power, shared learning and safeguarding considerations

My previous experience of conducting qualitative research was with a group of adult participants who had sisters with ID. Despite my professional experience, there was a degree

of trepidation in engaging C&YP in a research capacity, regarding their age, recognition of the adult child power dynamic, and potential associated vulnerabilities. I worried that open questioning in our conversations would prove unhelpful, possibly triggering or being damaging for them. Positively, I ensured safeguards were in place to signpost them and their families to support if needed (see appendices six, nine & 10). My worries were unfounded, in fact, quite the contrary. The C&YP were open and keen to share their knowledge and experience. I was able to positively draw on my experience as a learning disabilities nurse, a systemic practitioner, educator, and as a parent. I established an easy rapport with the C&YP, they put me at my ease and appeared to be at ease and empowered by sharing their experiences in the interviews.

The issue of C&YP versus adult power imbalance was always at the forefront of my mind. I was aware of my own sense of awe, in terms of their access to unique knowledge and experiences as siblings. In addition, as a novice in undertaking qualitative research of this kind, the process was collaborative with both the participants and me learning more about ourselves and one another. This was unexpected, I had not consciously thought about the process of the research engagement relationship in this way before. It was very much a shared experience, building my confidence as a researcher given the C&YP's openness in contributing their knowledge to inform the study. I adopted a semi-structured interview approach, providing a frame to guide the conversations. As a novice qualitative researcher, I reflected on the potential to rely on the pre-prepared guide, or to preference particular conversations. It is acknowledged therefore, that aspects of the C&YP's experience may have been missed. As reflected by other authors (Chu et al., 2017; Pope et al., 2000; Smith et al., 2022) my inexperience and the decisions made throughout, inevitably impacted the study and interpretations therein. This underlines the importance of continued self-reflexivity. Interestingly, this resonates with

Bronfenbrenner's concept of person-process-context-time, representing an evolution of my learning, engaging in qualitative research in undertaking this study (Hayes et al., 2017).

6.4.3 Using diaries or blogs as a research tool

The C&YP were invited to compete a diary or blog entry once a month for a six-month period. Four participants completed diaries and my instruction, provided to reduce the sense of burden of this as a task, was taken literally, that is, they completed a small number of between six and twelve entries. The value and importance of participatory research with C&YP was explored previously (see section 4.4). Consideration of the appropriate mode of data collection would be helpful in future research. Perhaps exploring more direct co-production of the method of data collection may be helpful, to gain their insights into the best approach to inform future studies. Subsequently, I reflected that C&YP live in a world of immediate access to information through multi-media platforms and perhaps using a 'touch base' virtual self-recorded online format for 'diaries' may be more engaging. Nonetheless the diaries provided further validation of the emergent findings.

6.5 Gaps in the literature and indicators for future research

Previous studies have indicated limitations in available research exploring sibling experience of ID, from their direct accounts. While this study adds to the body of knowledge, further qualitative research adopting similar methodology allowing for greater comparison to be made, would be beneficial. For the current study the interpretation of ID was self-determined by the parents. Subsequently, the broad application of the findings to siblings where their brother or sister has a differentiated diagnosis needs careful consideration. Research exploring siblings' experiences identifying common diagnosis of ID may be helpful. Qualitative research considering the socio-cultural and socio-economic context is indicated for future research as

well as exploring siblings' experiences of ID for fraternal twins, adoptees and single parent families, for the latter, specifically following the death of a parent. Future studies should consider equitable inclusion of siblings with ID and their typically developing brothers and sisters valuing their shared and unique perspectives. Longitudinal studies would be of benefit, given the dynamic nature of life experience, offering further application of the 'droplet model' related to evolving experiences over time.

6.6 Summary

In summary, this discussion outlined a comprehensive synthesis of the main findings from the study, referring appropriately to the literature reviewed. Family systems theory and Bronfenbrenner's bioecological model of human development were reflected as underpinning theories framing the findings throughout (Bronfenbrenner & Morris, 2006; Hayes et al., 2017, 2022).

A new term of 'assumptive overshadowing' emerged as a key consideration for those supporting siblings, prompting consideration of their context, unique experiences, vulnerabilities, insights and contribution, not only enabling a shared understanding of their needs as siblings, but also bringing an enhanced whole family understanding of siblings' experiences of ID. A new 'droplet model' (see figure 6.1) emerged from the findings as a tool to support professionals working with siblings and their families. The 'droplet model' offers a framework for exploring potential 'assumptive overshadowing', assessing individual and family needs, and attending to their holistic experiences, providing a lens through which both their strengths and vulnerabilities can be identified, informing enhanced assessments, interventions and support.

Testing the findings was discussed, identifying that further exploration of the 'droplet model' with C&YP who reflect the age demographic of the participants, would enhance the validity and application of the findings (Mandleco et al., 2003; Mandleco & Webb, 2015). Methodological issues of conducting the research were discussed. Potential gaps and indicators for future research were highlighted.

CHAPTER SEVEN: CONCLUSION

7.0 Overview

A qualitative approach was adopted for this study. Through the method of interpretative phenomenological analysis (IPA), the lived experiences of a purposive cohort of children and young people (C&YP) with a brother or sister with intellectual disabilities, was explored. The study, interpretation and analysis of the emergent data was underpinned and guided by two theoretical frameworks, family systems theory and Bronfenbrenner's bioecological model of human development (Hayes et al., 2022; Priest, 2023). The resulting findings both corroborated and differed from previous research.

This chapter provides a summary of the findings and explores the application of new emerging guidance and descriptive terminology to inform future practice for professionals in health, education and care provision, supporting C&YP who have a sibling with ID, and their families. Suggestions for the wider application of the model beyond the scope of siblings' experience of ID is offered, with indicators for future policy suggested. Finally, concluding comments are proffered.

7.1 Summary of the findings

For the C&YP in this study, their experiences and perceptions are drawn from within and interconnected with their families' experiences. The C&YP's knowledge of ID was provided by their parents and influenced by their family's constructs, beliefs, background, socio-economic status, cultural and wider context. Early experiences formed the foundations from which participants made sense of their world. Siblings' knowledge, and understandings of ID unfolds idiosyncratically over time, being continuously interpreted and reinterpreted, grounded in the nuanced and evolving contexts of their familial experiences, and wider social

interactions. They trust the knowledge provided by their parents. Access to information about ID is valued by C&YP and helps to frame their understandings. Some sibling experiences were not dissimilar to those of their peers, while others appeared to present more uniquely for them, and their family. The provision of age appropriate and accessible information supported the C&YP in coping with their day to day lives. Family constructs, culture, religious beliefs and values emerged from this study as important factors that influence siblings' experiences of ID within their family, as well as their relationships with extended family, with friends, and their engagement with others in their wider context. These factors are underrepresented in the literature and indicate further consideration for future studies.

C&YP and their families in this study, were impacted and influenced by other relationships and systems over time, e.g., with their friends, in school, or through their engagement with professional support services. The findings reinforce the importance of understanding the family as an integral system situated within a wider network of interactions shaped by the ideologies and cultural contexts of both their family of origin and the society in which they live. C&YP are influenced by their wider environment, which contributes both positively and negatively to their experiences of ID, impacting them directly, their siblings with ID, and their families. External networks such as the Down's Syndrome Association, siblings groups, and similar organisations provide opportunities for families to connect with others who share similar lived experiences. Such support systems were valued by the participants, reflected greater sibling acceptance of ID and enhanced family harmony.

The findings demonstrate that siblings have access to significant contextualised knowledge derived from their unique experiences of ID. They possess personal capacity and ability to understand, cope with, influence and navigate their life and experiences. Despite their

resilience, the findings also highlight siblings' potential vulnerabilities, both physical and psychological. The study identified that siblings' vulnerabilities may not always be overtly visible, articulated, or fully comprehended, either by the C&YP themselves or those around them. This relates to their chronological age in some instances, but also potentially to a lack of open discussion in the family. The findings suggest that parents may not always consider it appropriate to share information, possibly related to their desire to protect all their children. This aligns with findings from the literature, which similarly suggest that parents' accounts often underestimate siblings' understanding and capabilities.

Reciprocal care for and protection of their parents among siblings were also evident from the findings. Through efforts to keep things 'happy' or calm, and to avoid provoking less favourable communication or behaviours from their sibling with ID, both the siblings and their parents may inadvertently avoid discussing ID. C&YP's worries and concerns may not be shared, this presents a risk that siblings' needs and insights may be overlooked, their reactions misinterpreted, and their perspectives disregarded or missed altogether. It is important to be alert to this potential. In their efforts to protect their sibling with ID, their parents or their family narratives, siblings themselves may be at increased risk of more harmful and impactful vulnerabilities. Yet the findings from this study caution against the interpretation of siblings as passive 'victims' of their circumstances. While not denying their potential vulnerabilities, the C&YP were also empowered social agents, demonstrating capacity to cope with a diversity of life experiences. Siblings shared numerous examples of how they adapted, made sense of and coped with quite difficult and complex situations. It is essential for those working with siblings to adopt proactive and reflective strategies that recognise and nurture each sibling's potential, while remaining aware of and addressing their vulnerabilities, whether these are evident or less immediately apparent.

The majority of the C&YP in this study framed their sibling relationship as one of joy, care and love. They value their role as siblings and demonstrate considerable maturity, adaptability, and resilience in understanding and navigating challenges. Examples include coping with loss and managing situations in which they perceive their parents as deprioritising their needs in favour of siblings with ID, a dynamic they often recognise as driven by necessity. They seek and apply their knowledge of ID and positively contribute to the capability of the whole family in navigating their shared lives, including more challenging situations.

Friendships and relationships outside the family emerged as important factors supporting siblings' experiences of ID. The C&YP valued friends who had relatable experiences of ID, as well as those who accepted and tried to understand their sibling and ID. Siblings expressed a desire to step away and experience life as young people, seeking space to be themselves, separate from family responsibilities and their identity as a sibling, to enjoy positive, typical experiences as C&YP, such as engaging in hobbies and social activities with their friends.

For some, 'space' referred to their physical environment, having their own room or a private area where they could withdraw, which they viewed as essential for supporting resilience. This was described as a critical component in fostering personal development and enhancing their capacity to cope with more challenging situations at home. Parents, and those supporting siblings should be alert to their need for personal space and time away. Opportunities for siblings to engage in typical life experiences should mirror those of their peers. This is particularly important during adolescence, as it enables children and young people to develop greater independence and self-expression. While this aligns with normative life course development for all children and young people, it appears even more critical for those who have a sibling with ID, given the potential for increased complexity in their lives.

The C&YP were very proud of their siblings with intellectual disabilities, most of the participants enjoy spending time with their brothers and sisters. They value sibling companionship, having shared interests, and engaging in activities as a family. The participants recognise their brother or sister's needs related to ID as an integral part of who they are and value their individuality. Their focus for change is on improving support and reducing some of the challenges they experience. They expressed a desire for greater understanding and acceptance of their sibling with ID, and of their family, from others. They recognise and are hurt by the judgements of others outside the family. This indicates the importance of research such as this study in influencing policy and practice, and in raising awareness of ID and the experiences of siblings and families. It also highlights the need to advocate for greater tolerance and understanding in society, and to support equitable opportunities, experiences, and better outcomes for children and young people with intellectual disabilities, their siblings, and their families.

The findings also reveal how discerning the C&YP are. Siblings recognise that some of their experiences correspond to those of their peers, yet they also acknowledge important differences and advocate for greater awareness of these distinctions. Siblings shared examples of divergent experiences, including assumptions frequently made by others and situations where they were at risk or subjected to verbal or physical harm by their sibling with intellectual disabilities. These aspects were described as particularly challenging to manage and potentially more disruptive to their lives.

Siblings were proud to share their knowledge for this study. They all emphasised that research exploring their lived experiences of ID as siblings is important and has been largely absent from their previous experiences. The C&YP were motivated to share their understanding and

contribute to knowledge about siblings' experiences of ID, with the aim of informing and enhancing the experiences of other siblings in the future. They readily engaged with the research and demonstrated thoughtful considerations not just about themselves, but also considering how ID impacts their brother or sister, as well as their parents. They recognise that they all made sacrifices as a family. The siblings acknowledged that, at times, they felt their needs were de-prioritised. Most of the participants framed this in a mature understanding of the pressures on their parents, recognising the unavoidable nature of these circumstances relating to their sibling's ID and associated health and care support needs. Yet they were conflicted at times feeling left out and expressed a degree of loss in their relationship with their siblings, parents and wider family. It is important to note that all the participants in this study had apparent stability in their family life. Their parents were the gatekeepers to their involvement in this study. Several of the participants were linked to support groups and their engagement with the research indicated an existing recognition in their families, of the impact of ID for siblings. Future research of more diverse familial circumstances is indicated to explore wider application of these findings.

The C&YP expressed a sense of optimism for their future and that of their siblings with intellectual disabilities. The chronological age of the participants was acknowledged as a factor that may have determined their perspectives of the future. Only one of the participants spoke directly about a potential caring role for their sibling in the future. This was framed as part of their future ambitions and desire to provide support for their sibling and their family. Participants reflected a degree of uncertainty about their futures, which may relate to their age and developmental stage as C&YP, with most being in adolescence, a life stage characterised by change, identity formation, and the pursuit of self-determination. Given the potential for the sibling relationships to be lifelong, it is important to encourage age-appropriate and timely

discussions that provide opportunities for shared understanding of parents' and siblings' intentions, as well as the wishes and aspirations of the C&YP with ID. Such dialogue is a key consideration for parents, families, and professionals supporting them, as it promotes a shared understanding of their experiences and expectations.

The following section considers new knowledge that emerged from this study, considering potential integration and impact on practice and policy in supporting C&YP who have a sibling with ID and their families.

7.2 Knowledge contribution, application to practice and policy indicators

This study adds to the current body of knowledge contributing a new concept of 'assumptive overshadowing'. The concept acknowledges the coexistence of strengths and vulnerabilities in the experiences of C&YP who have a brother or sister with ID. In addition, a three dimensional 'droplet model' (see figure 6.1) was developed offering a visual tool to guide and support those working with C&YP who have a sibling with ID. The 'droplet model' provides a framework to describe and explain siblings' individual, and inter-relational experiences. The model offers professionals working with C&YP the opportunity to explore their context and the potential for 'assumptive overshadowing' of siblings vulnerabilities, strengths and resilience. Affording siblings' agency to co-produce the story of their experiences towards more holistic understanding, and the provision of more individualised and appropriate support towards better outcomes. The following sub-sections outline the application of the concept of 'assumptive overshadowing', and the 'droplet model' and their potential contribution to health, education and social care professional practice, along with suggested policy indicators, to inform support for siblings.

7.2.1 Assumptive overshadowing, application to practice

In this study, siblings were the primary authority of their experience of ID, however the findings suggest that their knowledge, needs and attributes are often overlooked. To inform and alert professionals and families themselves to this potential, a new concept of 'assumptive overshadowing' was introduced. This concept recognises that siblings' experience of ID and impact may be missed, exposing them to possible misunderstandings, risks, and less favourable experiences and life outcomes. Understanding this concept is amplified, given the co-existence of vulnerabilities for siblings, while concurrently acknowledging their unique insights, personal resources, and resilience, that may also be overlooked. Given the power imbalance that exists in the lives of C&YP, recognised in policy and practice guidance, professionals working with families should explore the potential for 'assumptive overshadowing' to inform a more inclusive and objective 'whole family' approach when assessing their needs. By facilitating the opportunity for them to share their unique experiences of ID, a more balanced and holistic understanding of siblings' and their family's experiences of ID is reached. From this more informed perspective, timely and appropriate interventions and support can be offered and co-designed by enabling siblings' agency. In addition, the concept encourages professionals to question and challenge potential unconscious biases in their own interpretations, as well as in the design, practice, and delivery of health, education, care, and familial support services.

Considering the potential for assumptive overshadowing of siblings' experiences of ID, the idea of a three dimensional 'droplet model' emerged to support a contextualised assessment of siblings' needs more specifically, when working with families who have children with ID. The application of the 'droplet model' (figure 6.1) to professional practice is suggested in the following sub-section.

7.2.2 Applying the ‘droplet model’ to professional practice

The ‘droplet model’ (figure 6.1) provides explanatory and exploratory visual guidance, i.e., a lens through which professionals are directed to more readily identify siblings’ individual and interconnected experiences of ID. The model promotes a systemic approach that remains sensitive to individual perspectives, for example by considering the potential for assumptive overshadowing, supporting age-appropriate engagement, and addressing issues such as accessibility, socio-cultural context, timely involvement, and differential power and agency for C&YP. It also explicitly directs attention to siblings’ unique experiences of ID, thereby addressing a significant gap in current practice. This enables tailored interventions to be co-designed with siblings, while also benefitting family understanding, relationships and outcomes. The ‘droplet model’ is not intended as a one-off linear approach, given the dynamic nature of C&YP’s development, and families experiences over time. The model recognises that further life changes and impact will present as a continuum over their life course. This is particularly relevant given the findings identified life transitions impact C&YP, with important milestones requiring a shift in family relationships and dynamics. The ‘droplet model’ is designed to be revisited in a ‘cyclical’ approach, in collaboration with the C&YP, as additional situations and experience occurs, resonating with Bronfenbrenner’s concept of development of the person-process-context-time (Hayes et al., 2022).

From the point of diagnosis of ID, a multiplicity of professional services may be involved with a family. The application of the ‘droplet model’ may be helpful for nurses working with people with intellectual disabilities, as well as for nurses and health professionals in broader contexts, health visitors, school nurses, teachers, social workers, and those in early years settings. It foregrounds a whole-family perspective from the outset to inform understanding, optimise assessments and outcomes, and support children and young people with ID, along with their

siblings, parents, and families, regardless of the specific role the service or intervention plays. In this way, a co-designed story of siblings 'experiences of ID can be shared within and across different professional services and environments, within their home, at school, and in other services, to inform coordinated care and optimise support for siblings and their families.

Enhanced directives of adopting a whole family approach in assessment and supporting the needs of families are evident in UK policy and practice guidance. However, the focus is often on C&YP with identified needs, such as ID, or emphasis on defined roles for their siblings, such as C&YP being identified as young carers. Service structures and pressures often result in interventions based on assumptions of deficiencies and need or are directed toward those already connected to a system of services or network of support. Considering the wider context of C&YP's experiences as siblings', exploring their attributes, and identifying their specific needs has less prevalence, even in family focused approaches. Applying the 'droplet model' directs an explicit engagement with and recognition of siblings' unique perspectives. The model provides a structured means of engaging in dialogue with siblings and their families to explore and consider their experiences of ID and their impact, contextualised within the reciprocal responses of the whole family. Adopting the 'droplet model' creates opportunities to identify and address siblings' particular needs, thereby enhancing holistic perspectives and informing comprehensive, whole-family assessments.

7.2.3 Wider application of the 'droplet model'

Core principles of the 'droplet model' see each person as unique, while recognising that their experiences are interconnected within their familial relationships. Offering visual prompts and guidance, the 'droplet model' may be adapted to focus primarily on the needs of other family members, including the person with ID, as part of wider family assessments. This positions the

term intellectual disabilities as a phenomenon impacting everyone in the family, supporting a systemic approach, rather than being solely embodied in the person with ID. This is empowering for the person with ID, all the while not denying ID as an integral part of their identity. This approach acknowledges shared familial impact and experiences of ID, providing opportunities to develop co-authored narratives and solutions. This has the potential to build collective capabilities and capacity in families, to help them in manage difficulties, address shared challenges, engaging their mutual resources and resilience. This is important for C&YP in the here and now and, given the longevity of the sibling relationship, in supporting the likely interconnection of their shared futures and valuing their unique sibling relationships, a strong finding that emerged from of this study.

Applying the 'droplet model in school environments may have value, given that this is an important primary system for C&YP outside of their family. By engaging C&YP collectively at school and facilitating open conversations about ID, a broader shared understanding may emerge. This offers an opportunity to explore the impact of C&YP's responses, develop their awareness and insight into the effect this may have, either directly or indirectly, on those around them. This has relevance to the findings, given siblings' experiences of the judgements and lack of understanding of others outside their families. Engaging with C&YP to develop their early understandings of ID aligns with this study's findings indicating the importance of early exposure to knowledge and information. This also connects with the value the siblings placed on friendships with C&YP who have more informed perspectives and understanding of ID. Knowledge exchange with peers was powerful for the C&YP, leading to better experiences in establishing friendships, building confidence, fostering acceptance through shared understanding of ID, and drawing on their unique knowledge and experiences of being a sibling.

In summary, by adopting the 'droplet model' professionals working with families are directed to consider the potential for 'assumptive overshadowing', building a more holistic understanding of the individual's and their family's experiences of ID. Recognising differential power dynamics, potential biases, and C&YP's vulnerabilities, while acknowledging their capacities and unique insights as siblings, enables a more nuanced and enhanced understanding of families experiences of ID, guiding targeted interventions and optimising outcomes for siblings and their families.

7.2.4 Indications for policy

Family policy in the UK indicates the importance of enabling C&YP's agency over their own lives. However, policy and professional guidance tend to focus on the immediate assessment of the needs of the C&YP with ID, their parents' capacity and support, or situations of care orders and protecting the rights of siblings' relationships in more extreme circumstances of family breakdown or challenges. While guidance recommends including siblings' experiences in overall family assessments, there is little or no policy requirement to do so. Equally there is limited explicit acknowledgment of the longevity and therefore potential lifelong importance of sibling relationships for C&YP with ID and their typically developing siblings. Future family policy in relation to the assessment, care and support of C&YP with ID, should explicitly factor a required exploration of siblings' experience of ID, and their relationships. This is relevant not only in relation to potential future care or guardianship roles for siblings of C&YP with ID but also in the early years, where timely and appropriate engagement with siblings is essential to promote shared understanding and recognition of the interconnected nature of experiences of ID across the family from the outset.

Services are often pressured to assess the presenting problem for C&YP with ID, providing support for them directly and for the parents. Professional services may engage with families at times of challenge or crisis, or for a limited time, in these circumstances siblings' needs may be missed. UK policy advocates early intervention, health promotion, and person-centred care for people with ID. Future policy and guidance for families of C&YP with intellectual disabilities should require early conversations and attention to siblings' experiences. Furthermore, family assessments and interventions could be strengthened by explicitly recognising, from the outset, the potential for siblings to assume some level of responsibility or oversight for a brother or sister with intellectual disabilities in the future, and by supporting families to explore this possibility. The provision of information and early support will inform collective views, alleviate misunderstandings and promote better outcomes for siblings, their brothers and sisters with ID, and their family.

7.3 Final thoughts

Siblings' experience of ID is often a secondary consideration in the overall assessment of needs for families with C&YP with ID. In conducting an IPA of siblings' experiences of ID, this study further enhances the understanding of this phenomena. A key strength of this study lies in drawing insight from the direct interpretative accounts of a purposive cohort of siblings, thereby contributing their meaning-making and unique perspectives to the existing body of knowledge. Analysis and interpretation were strengthened by framing these within the established theoretical frameworks of family systems theory and Bronfenbrenner's bioecological model of human development. Through developing the concepts of 'assumptive overshadowing' and the 'droplet model', this study makes new and significant contributions to the body of knowledge, enhancing the understanding of siblings' experiences of intellectual disabilities. These conceptual innovations have the potential to inform and strengthen systemic

approaches to professional practice by offering holistic insights into both individual experiences and the interconnected dynamics within families. It is hoped that the findings and insights from this study will inform and strengthen the support offered to siblings, their brothers and sisters with ID, and their families. Notably, the findings underscore the importance of recognising C&YP not merely as passive recipients of information and support, but as active agents with capacities and distinctive insights shaped by their lived experiences as siblings with a brother or sister with ID. They highlight the value of acknowledging C&YP as co-contributors to whole-family perspectives and as holders of unique knowledge about their collective experiences of living with children and young people in their family with intellectual disabilities.

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APPENDICES

APPENDIX ONE: Literature review summary, collation and coding of themes,

using Sample, Phenomena of Interest, Design, Evaluation, Research (SPIDER)

	Author & Publication Date	***Sample* - Participant Group**	***Phenomena of Interest* - Title**	***Design* - Methodology**	***Evaluation* – Quality/Validity**	***Research* – Key findings, Emergent Themes**	***Research* - Gaps Identified and consideration for future research**	***Theme Coding***
1.	Aksoy & Bercin Yildirim, (2008)	16 Special needs schools or rehab centres, 228 children with siblings with range of ID.	A Study of the Relationships and Acknowledgement of Non-Disabled Children with Disabled Siblings	Descriptive study using survey model of relationships of 10-17-year-old with their sibling. Ankara (Canada)	This was a broad sample, three forms were used to collect data: Attitudes towards Disabled Sibling (ATDS) Questionnaire, Attitudes towards Disabled Person (ATDP) questionnaire, and a personal data from. Data from ID siblings' files and information from mothers was also collected. Paper does not explore the ethical issues and is limited in the scope of literature used in conclusions and	Study concluded children display positive attitudes to their siblings in the family environment but less positive towards other people with ID. The degree of disability and diagnosis is a factor in their attitude and experience. The study included siblings for children with learning. disability, mental retardation, cerebral palsy, mental-motor retardation, Down's Syndrome or autism.	No direct sibling narrative. The paper identifies the need for further studies to explore the type and level of ID and the sibling relationship. The authors also note the need for comparative studies of siblings of disabled and non-disabled siblings.	(i) (ii) (iii)

					discussion. Value of including a broad range of ID this enable comparisons to be made of different responses-based ion diagnosis.		They suggest studies with larger samples would be helpful and more longitudinal studies.	
2.	Benderix, & Sivberg, (2007)	14 siblings from 5 families with siblings with 'mental retardation' and autism (Sweden).	Siblings' Experiences of Having a Brother or Sister with Autism and Mental Retardation: A Case Study of 14 Siblings from Five Families.	Qualitative content analysis	Small sample size. Focus on families already in crisis. The limitations of the study were not well explored, but the discussion referenced previous studies and identified areas of emergent considerations in terms of early intervention for parents, sibling peer support and recognition of the subjective experience of each sibling and the difference the level of ID and combination of	1. Precocious responsibility 2. Feeling sorry 3. Exposed to frightening behaviour 4. Empathic feelings 5. Hoping that the Group home will be a relief 6. Physical Violence made siblings feel unsafe and anxious 7. Relationships with friends were negatively affected	Focus was on families in crisis so broader participant cohort would be of value for future research. Also, before families reach crisis.	(i) (iii) (v) (vi)

					issues i.e. ID and autism can have on the sibling experience.			
3.	Begum, & Blacher, (2011)	70 Sibling dyads. Each dyad consisted of one 12-year-old with or without ID.	The sibling's relationship of adolescents with and without intellectual disabilities	Cohort identified and analysed using data from a sub sample of a larger longitudinal study, that used a number of tools to measure intelligence, behaviour, sibling relationship, social skills ratings and child behaviour. This study aimed to address analysis in controlling child characteristics and same sex dyads as inclusion criteria to address deficits in this area for other research. Three research questions, were applied 1. Group differences of warmth, conflict	Value of the study addresses the impact of ID siblings on TD siblings and vice versa. The authors provide good discussion of the data and a broad range of literature is included in their review. The limitations of the study are identified referenced as sample size and reliance on mothers' reports.	More positive, warmth in relationships with same sex dyads between typically developing siblings (TD) and sibling with ID. Authors report this may be related to more care giving role and awkwardness of this with opposite sex dyads. Birth order does not affect power status in TD-ID dyads. Though this is questioned due to the sample size. Conflict occurs for both TD and ID siblings however for TD siblings this can be related to internalised behaviours for ID this can be related to external behaviours. The study showed that warmth and conflict did not	No sibling self-reports. Mothers were used as sources of data. They suggest further longitudinal studies would be of benefit.	(i) (ii)

				rivalry, status or power for siblings based on birth order, gender, and same sex or opposite sex dyads. 2. How these factors related to behaviour problems. 3. How these factors related to social skills of siblings with and without ID.		relate to social skills in either group. The study demonstrates differing findings comparative to other studies, citing their reliance on mothers reports only for this aspect of the data.		
4.	Burke, (2010)	Paper drawn from a pilot and two studies conducted by the Author in 2000 (pilot) 2003 and 2007. 116 families, 344 children or whom 118 had a disability	Brothers and Sisters of Disabled Children: The Experience of Disability by Association	Both quantitative and qualitative approaches used. First study pilot as outlined below Burke & Montgomery, (2000), with follow up interviews with 22 families. Second study in two stages first a survey response from 60 families with follow up interviews conducted with 15 families in the sample.	The authors discuss the validity of the data. They have used both quantitative and qualitative methods. The two studies were located in the North of England but sought to explore different geographical area. The sample size is robust in both studies. There is an opportunity to ask parents but also	1.Expressions of regret 2. Limited opportunity to do things together 3. Caring responsibly of siblings 4. Benefits and life restrictions 5. Achieving best outcomes for siblings Both positive and negative experiences identified. Need for Professionals to be specifically aware of sibling needs in formal family	More work needed to explore cultural and socio-economic difference and impact on experiences.	(i) (ii) (iv) (vi)

				First cohort majority of siblings attended a support group, 56 families. In the second study the majority did not attend any support groups. 60 families.	question siblings directly.	assessments is indicated by this research so further work required to validate this. Phrase of 'disability by association' emerges.		
5.	Burke & Montgomery , (2000)	Pilot of study. Accessed eight Families. Four sibling interviews	Siblings of Children with disabilities	Pilot element of a three-stage research 1. Pilot questionnaire 2. Sample of families from groups of 55 with children attending at sibling support group 3. Comparative data of siblings not attending a support group.	Valuable as a pilot. Paper discusses the use of the pilot and notes the need to explore wider cohort and gender issues.	Both positive and negative experience of siblings Caring responsibilities noted and gender difference identified as worthy of further exploration Value and need to a sibling support group. Self-support purporting isolation for families. Siblings receive less parental attention and share caring responsibilities. Gender imbalance in caring? Sibling support group role. Sibling needs important consideration for service providers.	Need a broader cohort, but this is proposed as the study is a Part 1 pilot. Gender issues to be considered in future research.	(i) (ii) (vi)

						Need to explore the "neverland" views of children with ID and different 'future expectations'.		
6.	Cooke, Smith, Miguel, Staton, Thorpe & Cawla, (2023)	Eleven siblings aged 5-15 yrs. 11 parents from 8 families with a child with Down's syndrome in their family.	Siblings' experiences of sleep disruption in families with a child with Down's syndrome (DS). Exploring what it is like for siblings with a brother or sister with DS and sleep disruption, how this affected siblings, and their families. Study conducted in Australia	Part of a wider mixed methods study on '*Sleep Difficulties in Children with Down's Syndrome: An Evaluation of Parent/Carer and Family Quality of Life' with 31 families.* This is a qualitative study, with 11 families, conceptualising children as social agents, seeking to elicit their experience and perception of sleep disruption experienced as a result of having a sibling with DS who experiences sleep disorder/ disruption.	Small sample of 11 families, though appropriate for an in-depth exploration of this cohort. Authors acknowledge sample size, cohort mainly English speaking, primarily nuclear families. Parents were interviewed as well as siblings. All interviews were conducted via 'zoom'. Parents provided consent; siblings affirmed consent verbally. Parents sat with younger siblings when interviewed. Older siblings chose to be interviewed alone.	The results present two domains, (1) Siblings experience of sleep disruption; (2) Parents experience of sleep disruption. Five themes emerge: (i) siblings experience adverse effects from sleep disruption; (ii) siblings view sleep in a relational way; (iii) siblings cope with sleep disruption. (iv) Parents can underestimate siblings' sleep disruption; (v) parents are uncertain whether siblings' symptoms result from sleep disruption or other causes.	This study addresses a gap as a first known study of its kind. Sibling accounts are valuable as an approach in future research. More research is needed into the experience of siblings and families from more diverse cultural backgrounds and family structures.	(i) (v)

				Semi-structured interviews undertaken, data analysis through reflexive thematic analysis. .	Reflexive thematic analysis involved several authors undertaking different aspects of the analysis. A comparative approach was used to explore sibling and parent responses from the same families. Reflexivity of the authors is attended to, conversations between the authors and recognition of professional expertise e.g., one had expertise in sociology of childhood, one worked as a clinical nurse, with sleep expertise, utilized in reviewing the data, and developing the themes. The authors are attentive to wider literature and	The authors note this is the first study of its kind. The results point to the importance of family dynamics and considerations for clinicians in supporting C&YP with sleep disruption, noting this requires a whole family approach to maximise support for siblings with DS, their brothers, sisters and parents. Parents underestimate or are uncertain of the impact of sleep deprivation on their C&YP without DS in the family. Emphasises the value of sibling self-reports in informing future practice and further research.		

					relate this in the discussion. The study is considered unique in exploring sibling experience of sleep deprivation for this group with a sibling with DS.			
7.	Correia, & Seabra-Santos, (2022)	Six participants, who are siblings with a brother or sister attending one specific day care centre. 5 sisters and one brother age range 17-45yrs. (3 of the siblings were 17-18yrs included the one male participant).	"I Would Like to Have a Normal Brother but I'm Happy With the Brother That I Have": A Pilot Study About Intellectual Disabilities and Family Quality of Life From the Perspective of Siblings.	Qualitative study. Participants recruited from a day service. In-depth semi-structured interviews conducted to elicit (1) sibling experience, (2) sibling and (3) family quality of life. Data gathered, transcribed and results presented as a themed analysis divided into (1) experience of sibling, (2) sibling quality of life and (3) family quality of life.	This was a small sample of six siblings. There was quite a diverse age range, so a merger of adolescent and adult views, difficult to differentiate sibling perspectives at different life stages. The siblings were recruited from one service. The author was involved as a clinical psychologist in supporting the participants' brothers and sisters with ID so a potential for inside knowledge and bias. This	Results are discussed under three main aims of the research. (1) Experience of sibling discussion of six themes: *the reaction when they found out their sibling had ID; process of acceptance; how having a sibling with ID influenced their lives; differences that the ID brought to their siblings with ID' life and to their family life; future.* (2) Quality of life as a sibling themed under three headings: *wellbeing of the*	Highlights the role of the extended family in particular siblings-in-law, who were identified as a core support group for siblings in later life. Acknowledges the life-long relationship of siblings extended beyond parental life span, therefore need for	(i) (ii) (iii) (v) (vi)

		Their sibling with ID ages ranged from 15-49- diagnosis of Down's syndrome (2), Cri-du Chat (1), Fragile X Syndrome (1) Cerebral Palsy (1) and Autism (1) Study in Portugal.			is attended to in the methodology with others being co-opted to validate the approach and findings, but this is not discussed robustly. Gender is weighted to female siblings, the context was limited being recruited via one service, in one location.	*sibling with ID; private time; family relationships*. (3) Family quality of life seven themes: *family relationships; acceptance of disability; health, influence of values; financial wellbeing; support from others; leisure activities.* The research offers valuable insight for this cohort, particularly the potential influence of religious beliefs, albeit for one Christian (Catholic) faith group. Faith is often omitted in the literature. A new domain for family quality of life emerged with *acceptance of ID* as a factor impacting family harmony and development, close alliance of parents' response	future research eliciting siblings' perspectives to inform programmes of early intervention, preparation for the future and wider support for people with ID, their siblings and families.	

						influencing siblings' response and acceptance and subsequently whole family experience.		
8.	Freitag, Motta, Milbrath, Bazzan, Debatin, & Gabatz, (2022)	20 Siblings aged between 7 and 18 yrs., (10 children and 10 adolescents), who live with their sibling with ID' aged between 3 and 20 yrs. Study in a municipality of Southern Brazil.	"He is normal" phenomenological considerations of child/adolescent's perception of their disabled sibling.	Qualitative research study, grounded in hermeneutic phenomenological approach. Study to elicit the experience and meanings attributed by the siblings, asking the question "Tell me how you see your brother or sister". Following the phenomenological interview, interpretative hermeneutics was used to analyse the data, and two units of meaning were identified and subsequently discussed by the authors 1) "He is	The authors note the sample of 20 participants enabled the researchers to reach "sufficiency of meaning" in interpreting the data. Qualitative interviews were carried out in own home or in a private room in the Association of Parents and Friends of Exceptional Children (APACE). All the families were accessing rehabilitation/support/ treatment via APACE. Interviews were recorded, transcribed, checked by the author and a third-party researcher.	The research identified siblings positive view of their sibling; in that they accept the person for who they are. The Authors note from Heidegger's perspective, the sibling had ID, their family have only ever known them with ID, so this is considered their norm, their normative existence. There is an acceptance of the person as they are. The paper notes the impact of the subjectively of the person, the family and their social context, in particular, the parents' perceptions influencing that of the siblings. None-the-less the research highlights an acceptance of the sibling	While the discussion in the paper draws on literature from the experience of siblings with cerebral palsy, and Down's syndrome, there is a need for further research that identifies if there are differences between diagnosis. Religion and religious beliefs of participants were referenced in the results, but no real discussion	(i) (ii) (iii) (iv) (v) (vi)

				Normal", 2) "He is Special".	Ethical protocols were followed and noted.	with ID as "He is Normal", while understanding the "He is special" uniqueness of their sibling, i.e., there is no denial of their ID and some of the challenges and discrimination they and their families may face. The paper does discuss societies constructs of disability and the lack of acceptance and stigma ascribed by others, but it is overall positive about siblings' experience and perception of their sibling with ID.	on whether this influenced responses, therefore this requires further exploration. The authors highlight the limitations of the paper suggesting further research is needed to include the views of other family members, not only siblings.	
9.	Giallo, Gavidia-Payne, Minett & Kapoor, (2012)	52 siblings aged 10-18yrs with brother or sister with a wide range of disability types, defined as ASD, Intellectual disabilities	Sibling Voices: The self-reported mental health of siblings of children with a disability. The study aimed: to report on siblings' self-reports of mental	Participants were recruited via organisations supporting families of children with a disability via email and telephone contact. Participant families were accessed via	Descriptive statistics were analysed by gender exploring the SDQ sub-scales of participant responses. I.e., emotional symptoms; conduct problems; hyperactivity; peer problems; pro-social behaviour; total difficulties.	Results are discussed and related to other relevant literature and wider factors impacting experience. E.g., noting they could not discount that some siblings themselves may have a degree of disability not reported by parents.	Focused on one means of siblings' self-report, further research including self-reports advised. Research was not completed with direct contact	(i) (iii) (v) (vi)

		and cerebral palsy. Age range of sibling with ID was between 5 and 30yrs. Undertaken in Australia.	health; to compare sibling mental health with expected norms; to identify socio-demographic and disability characteristics associated with sibling mental health difficulties.	parents and consent provided. Parents were sent and completed demographic questionaries and provided information of the nature and severity of the disability of their child. Siblings completed a Strengths and Difficulties Questionnaire -Self Report Version, (Goodman 1997), these questionnaires were then returned and analysed by the authors.	Results demonstrated that overall siblings reported good mental health, with some more emotional and conduct or behavioural difficulties reported. Siblings do not experience lower social competence or more peer problems. Female participants showed greater pro-social behaviours. Scores for siblings in the 'non-clinical, at risk and clinical ranges' categories of the SDQ were reviewed, as compared to expected normative population statistics. Siblings scored higher on total difficulties,	The authors note the sample size was small for this type of research, with mainly two-parent English speaking families. While the study attempted to include socio-demographic and disability characteristics, the small sample size did not enable sibling adjustment related to their sibling's disability type to be explored, only gender differentiation was explored. Research contributed to greater understanding of self-reported experience of sibling mental health in Australia. Points to the importance of family perspectives in support for people with ID and their whole family. Valuing the lifelong nature of siblings relationships and consideration of health,	with the siblings by the researchers. Parents' involvement and the involvement of participant families with existing support agencies may limit the scope of the research and application thereof. More longitudinal research is indicated.	

					emotional symptoms, conduct problems and hyperactivity-inattention. Logistic regression was performed to identify demographic and disability characteristics. None of the demographics of sibling age, gender, position in family, family structure, language spoken, number of children, or sibling with ID characteristics significantly predicted being in the 'at risk' range on any of the sub-scales.	wellbeing, care needs of their siblings throughout the life course is a significant consideration from the research.		
10.	Giallo & Gavidia-Payne, (2006)	49 Siblings and parents.	Child, parent and family factors as predictors of adjustment for siblings of children with a disability	Surveys sent in the post to families following advert in fifteen disability service providers. Mothers and siblings completed the survey varied tools	The paper gives a robust review of the validity of the research and highlights a number of areas for consideration. Limited sample size for quantitative approach.	Internalised problems are associated with having a sibling with ID. Parent stress and family functioning impacts on the sibling adjustment.	More research needed into the value of sibling support groups.	(i) (v) (vi)

				were used to support the study, e.g. A strengths and difficulties Questionnaire, The Perceived Stress Scale, The Parent Behaviour Questionnaire.	Families volunteered. Mixed disability groups. Self-selection may already suggest concerns or challenges. Research reports siblings completed the tools themselves, but other measures used relied on parents mainly Mothers to complete. Reports were sent out in the post. Cannot validate the sibling self -reports or parental influence.	Sibling support groups or interventions may be beneficial but can also be stressors in themselves. Positive family experiences important in enabling positive sibling adjustment. Parent stress and family conflict negatively impact on siblings. There is an inter-relationship in this. Family resilience overall supports resilience of siblings. Routine helps adjustment for siblings. Good communication and problem solving modelled in the family supports better adjustment for siblings.		
11.	Graff, Mandleco, Dyches, Coverston, Roper & Freeborn, (2012)	21 adolescent siblings of children with Down's Syndrome and additional health needs	Perspectives of Adolescent Siblings of Children with Down's Syndrome who	A qualitative descriptive design was used. One to one interview was conducted. Parent's completed family demographics from	Noted the limitation in terms of 11 families in the research 23 siblings. All white middle-income families in one area/state. Comment that researcher not known to the	Siblings learn about the brother or sisters ID from parents. Both positive and negative experiences were represented.	Research should focus on different socio economic and cultural diversity.	(i) (ii) (iv)

		and caregiving demands.	have multiple health problems.	The Child with Special Needs Description. Tool created for the study. NVivo * was used and an inductive analysis located themes. Other investigators read the transcripts and suggested modifications to themes. Data saturation was assured by re-examining transcripts until no new data emerged.	siblings, responses may be influenced by 'social desirability".	Most focused on positive aspect of having a sibling with ID and would not change their experience. They acknowledged the caregiving needs in the family and the impact of this and the long-term needs of their sibling.	Gather data of time-longitudinal, also compare differences across siblings in the same family.	
12.	Hames, (2008)	Longitudinal study of 10 families (variation of families and sibling number of time). conducted over 12-year	Siblings' Understanding of Learning Disability	Longitudinal qualitative study. Used content analysis. And identify emergent themes.	Positive that this is a longitudinal study. The Author is honest about missed opportunities in the research process. Of note that paper identifies that ethics approval could not be sought due to appropriate procedures not being in place when	A number of themes emerged, listed under Key stage Development. Pre School Shared experiences Older child as a baby doll Care giving behaviours Early changes of behaviour and awareness of difference	Notes the need for further research to include gender and age considerations for siblings, socio-economic status of the family and ethnicity.	(i) (iv) (v)

		period. 11 siblings interviewed after 6 years into project. Interviews annually.			this started 12 years earlier. Though written consent was gained from the families to complete and disseminate the research.	Early comments and questions about disability From babies/dolls to human beings. Key Stage 1 Social Awareness Understanding of relative ages Disability versus illness Being treated more as a human being Key Stage 2 (7-11yrs) Awareness of social aspects of disability. Able to describe the impact of ID Knowledge of ID, social awareness and thoughts for the future Noted parents valued the research, being involved and an opportunity to help other parents. This was not noted by the Author in terms of sibling experience?	Also, to consider wider systems influence e.g. wider family influence and support mechanisms for the family.	

13.	Hayden, Hastings & Bailey, (2023)	500 primary caregivers of siblings in families where at least one child between 4 yrs. and 15 years 11mths, has ID. Study conducted in the UK.	Behavioural adjustment of children with intellectual disability and their sibling is associated with their sibling relationship quality. Explored whether in sibling dyads, the behavioural adjustment of both siblings with and without ID is associated with quality of sibling relationship. - Addressing reciprocity of experience of both sibling with ID and their brother or sister. Seeking to	Quantitative study. Primary caregivers completed the Strengths and Difficulties Questionnaire (SDQ) (Goodman 1997). Externalising problems, internalizing problems and pro-social behaviours were scored. In addition, the Sibling relationship quality Questionnaire was used to assess the quality of sibling dyad relationships, with 10 of the usual 39 items included to reduce participant burden. Primary caregivers responded on a 5-point scale from *hardly at all…to extremely much.*	Full ethics approval and consent sought. Cohort of 500 siblings. Families recruited from a UK wide study wave 1 1184 primary caregivers. Inclusion criteria for this study, 500 sibling pairs, one with ID, age range 4 -15yrs. Closest in age sibling included. Surveys completed online and postal surveys offered. Only primary caregiver completed questionnaires, limitation. Analysis measures and are outlined. Control variables were identified from existing research, i.e., sibling birth order, gender, family poverty,	Results show the behaviour of both children in the sibling dyad is associated with sibling relationship quality, validates the reciprocal nature of their relationship and interaction. Children with ID with higher pro-social behaviour may have milder ID, more social skills, therefore engage with siblings in a more equal way being so both engage in more antagonism-quarrelling and more intimacy-companionship at the same time, in their relationship. Older siblings may take on more caring role, more responsibility, may disengage or avoid antagonism, at the same time this may mean this avoidance leads to less exposure in the relationship	Longitudinal data required to understand sibling relationships over time. Parcelling was used, authors suggest using different measures of sibling relationship quality in the future, particularly considering one sibling has ID. Age-related analysis not just older or younger data should be explored, e.g., age gap.	(i) (ii) (iv) (v) (vi)

			address deficient where assumptions of sibling with ID impacting relationship of their brother or sister and assumptions this is often a negative impact.		whether children had ID diagnosis of Down's syndrome or autism. Measurement models and structural models are identified with clear tables to show process of analysis. Parcelling was used to ensure a 'fit' referred in literature (Matsunaga 2008).	and less intimacy-companionship. Both elements of the relationship are found not to be binary constructs I.e., both can exist for both siblings and simultaneously. Both siblings' behaviours have BOTH positive and negative impact on one another i.e., the reciprocity of their relationship. Findings indicate that systems theory alone can adopt a focus that assumes negative impact of sibling with ID on the dyad. Important to explore systems *and* social learning or other theories to support broader interpretation and focus on the whole family system and the reciprocity of sibling dyad relationships.	Primary caregivers were the participant respondents, should include self-reports from both siblings with and without ID in the family, and others' contributing. Authors point to value of future qualitative research. Apply different theoretical frameworks, e.g. systems and social learning theory to inform complex and	

							reciprocal nature of relationships.	
14.	Hayden, Hastings, Totsika, & Langley, (2019)	Secondary analysis of the "Millennial Cohort Study (MCS)" UK longitudinal birth cohort study. 257 children identified as having ID, having at least one older sibling aged between 5-15yrs.	A Population-Based Study of the Behavioural and Emotional Adjustment of Older Siblings of Children with and without Intellectual Disability. Aiming to explore if there are group differences in behavioural and emotional adjustment for siblings of children with and without ID; secondly if differences were identified, using correlates from	Secondary analysis of a population-based study. Data was collected from the primary respondent [usually a parent mainly mothers i.e., 99.8%]. The cohort included were the nearest in age older sibling to the child with ID. Comparative demographics were included for siblings with or without a sibling with ID, gender, age, socio-economic factors, etc. Behavioural and emotional adjustment of siblings was measured suing the Strengths and	Ethics approval is noted as being obtained from the MCS study and consent was obtained from the primary caregiver on their behalf and on behalf of the siblings for the current research. Sibling behavioural and emotional mean scores were recorded, considering total behavioural problems, peer, conduct, emotional, hyperactivity and prosocial problems. Elevated SDQ scores were identified for siblings with and without a sibling with ID with	Older siblings of children with ID were 1.5-2 times more likely to have problems in 3 SDQ domains, i.e., total problems, peer and conduct problems. Siblings are an at-risk group. Once additional factors and correlates from the existing literature was considered, the siblings of children with ID group were not at significantly increased risk of behavioural and emotional adjustment issues except for being identified as having higher results in the SDQ domain of hyperactivity.	More longitudinal research needed to explore the broader variables that may impact sibling behaviour and adjustment, i.e., poverty, family status [single parent families], psychological problems for carers and for sibling with ID. Need to consider older and younger siblings and the number of siblings in families.	(i) (ii) (v)

			existing literature, to explore how these relate to sibling adjustment.	Difficulties Questionnaire, administered by the primary caregiver. Socio-economic deprivation factors were included.	comparison results discussed. SDQ is a measure for mental health rather than specifically sibling psychological adjustment, this is a limitation of the study. Limitations as this only sought primary caregiver responses, not sibling reports. Focus was only on older siblings. Relationships may be more positive for older siblings. Authors suggest likely cohort of children with mild to moderate ID as part of MSC capture population.	The authors findings suggest siblings are not at increased risk simply or solely because they have a sibling with ID, but that there are wider factors impacting their experience that are equally applicable to the population of siblings without a brother or sister with ID. I.e., Socio-economic issues for the family, being in single parent households, primary carer experiencing psychological distress, or their sibling with ID having elevated behaviour and emotional problems, these are more likely to impact siblings behaviour and adjustment. Hence sibling behaviour should be considered from a multi-layered systems perspective.	Use of alternate tools to measure sibling psychological adjustments. Sibling self-reports inclusion of others' e.g., teachers to balance interpretations, i.e., not just parental reports.	

						There is discussion about the parent respondent perception of behaviour, i.e., their assessment may be based on comparison to the sibling. With ID, i.e., by comparison the older siblings' behaviour, or hyperactivity is not considered out of the norm range.		
15.	Jacobs, & MacMahon, (2016)	Purposive sample of six participants with a brother or sister with ID attending a specific residential school, in a defined area of the UK. Age range of participants 16-22yrs.	'It's different, but it's the same': perspectives of young adults with siblings with intellectual disabilities in residential care	Interpretative phenomenological analysis (IPA) study. Seeking to explore the perspectives of siblings, adolescents and young adults who have a sibling with ID placed in a residential school.	This is a purposive sample of six siblings. 4 sisters and 2 brothers. The author acknowledges the context of the study, being in one residential school, a small purposive group and given the influence of the researcher and their interpretation. The author previously worked at the school though not at the time of the study and recognises the potential impact of this factor,	As an IPA, the study explores the experience of siblings in a unique cohort and identifies complexity in relationships with some conflicting perceptions emerging, of positive support from residential school, while experiencing guilt of separation. Consideration of future roles and responsibilities are explored, with the potential for the physical distance and separation of siblings in this circumstance, impacting the	No significant recommendations are made for future research. However, the author acknowledges the potential distance of siblings in this circumstance (residential school), so a degree of separation perhaps giving less appraisal to	(i) (ii) (v)

					though this was acknowledged transparently as part of the research design. Limitations of the broad application of the research is noted, given the participant size, context and IPA approach. No breakdown of the ethnicity or socio-economic background of the participants is given.	current appraisal of their future roles and the care needs of their siblings in the future.	the potential realities of future needs of the sibling with ID and the role they might pay therein.	
16.	Kaminsky & Dewey, (2001)	Included as this study investigated children with autism and with Down's syndrome and typically developing siblings. 90	Sibling Relationships of Children with Autism	Observational study. Used a number of tools self-completed by the participants and researchers interview using the sibling-relationship questionnaire, adaptive behaviour questionnaire, Gilliam	Authors comment on moderate size of the sample for this type of study. But it is consistent with other studies of this kind and that is referenced. The age demographic of siblings is noted as many were older and thus the	Sibling relationships in families with autism were characterised by less intimacy, pro-social behaviour and nurturance than those of family with a sibling with Down's syndrome or typically developing siblings. Siblings of children with autism and	More research in socio economic differentiated groups. Need for more gender diverse research particularly for sibling with	(i) (ii) (iii) (iv) (v) (vi)

		siblings between ages of 8-18. Three groups of 30 siblings in each demographic		Autism Rating scale and a demographics questionnaire.	application of finding to younger siblings may be limited. More boys with autism in population impacted on participants with gender imbalance in this group in favour of boys. Same sex and opposite dyads could not be explored. Families were recruited through parent support groups so were already active and already identified the need for engagement this may not be representative of wider population across the three groups. The socio-economic diversity was also restricted. Valuable to undertake comparative study across autism Down's syndrome and TD siblings.	Down's syndrome reported better relationships, greater admiration for their sibling less competitive aspects to relationships and arguments featured less.	autism in the family. More research with younger siblings to test transferability of findings.	

17.	Kao, Romeo-Bosch, Plante & Lobato, (2011)	15 Latino families who had a child with developmental disabilities. Parents (15 mothers 1 father) and 17 siblings (10 girls 7 boys). interviewed.	The experiences of Latino siblings of children with developmental disabilities	Consensual Qualitative Research (CQR) method was used to organise interviews into domains and categories. Researchers worked as a team first pair conducting primary coding. Team developed domains and categories for two randomly selected sibling and parent interviews. Domains and categories were reviewed based on the random sample reviewing coding. General, typical, variant or rare categories were identified.	The study is robust the sample size is consistent with a qualitative study and use of CQR approaches. Authors comment on bias and validity recognising the demographic differences within Latino community. Need to involve Fathers more, research did not differentiate child's ID diagnosis, nor age range so developmental stage and impact on perceptions not captured. Good to have comparative parent and sibling views.	Five domains reflecting communication, relationships and emotional experiences were identified. Sibling communication about disability Sibling-child relationship Sibling-peer relationship Sibling positive feelings Sibling negative feelings Sibling advice question Parent `Interviews Parent-sibling communication about disability Parent explanation about disability Parent perspective on sibling relationship. Parent perspective on sibling feelings.	More research needed into ethnic minority populations. Multiple family members to be included in future research. More qualitative research is of value in growing the body of knowledge to allow subjective perspectives to be obtained.	(i) (ii) (iv) (v) (vi)
18.	Lobato, Kao, Plante, Seifer, Grullon,	100 Latino (LID) and non-Latino (NLID)	Psychological and school functioning of Latino siblings of	Observational controlled study with Siblings parents and teachers completing	Controlled study. Acknowledged limitations in terms of diversity of population.	LID siblings were found to report significantly more internalized and emotional symptoms. They had poorer	Paper notes difference in parent reports and children own	(i) (ii) (iv) (v)

	Cheas & Canino, (2011)	siblings of children with ID age 8-15 years. & 100 Latino (LC) and non-Latino (NLC) control siblings.	children with intellectual disability	standard questionnaires about siblings' emotional and behavioural functioning; sibling school report cards were obtained. Analysis considered parent age and family income factored.	Though the Authors have control groups this was still a local population of a Northwest US state with Latino community from particular geographies. The study addresses gaps in other studies in tacking socioeconomic issues and cultural diversity but equally recognises the diversity within different groups e.g. Latino.	awareness of their emotions and were more reluctant to express these. Separation anxiety disorder scored higher for LID siblings. They experienced more school absence and lower academic performance. The results referenced the socio-economic impacts, LID and families appeared to be more deprived than other families in the study. The study speculated that this may cause greater maternal stress (as Mothers are main carers), more financial hardship so may impact on greater demand to be in caring roles and support needs a more overall family stress in families of LID siblings.	reports. Acknowledges the need for more refined cultural contextualised research, in wider population.	(vi)
19.	Luijkx, Van Der Putten &	Qualitative study using photo elicitation	"I love my sister, but sometimes I don't": A qualitative study	Qualitative study using photo elicitation interviews thematically analysed with domains	Reliability verified with two researchers independently coding the transcripts with 75%	Both positives and negative experience emerged. Negative experience around practical consequences not	Future research should focus on needs of younger siblings.	(i) (ii) (iii) (v)

	Vlaskamp, (2016)	interviews with 19 children ages 6-13 exploring the positive and negative aspects of being a sibling of a child with profound intellectual and multiple disabilities (PIMD).	into the experiences of siblings of a child with profound intellectual and multiple disabilities.	based on Moyson and Roeyers (2012) study. More detailed sub-domains then identified, reviewed and refined coding of sib domains.	reliability. Autor notes the short period of time photos were elicited.	being able to do things with their sibling, sometimes difficult to accept their sibling's disability. Positive experience around joint activities with their sibling and feeling their sibling was content.	Research should explore longitudinal view of young child, adolescent and adult to see if views change over time. Perspective of siblings differs to that of parents, important to ensure sibling views are considered in research and in overall assessment of Family Quality of Life.	(vi)
20.	Macks & Reeve, (2007)	51 Siblings between ages of 7-17 of children with	The Adjustment of Non-Disabled Siblings of	A number of data collection tools were used. Siblings competed Children's	*Paper was included as although ASD was not in the literature search inclusion criteria, this*	A child with autism appears to enhance the psych-social and emotional development of their siblings. However,	Further research to compare parent and sibling responses when	(i) (iii) (iv) (v)

		autism and 35 siblings of non-disabled children and 1 parent of each sibling included. Recruited through Schools and family centres.	Children with Autism	Inventory short Form and Piers-Harris Children's Self Concept Scale. Parents completed the Behaviour Assessment System for Transparent Rating Scales and a demographic questionnaire. Packs were posted to participants.	*emerged as frequently referenced in the hand search of wider literature.* Paper recognises this is a small sample size. Participants were recruited from families already receiving a service of support. Mothers were the only parent respondents so not applicable to Fathers	this is dependent on wider demographic factors. When demographic risk factors increase, (being male, coming from lower socio-economic group, only having one sibling being younger than their sibling with autism.	using same assessment tool for both and where this is the intention from the outset. Research for siblings where their brother of sister with autism is in residential support. Longitudinal or studies to assess adult sibling views of value, given the care giving role and eventual pseudo parental responsibilities.	
21.	Mandleco, & Webb, (2015)	The review included siblings	Sibling perceptions of living with a	Integrated review of 28 studies between 2000 and 2014 of	The authors identify the limitations of the review, notably the literature	The literature was reviewed under four headings:	The authors highlight the need for research to	(i) (iii) (iv)

		between 4 and 21yrs, of papers related to siblings' perception of experience of living with a young person with ASD or DS.	young person with Down's syndrome or autism spectrum disorder/; An integrated review.	quantitative, qualitative, and mixed methods research, exploring Sibling perceptions of living with a YP who has DS and who has ASD.	represented cross-sectional studies, the date range only reviewed 2000-2014, the literature included different methodologies and did not consider how this might have impacted the results. The review did not differentiate the degree of impact of the specific ID, for the YP with ID. The authors note bias potential in the studies reviewed.	Knowledge; relationship with others; emotional reactions; behavioural/personality outcomes. These were compared in the discussion and an overview provided in implications and conclusions. Overall, the experience of siblings had similarities and differences dependent on the diagnosis of DS or ASD, degrees of differentiated experience cited and consideration for professionals (nurses) supporting families in the future was suggested, i.e., to include greater awareness and emphasis on siblings' experience.	explore siblings' perception from their own perspective. They acknowledge the lack of research across different ethnic backgrounds, family type, socio-economic status, education levels. They note further research should consider birth order, age and gender, and comparative studies of parents and siblings' perceptions.	

							They point to an emphasis on studies that identify fewer positive perceptions of siblings' experience, noting a need for research to explain different and more positive perceptions. The body of knowledge would benefit from more longitudinal studies.	
22.	Mascha & Boucher, (2006)	14 siblings from 11 families 10 female and 4 male participants. Age between	Preliminary Investigation of a Qualitative Method of Examining Siblings' Experiences of	This was a pilot study to explore a method to elicit subjective experience and feeling of typically developing siblings with a brother or sister with autism	This is acknowledged as a pilot study and small sample size. Noted that majority of participants were older siblings so the results not applicable to younger siblings.	Both positive and negative experiences expressed. Majority of siblings experience positive aspects in their relationships with their siblings. Most experience negative	More evidence required. Larger sample size.	(i) (iii) (vi)

		11 and 18. !2 older siblings 2 younger.	Living with a Child with ASD		therefore, the Authors are clear about their results being suggestive and preliminary. Nonetheless this does link with other findings in similar more robust studies. The study achieves what it set out to demonstrate the effectiveness of this approach to elicit subjective views of siblings.	particularly around experience of aggression and temper tantrums and explosiveness. Concern also expressed over others' perception of their sibling and experience.	More robust methodology and use of a control group.	
23.	Mazaheri, Rae-Seebach, Preston, Schmidt, Kountz-Edwards, Field, Cassidy & Packman, (2013)	12 mothers and 13 siblings, aged between 12-19 yrs., 8 sisters and 5 brothers of a child with genetically confirmed diagnosis of Prader-Willi syndrome.	"The impact of Prader-Willi syndrome on the family's quality of life and caregiving, and the unaffected siblings' psychosocial adjustment" Study aimed to better understand	Mixed methods study. Using Brief Symptom Inventory; Pediatric Quality of Life Inventory – Parent proxy; PedsQL Family Impact Module; PedsQL Child/Teen Report. And in PWS Interviews – semi-structured interviews conducted	Results from mothers compared with normative data in families without impact of PWS. Comparison of mothers' perception of siblings psychosocial adjustment to a comparative study (Varni et al., 2004) were conducted i.e. families not impacted by PWS, but with children with complex health	*Quantitative results* -Parents psychological health showed increased levels of stress for mothers; -Psychosocial adjustment of siblings, 12 of the siblings reported moderate to severe PTSD in the cohort studied when compared to self-report of siblings in related studies, (Fine 2004) & (Pat-Horenczyk et al., 2007).	Further research required to include mothers and fathers, more diverse populations, potentially different modes of recruitment. Use of broader samples.	(i) (ii) (vi) (v)

		Families were all two parent households. Research conducted in California USA.	the functioning of families both mothers and siblings. Questions: -Do families show significant differences in overall family functioning? -Does raising a child with PWS affect parent's psychological health, evidenced via self-reports. -How is psychosocial emotions and behavioural functioning of the sibling impacted? -What is the parent's perception of the psychosocial	with mothers (48 item questionnaire background, medical and psychosocial information, and sources of social support). Semi-structured interviews with siblings (17 item questionnaire about feelings of impact of PWS on siblings and family relationships). A multiple case study approach was used to explore commonalities and differences in the participant families. Responses were examined by the co-authors and coded, discrepancies in coding were discussed. 4	conditions such a cerebral palsy residing at home or in long-term care provision namely the REACH study. Comparator for child/teems reports tested against REACH study (i.e., in families not impacted by PWS). All above used to test validity of tools. The authors report that the use of a PTSD measure is a unique element of this study to their knowledge. Small sample of the study is reported as a limitation, thus results interpreted with caution. Participants were linked dot PWS	-Quality of Life, when compared to normative populations mothers had a different perception of siblings psychosocial adjustment to PWS, they perceived this to be poorer than the siblings reported. *Qualitative examples* Mothers provided varied accounts; their support networks impacted their ability to manage caring responsibilities. Mothers reported higher levels of emotional stress, poorer quality of life, difficulties with family communication, more worry, increased family conflicts than parents with children with chronic illness. Siblings accounts also differed (both were female	Authors note further research on younger siblings would be valuable.	

			adjustment of the sibling, and how does the parent's perception relate to sibling's report.	participants were selected for the case studies, this included 2 mothers and 2 siblings.	national/regional conferences and networks. Mothers were therefore actively seeking more information on PWS and potentially support. All parental reports were mothers, this is a limitation.	siblings aged 15 and 16), some siblings can negotiate difficulties and show resilience while others struggle. Siblings in the study reported increased arousal, avoidance, hypervigilance, feelings of anger, sadness when reminded of their siblings' illness, startled responses, sleep problems and pessimism about the future. Mothers consistently reported lower quality of life reports for siblings than the siblings themselves. Reflects the differentiated experience of different family members, and different perceptions of other family members experience within families.		

24.	Moyson, & Roeyers, (2012)	50 siblings with a brother or sister with ID, or profound or multiple disabilities from 37 families, age 6-14 to ascertain their views on the quality of life as a sibling. Recruited in Flanders-Dutch-speaking Belgium, EU.	'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives.	Qualitative study using in-depth phenomenology-based interviews. Three interviews carried out. Data processed using grounded theory continuously coding and recoding. Member checking was used asking siblings to check the text from interviews. Focus groups used in second phase to allow siblings to talk with other siblings. These were videotaped and transcribed verbatim. Also, one of the researchers also took notes to capture further level of data. Third phase siblings asked to refine quality of life domains.	Validity verified by using different methods of data collection and member checking. Authors note the participants are young and therefore contacted through their parents so may not have been willing if not 'encouraged'. However strong value of self-reporting of children and co-participant status is central to the study. Variables were considered in recruitment, age, birth order, family size, gender, and geographical region, though all in Flanders. Socio economic status of the recruited cohort is noted as limited restricting the application of findings.	Nine domains are identified to assess sibling quality of life: Joint activities – enjoy doing things together, prepared to adapt, recognition of limitations for sibling with ID, reflect a sadness of what they cannot do, at this age reference to caring but see this as positive help Mutual Understanding – desire for understanding one another, within this a recognition of difference, communication issues Private Time – to be themselves and not just a sibling, to have their own space e.g. bedroom, this helps build resilience in dealing with more difficult situations. Acceptance – Seen as important for sibling wellbeing, increases	Domains identified are broad the Authors recommend further study to refine sub-domains. Need to apply sibling quality of life concept to studies with siblings who have a brother or sister with other disabilities, autism or physical disabilities to explore the application of the domains. Self-reports are valuable. More research with young siblings,	(i) (ii) (iv) (v) (vi)

						understanding. Also, a recognition of the ID being integral to their sibling with ID. Missing sibling experience that relates to that of their peers. Forbearance – sibling with ID' behaviour is a key factor in siblings' quality of life, authors note siblings develop coping strategies, are proud when their sibling is 'well behaved". Trust in well-being – care and concern as key themes, siblings want their sibling with ID to have a good life, opportunities and be settled. Imply they feel sorry about the ID for the impact on their sibling as well as on themselves, an empathic sense emerges. Exchanging experiences – suggest sibling support groups are helpful not just	value their perspectives. Research carried out in Flanders so a need to carry out research in other countries to test the concept of sibling quality of life domains emanating from this study for other countries. Studies to include broader socio-economic status.	

						therapeutically but a freedom to be themselves without explanations being needed. Also good to be on their own e.g., at school and not being seen as a sibling. Social Support – Recognition of the need for help and support for their sibling, their parents and themselves. A need for respite, time with their parents without their sibling. Friends being important to 'help you forget' about being a sibling for a while and be yourself. Dealing with the outside world. – Others can be a support, there is a need for them, their sibling with ID and family to be understood and valued. When this is not the case, others and their lack of understanding can be a major stressor.		

25.	Múries-Cantán, Giné, Brown, Aguiar & Schippers, (2023b)	14 siblings aged 5-14yrs recruited from contacts in four special educational needs schools and via two NGO's.	Siblings of children with intellectual and developmental disabilities: Quality of life perceptions from Catalonia	Qualitive study to elicit siblings' perceptions on quality of life. Semi-structured interviews conducted, data coded, and thematic analysis conducted, Discussion presented as nine domains of quality of life referenced to Moyson and Roeyers (2012) quality of life domains.	This was a small sample but valuable as a purposive cohort for a qualitative study. The authors sought to address a deficit in the literature in a broader geographical location, i.e. Catalonia, and attempted to draw from a wider participant group recruiting through several schools and NGO's. Ethical considerations were referenced, and care taken to ensure support for the participants as young children. Parents role in consenting to the study is noted, i.e. potential influence on siblings' participation. provided demographics information this was used as an opportunity to elicit some open-ended	Key findings presented using Moyson and Roeyers (2012) nine domains of quality of life: *Joint activities; mutual understanding; private time; acceptance; forbearance; trust in well-being; exchanging experience;, social support; and dealing with the outside world.* Findings suggest strong and mainly positive connection between, siblings, a tendency for siblings to report more balanced and positive aspects of their relationships with their siblings and experience, than their parents. The study positively reflects the value of sibling self-reports and involvement in research to elicit their perspectives. Notes the value of siblings' perspectives, evidence of having "their	Future research eliciting siblings self-report warranted and validated by this research. Recognition of social agency of C&YP differentiated form their parents and other family members. Research involving siblings with ID as well as their brothers and sisters would add to the body of knowledge. Recognises the unique nature of sibling experience	(i) (v) (vi)

					question responses from parents, and these were compared to that of siblings in the discussion.	own voice and agency" as opposed to parents and other family members.	research given the lifelong and enduring relationship, care, and support role and to support a more balanced understanding for all family members at an earlier stage to positively impact quality of life and perceptions for all.	
26.	Petalas, Hastings, Nash, Dowey, & Reilly, (2009a)	22 siblings with a brother with ASD and ID recruited from a local parent group, school, national disability charity, local paper and via	*"I Like That He Always Shows Who He Is":* Perceptions and experiences of siblings with a brother with autistic spectrum disorder.	**Included in lit review as* although reports on ASD a number of participants siblings are identified as having ID, this was a frequently referenced, as a qualitative study, using IPA as method of data analysis.	Clearly referenced as a purposive sample to elicit sibling accounts of their experiences. Small sample size is acknowledged, and caution noted of the potential generalisation of the findings, nonetheless value of self-reports and	*Emergence of five main themes:* *1) Living with a brother with ASD: Siblings accounts of the impact on themselves and their families* Experience unique to each sibling; typically, negative impact of having sibling with ID for their sibling and	Future research should explore the age differentiation and impact on siblings' experience. This cohort were age 9-12 further research required	(i) (ii) (iii) (iv) (v) (vi)

		UK NAS website. Study reports on a sub-set of eight sibling participants, who are biological siblings, age range between 9 -12 yrs. Three brothers and five sisters of brothers with ASD between 5 and 17 yrs. Study included four older siblings, one twin. All but one resided at home with	Study aim was to investigate the perceptions and lived experience of siblings in middle childhood who were growing up with a sibling with ASD.	Data collected through semi-structured interviews to elicit: *1) siblings' knowledge and perception of their brothers' ASD; 2) siblings perception's and experiences of their relationships with their brothers with ASD.*	contextualisation of this noted in the dearth of literature available eliciting sibling direct accounts of their experience and perceptions. Methodology clearly articulated, two researchers working together to check and validate themes and emergent discussion, reading re-reading and ensuring the findings were embedded in the transcripts.	the family; disruption to their lives and family life; atypical roles required e.g., caring roles; struggles with sibling with ASD idiosyncratic and eccentric and aggressive behaviours; disruption to family life. *2) Others' reactions: Implications for Siblings* Prejudice and misunderstanding; feeling angry and embarrassed, anxious; having to explain to others, silence withdrawal from others not wanting to have to explain; social awkwardness and embarrassment; managing curiosity of others. *3) Acceptance and Wanting Change* Positive acceptance of sibling with ID for who they are significant finding from this study, sibling	with older siblings as comparator. Future research should examine the correlation between siblings' perceptions and their coping responses and adjustment outcomes. Recognises the 'chronic nature' of ASD over time and the need therefore for future research to explore the longer-term changing needs of siblings with ASD and their typically	

		their sibling with ID. Research conducted in Wales UK.				recognising inseparability of the ID from the person; tension between acceptance yet wanting to change their experience, understanding the 'lack of control' of sibling with ASD for some of their actions/behaviours, some desire for normality to improve opportunities within the sibling relationships (a wish for difference); reflection of the dynamic nature of sibling relationships question whether conscious awareness of tensions or ongoing processing and appraisal of their experience (in part impacted by the engagement with the research). *4) Positive Views and Experiences* Having fun with siblings; feeling proud of their sibling	developing brothers and sisters' perceptions and experience.	

						with ID; enjoying time with their sibling; proud of some idiosyncratic abilities and skills of sibling with ID *5) Support* Recognising the value to formal and informal support; welcome interaction with others who are siblings of a person with ID; effective communication between parents and siblings positively impacts siblings' adjustment; value respite to have time with the family and sibling with ID to have their own time to enjoy leisure activities themselves; value being able to confide in others but recognise limitations i.e., cannot speak to those who do not understand their context, risk of social isolation of siblings noted by the authors.		

						Value of the study in raising awareness of issues faced by siblings; interactive training for siblings may support reduced conflict with their sibling with ASD; parent child communication, parental responses and coping - importance thereof emphasized in sibling acceptance, resilience and adjustment; sibling support groups of value; consideration of uniqueness of 'middle childhood' for siblings; practitioner to build on positive acceptance of siblings of their brother with ID. Overall value to sibling self-accounts in research approach.		
27.	Petalas, Hastings, Nash, Reilly,	12 siblings, as a sub-set of 22 siblings drawn	"The Perceptions and experiences of adolescent	Qualitative study using semi-structured interviews and IPA as	The influence of the research in the interpretation in IPA is	The analysis elicited six themes:	Limitation as a purposive cohort.	(i) (ii) (iii)

	& Dowey, (2012b)	from a broader research sample. Siblings in this study were adolescents between age 14 & 17yrs, 6 brothers and 6 sisters with a brother with ID aged between 4 -17yrs. Recruited via a parent group, school, local branch of national disability charity, advertising locally and with NAS.	siblings who have a brother with autistic spectrum disorder". Study to elicit the perceptions and experiences specifically of adolescent siblings with a brother with ID.	means of analysis of data. Semi-structured questionnaire developed by research team. This was piloted on first participant; this data was excluded. Alterations made. Ethical procedures followed; written consent gained from primary caregiver as gatekeeper. Child with ASD also asked to consent to the researcher and their sibling discussing their diagnosis as part of the research. Face or face interviews conducted, in the siblings' home.	noted by the authors. The limitation of the sample of 12 adolescent siblings is referenced, regarding caution in the potential application and generalisation of the findings, also given the participants come from the same geographical region. Co-authors used discussion to ensure authenticity of themes being grounded in the data, transcripts, adjustments were made to initial themes following discussion.	1) *Difficulties/negative impact* Siblings reported their brother's aggressive behaviour impacted their lives negatively, and stressors on the whole family; they reported tensions between irritation at their sibling' behaviours but feeling empathy knowing their siblings' diagnosis and struggles, this was described as 'emotional conflict within them'. Embarrassment in social situations, conflict between being judged by their peers and a sense of fairness and justice for their sibling, i.e., in how they should be accepted and understood in social situations. Trauma experienced from major incidents, such as their sibling being unwell or	More research needed in wider more diverse communities, and geographical area. Participant siblings with ASD were all brothers. No comparison to siblings experience of other ID.	(v)

		Conducted in Wales UK				hospitalised; or their sibling being unable to comprehend loss and grief, e.g. of a loss of a grandparent. *2) Others' reactions and social comparisons* Reactions of others to their sibling raised anger, frustration, disappointment. Friends showed lack of understanding, other friends when they were supportive were valued. Recognition of invisible nature of ID, leading to others drawing unfair conclusions about observed behaviours. Siblings have to provide explanations, can find it difficult to explain to others. Also, a sense of loss of what they perceive their peers have in sibling relationships that they miss, but recognise in teens this might be		

						positive too, as TD dyads can experience more conflict. Siblings of those with ID more tolerant and better relationship at this life stage. *3) Change. Then and now: Looking back.* Siblings located their relationship and experience in a timeframe, could contextualise this over time, relationships were perhaps better when they were younger; more difficulties when they were older as they grew apart; in contrast other siblings appreciated and understood their sibling better as they grew older, so relations improved. *4) Acceptance, tolerance, and wishful thinking* Authors describe a 'continuum of acceptance', ranging from positive		

						acceptance to wishing for change, for them and their brother with ID. *5) Positive perceptions and experiences* All siblings expressed positive experiences to varying degrees, time spent together is valued, their brother's skills e.g., ability with computer praised; shared fun; holiday memories; shared pleasures. *6) Thoughts and worries about the future.* Varied, but all spoke in some way about the future, many reflected they would have a role, but there was tension and conflict e.g., in parents wish desire for sibling to be a future carer, and their independence, i.e. for both sibling and their brother.		

28.	Pollard, Barry, Freedman, & Kotchick, (2013)	Study recruited 119 siblings, 55 boys and 74 girls, ages ranged from 11-17yrs. 81 participants had a sibling with ASD, 38 with a sibling with DS. Recruited via support groups and 'listserves' research registry. Conducted in USA.	Research seeking to answer 4 hypotheses related to relationship quality as a moderator of anxiety in siblings of children diagnosed with Autistic Spectrum Disorders or Down's Syndrome.	Research conducted via online survey, with parents completing demographic information and siblings completing online questionaries. Authors present 4 hypotheses. 1. Siblings of children with DS would report higher levels of perceived relationship quality than those with ASD. 2. Siblings of children with DS would report lower levels of anxiety. 3. Relationship quality would be related to anxiety regardless of	Participants recruited via parental gatekeepers in circumstance where they were already engaged with or seeking intervention/support for their children. Background information was gathered to support making comparison in gender, diagnosis, age of both siblings, whether they were adopted, as well as family structure, parental ethnicity, and parental educational level. Sibling quality was assessed using sibling domain of the Network of Relationships Inventory (Furman and Buhrmester 1985), while a valuable tool, however this relates to siblings in general, not specifically	Results of the study supports 3 of the 4 hypotheses. Differences in sibling relationship quality No difference by gender, number of children in the family or parental education Fewer social support qualities and more negative interchanges reported for siblings for children with ASD than with DS. - *Differences in anxiety* No significant association with anxiety and sibling age, gender, no. of children in the family or parental education. - *Sibling relationship quality and anxiety* Anxiety significantly and negatively correlated with overall quality of sibling relationship. When overall sibling relationship quality is high there was no significant	In person face or face or telephone methods of data collection required in future studies, to add to reliability of future research when eliciting self-reports. I.e., to ensure sibling direct reposes and not parents responses on their behalf. Other diagnoses of ID to be included as variables for future research in relation to relationship quality as a moderator of sibling anxiety.	(i) (iii) (v) (vi)

				diagnosis of sibling with ID. 4. Sibling relationship quality would moderate relationships between sibling self-reports and diagnosis of anxiety, i.e., lower levels of sibling quality of relationship. Quantitative measures applied to analyse the data, to support and challenge hypotheses.	to sibling dyads where one has ID, so comparisons may be misleading. Online data collection is more difficult to verify this was the siblings' self-reports. Hence the validity is reduced. Efforts in methodology to try to address this by including 5 questions related to favourite, music, television, artists subjects, websites, the data collected was subject to a visual review to ascertain typical answers from a child rather than a parent. Questionnaires that did not reply to these 5 questions were eliminated from the analysis. The Authors give no reference for the	differences in anxiety in siblings of children with ASD and DS. When sibling relationship quality was low this changed with siblings of those with ASD more likely to experience higher levels of anxiety. - *Sibling diagnosis and relationship quality* Siblings of children with DS reported higher levels of social support within the sibling relationship. Sibs of those with ASD, had fewer interactions, experienced less closeness and understanding, felt more isolated than siblings of children with DS and other disabilities. - *Perceived relationship quality and anxiety* Siblings who reported more negative interchanges with	Where the sibling relationship is in itself the cause of anxiety, this requires further exploration considering actual or potential sibling psychological maladjustment to having a brother or sister with ID (more nuanced research required). Within ASD – future research to explore specific differentiated behaviours in ASD when considering sibling effects.	

					validity checking i.e., what constitutes a 'typical' answer? A sample of children and adolescents N = 2,698 was used to assess the reliability of the responses to the Multidimensional anxiety scale for children (MASC March 1997), the tool used to assess the siblings' self-reports of anxiety, the Authors note a correlation in the results from .60-69, while this is referenced, there is not discussion of the wide scope for differentiated responses from siblings of children with ID than typically developing dyads, thus reducing the validity of the tool for use in this research.	their sibling with ID were more likely to report anxiety. Notes when the sibling relationship itself is the cause of anxiety, despite social support and family understanding, siblings can still experience anxiety and psychological maladjustment. This points to the need from more research given the impairments of social interaction and communication more prevalent in ASD. - *Sibling diagnosis related to anxiety.* Overall anxiety was not significantly different between children of siblings with ASD and DS - *Relationship quality as a moderator* Sibling self-reported relationship quality was	Further research needed to determine relationship quality measures reliability, specific to dyads where one sibling has ID to be assured of results, as a relative comparison to measures used in this study and pervasive in the literature that related typically to tools and measures applied to broadly developing dyads.	

					Larger number of the participant sibling sample had ASD than DS. No other ID diagnoses were considered.	found to positively moderate self-report of anxiety. - *Relationship Quality ad a moderator* Siblings of children with DS who perceived low levels of relationship quality with their sibling reported lower levels of anxiety than those with a sibling with ASD. - *Main effect findings.* Differentiated behaviours in ASD should be considered when exploring sibling quality of relations when sibling behaviour is associated as the cause of sibling anxiety, and psychological maladjustment.		
29.	Reimers, Hess, Johnson, Martino, Mort &	5 Adolescents with a sibling with ID, substantial enough to impact them	Resiliency perspectives among older siblings of children with	A post-intentional phenomenological study. Methods of data collection used were varied, a check in journals; photo-	Appropriate permission sought from university review board re:" ethical approach. Initial meetings held with the participant and their	Five themes emerged. Learning about the disability and early challenges; *knowledge and learning about difference. Worry, confusion, building*	Need greater diversity, ethnic, culture, religious beliefs, economic backgrounds.	(i) (ii) (v) (vi)

	Ybarra, (2023)	and their families, (self-identified by participant family – i.e., parents).	significant disabilities. Focus on the self-reported experience of older siblings with a younger sibling with ID.	elicitation interviews and semi-structured interviews, with filed notes and use of a reflexive diary. Data analysed in a. Systemic pattern, reading of data sources, extracting meaningful statements, coding and grouping into similar and distinctive units.	guardian., consent agreed before any data collection. Members checks completed with families. Standards of reporting qualitative research guideless used. Acknowledge small cohort but recognise this was the intent and value their perceptions. From recruitment the cohort mainly middle-class, similar demographic area of residence, all engaged with support communities. Specific ID not defined and acknowledge this may lead to different experience e.g; other	*knowledge together as a family* The nature of the sibling relationship; *roles and responsibilities change over time, caring role, unique bond positive, defines who they are, enjoyment, teacher, protector.* Changes and adjustments made within the family system; *family routine challenged, things require more planning, make personal sacrifices, importance of time with parents alone, respite needs.* Perceptions and meaning made of experiences; *being older sibling can be difficult, sense of loss and lost opportunities, acknowledgment and acceptance, similarities to 'just being a sibling', not always different.*	Benefit in exploring a lifespan perspective. Nature of risk, for siblings and increased protective process and adaptation across different periods of life would add to future studies.	

					authors have suggested difference between siblings who have a sibling with ASD or DS.	Feelings of personal growth. *Personally grown from experience, patience and maturity, learning from responsibilities, increased tolerance and understanding, positive joy and fun, being entertained by different ways siblings' see the world, strengthened bonds of families as they navigate this together.*		
30.	Shivers, McGregor & Hough, (2019)	215 TD siblings with a sibling with ASD 116, or DS 99. Age of siblings 12-18 mean age was 14-15yrs. 115 sisters, 157 brothers. Average of 3.27 siblings	Examined self-reported stress among adolescent siblings of individuals within two groups, one with a sibling with autism spectrum disorder and the other group with a sibling with Down's syndrome.	Quantitative study. Data elicited from distribution of online questionaries. In USA, National organizations were used to identify the cohort, emails sent to organisations to distribute to those registered. Data collected measuring, Perceived stress scale; individual stressors,	Survey was piloted with 5 adolescents to determine readability and approximate completion timings. Survey was online for 8 months. Parents and siblings completed the survey, focus was to elicit siblings' self-assessment, reflects the age demographic of the participants.	Overall results indicate siblings with a sibling with ASD report higher levels of stress. Note the correlation of higher levels of stress reported in this cohort with similar results for Mothers of children with ASD. Siblings had a higher level of behavioural problems. Environmental and behavioural issues for	More variants in future research not only behaviour problems and stress. Using other measures not only questionnaires. Explore socio-economic factors and include	(i) (iii) (v)

		in each household. Noted that there were differences in the two groups with more children in families with DS siblings, more males in families with ASD siblings. Study conducted from Virginia in USA		demographics; muti-dimensional scale of perceived social support, development behaviour checklist. Data analysis variance measures for each group. Comparison between both ASD and DS groups conducted.	Limited demographics were recorded. As an online survey the breadth of representative cohort could not be determined. Authors acknowledge this may have skewed the demographic to certain socio-economic and geographic (state) locations in the USA determined by access to and ability to use online forum.	sibling with ASD may impact. Siblings with siblings with ASD did not report less social support from family, friends, or others than those with siblings with DS. Authors note importance of this as a differentiated finding, i.e., though siblings in ASD family report more behaviour problems they did not report feeling any less supported by their families, different from other findings. Study provides helpful insight into self-reports.	broader participant demographics in future cohorts.	
31.	Shivers, & Dykens, (2017)	US study, 97 parent-sibling pairs in two	Adolescent Siblings of Individuals With and Without	Study conducted online, contact with families via local, national agencies and	Online study so no direct interface with participants.	The authors note Mothers report higher levels of impact for siblings of a child	Points to a need for research utilising more	(i) (iv) (v) (vi)

		sibling families only. 49 children with ID, 48 no children with ID. Age range of siblings, between 12 18yrs, for ID families, 27 respondent siblings were female, 21 male. Mainly Caucasian families, (84.5%), married parents (80.4%) with household income of over $100,000.	Intellectual and Developmental Disabilities: Self-Reported Empathy and Feelings About Their Brothers and Sisters	groups supporting people with ID. Four-part survey, with part four directed at the sibling. Sibling measures explored: sibling empathy; feelings toward their brother of sister. Parent measures included: demographics; parental optimism, behaviour problems of child with ID; functional abilities of child with ID; parent perception of child with ID impact.	Clear ethical procedures followed. Open discussion of limitations by authors, consider response rate low, contact via third party agencies and via email may have limited exposure of the study. Verification of identity not possible via internet survey. Different ID were not compared. Recognition that families who are in contact with support agencies may have more motivation to complete surveys. Parental response almost entirely female.	with ID than for the non-ID family. Siblings with a brother or sister with ID reported higher anxiety levels but no difference in levels of empathy were found between the sibling of ID and of a typically developing (TD) sibling. Findings suggest the importance of recognising broader factors and individual difference in relation to empathy noting adolescence as a complex life stage, social experience and cognitive development of the siblings may also impact empathy and wider perceptions of their experience.	direct sibling accounts. Broader demographic of participants to include wider ethnicity, socio-economic backgrounds. Findings highlight the need for greater emphasis on understanding heightened sibling anxiety, points to the potential of this reflecting their own levels of self-esteem, worry about the impact of their sibling's behaviour on how	

							they are perceived by others, or potentially their emerging awareness of uncertainty for their future and that of their sibling, pertaining to their likely responsibilities in the future.	
32.	Shojaee, Hemati Alamdarloo & Nikoobin Borujeni, (2020)	141 Siblings, mean age of 14-15 yrs.49 with a sibling with ASD; 42 with a sibling with ID, 50 siblings of typically developing (TD) children.	Adjustment difficulties of siblings of children with disabilities and typically developing children. Aim to explore and compare what if any are the adjustment difficulties, emotional	Quantitative study conducted in Iran, participants were recruited from advertising within and recruiting those expressing and interest within special needs schools and random sampling from TD elementary schools, in Iran. Strengths and Difficulties	Authors contextualise the study as a deficit in Iran. They note the varied findings of prior research regarding impact of ID on siblings. Study aims to look at comparison groups, ASD, ID and TD. Sample characteristics were considered, with no significant statistical difference in age range,	Findings are varied, overall, the results suggest Iranian siblings of a child with ID are at risk of adjustment difficulties, (including ASD and ID as no significant difference in adjustment found). Rationale suggested an impact of parents caring demands, need to engage in caring themselves, or household chores, less parental attention.	Future research should explore more diverse ID. Further demographic variables of parental education, more diverse age groups also suggested	(i) (ii) (iii) (v) (vi)

		Study conducted in Shiraz, Iran.	problems and conduct problems, of siblings of children with ASD, ID and TD.	questionnaire distributed. Analysis of variance and multivariate analysis of variance tests were used for data analysis.	ratio of male and female siblings, birth order, family size, maternal education level or family income. Siblings and parents gave consent. Ethical approval was sought from Regional Education organisations.	Siblings of children with ASD, more likely to experience emotional problems, Rationale suggested, they are exposed to more behavioural problems associated with ASD. Recommend programmes to support siblings coping mechanisms. Increase training for families on experience of siblings. Family management approach. Siblings of ID and ASD, more hyperactive than siblings of TD siblings. Suggestion of connection between behaviours of siblings with ID and ASD and neurocognitive impact on their siblings. Can impact		

						sadness, loneliness, shame, anger, anxiety, depression. Peer relationship problems being ashamed of sibling with ID or ASD, embarrassed, unsure of explaining to friends.		
33.	Stalker & Connors (2004)	38 Parents, 26 Disabled Children & 24 Siblings. 18 Interviews were conducted with siblings (six joint interviews with two C&YP) Siblings were aged 6 -19yrs	Children's Perceptions of Their Disabled Siblings: 'She's Different but it's Normal for US	Qualitative study conducted in Scotland UK, using semi-structured interviews with parents, C&YP with ID and with their siblings.	Content analysis conducted to elicit emerging patterns, common themes, and key points from transcripts of interviews. Positive involvement of people with ID to advise on process of conducting research. Initial findings were cross analysed to elicit difference by age, gender, and impairment (type of disability), though no significant differences were identified.	The primary aim of the research was focused on C&YP with ID exploring their understanding of disability and how they negotiate day-to-day experience. A further aim was to explore C&YP as siblings and their views and experience of having a brother or sister with ID. Findings were presented as siblings' views of impairment, disability, and difference. Age was a defining factor with older siblings viewing impairment	All respondents were white, the authors comment this is reflective of the population in Scotland UK. Highlights the need for studies seeking to recruit participants from more diverse backgrounds. Points to potential value of more in-depth primary research focusing on siblings'	(i) (v) (vi)

					Limited consideration of the ethical issues of conducting this research with siblings. Primary focus of the study was not solely on sibling experience and may have diluted the focus on this cohort.	as being more permanent. Difference was subdivided as, no difference; difference due to physical appearance or personality; difference due to impairment, difference due to disability. Overall siblings saw their brother or sister with ID as "holding various identities and their shared biographies as members of the same family"	experience as the core aim.	
34.	Wakimizu, Fujioka, Nishigaki, & Matsuzawa, (2020)	789 siblings of children with severe motor and intellectual disabilities. (mean age 12.22yrs). Primary caregivers were also participants.	Quality of life and associated factors in siblings of children with severe motor and intellectual disabilities: A cross-sectional study	Self-reporting questionnaires to inform a cross-sectional study. Participants accessed via special schools in Japan.	Participants were volunteers, recruited via dissemination of information by Teachers in the Schools selected. Only one sibling included (who had lived the longest with the sibling with ID). No clear differentiation of what is meant by Severe motor and ID.	Results were a surprise to the Authors, quality of life of siblings of siblings with SM & ID showed a higher trend that that of the general population of participants of a similar age.	Focus of the study was on caregiving roles. Suggest exploring other variables, siblings quality of life impact of clubs, social support wider relationships friends.	(i) (ii) (v) (vi)

		Study conducted in Japan.			Much of the prior literature refers to studies involving studies focused on physiological disabilities, so the relationship of the literature is questionable. Recognise the context of the study being in Japan, cultural differences.		Relationships between individuals and family members acknowledged as being complex, suggest future research needs to address this complexity.	
35.	Yaldiz, Solak & Ikizer, (2021)	72 siblings (47 F 25 M) with a sibling with ID, ASD or Down's Syndrome. Comparator group of 109 siblings of siblings who did not have ID. Interpreted adolescence as a higher age	Negative emotions in siblings of individuals with developmental disabilities: The roles of early maladaptive schemas (individual) and system justification (System factors). I.e., Unique focus on both the roles	Quantitative cross-sectional study, including adolescents who have siblings with ID and without.	Study explores early maladaptive schemas and emotions, considers systems justification theory and emotions. Participants were recruited via snowballing approach. Also contacting special education and rehabilitation centres. Questionaries were sent to participants with data collected via online	No significant difference was found in relation to negative emotions for siblings with a sibling with ID. Siblings generally show positive psychological have a shared history, strong bonds, care for one another and provide support and companionship. Authors note conflicted feelings of care and love and at the same time resentment and due to some of the self-	Authors cite difficulties in accessing this cohort of participants and point to a lack of diversity therefore in relying on snowballing, need to ensure more diverse groups for future research. Note therefore limitations in	(i) (v)

		group between 16-24 years. Mean age of participants was Gp. 1 18.65yrs, Gp. 2 18.92yrs. Study conducted in Turkey.	of the individual and system related factors on negative emotions of adolescents with a sibling with ID.		questionaries, 9paper copies were provided where internet was an issue n2 participants).	sacrifices made, anger regarding less parental attention, over-responsibility, potential for isolation and loneliness. In the 'other directedness' schema, suggesting a potential for increased depression and anxiety, though this was not shown as significant in the findings. Findings support need for a secure, stable and supportive family environment benefiting siblings' emotions. Highlight a need for professionals to be aware of this and encourage sibling to be aware of their own emotions and express this to support better wellbeing and outcomes, from an early age.	being able to generalise findings. Female gender (associated with higher frequency of fear and anger) and income (associated with anger) were both variables suggested for consideration in future studies. Family orientated approach to future studies beneficial. Point to differentiation of ID needing to be explored for future studies, i.e., they grouped ID, ASD and DS.	

36.	Zaidman-Zait, Yechezkiely & Regev, (2020)	Mothers and siblings (59) aged 8-13 years some with a sibling with ID (28) and some with a typically developing sibling (31). Gp. 1 50% boys, aged 10.4yrs on average Gp. 2 60.7% boys aged 11/4yrs average. Study conducted in Israel.	The quality of the relationship between typically developing children and their siblings with and without intellectual disability: Insights from children's drawings.	Measured used to gather data included family background questionnaire; sibling relationship quality; sibling relationship questionnaire; Drawing of sibling relationship; Children's emotional and behavioural adjustment. Multi-variant analysis of covariance of mothers' education and siblings age and sex used as covariates. Stepwise regression analyses used. Age, sex, group members (TD or DD) and sibling relation measures, regressed against internalizing, externalizing and pro-social behaviours.	Demographics were compared, on average no difference in participants in siblings' age, sex, nor of their siblings' with IOD. Similar marital status for mothers, though difference in education level. Ethics approval obtained. Ministry of Social Affairs and University Review Board. Drawings considered a positive projective technique that can provide a perspective of the person's inner world and as such seen as valuable. Authors note this was reviewed by the researchers and did not include any self-assessment by the participants.	Mothers reported higher levels of empathy and teaching behaviours in siblings with siblings with ID, and lower levels of conflict and rivalry. The Siblings also reported lower levels of conflict and higher levels of closeness in their relationship. Less quarrelling, less competition and unkindness with more positive interactions and an appreciation of their sibling with ID. Drawings were reviewed through a predetermined measure of (distance, size and location) reviewing relationship as represented in the drawings. Having a sibling with ID found to have no significant negative impact on children's adjustment.	Note the limitation of the sample size. Mothers were the only reporters of children's adjustment. Would be better to seek siblings' direct views. Adding qualitative element to the research i.e., siblings' own interpretation of the drawings would advance the methodological approach and enhance the results and broader application.	(i) (v) (vi)

				Sibling relations were examined using TD siblings' drawing to represent their relationships. Questionnaires completed by TD siblings and Mothers. Suggest this is the first to use drawing as a method.		Acknowledges that sibling conflict for siblings' with and without ID and children's behaviour problems are impactful.		

Core Themes Key

(i) Siblings' positive and negative experience.
(ii) Caring role and future responsibilities.
(iii) Nature and degree of intellectual disabilities.
(iv) Cultural context and socio-economic factors.
(v) The family system and inter-relationships.
(vi) Value of self-reports and sibling resilience.

APPENDIX TWO: Ethics approvals (a – e)

a) aHSK/PGR/UH/02318;

b) aHSK/PGR/UH/02318(1);

c) aHSK/PGR/UH/02318(2);

d) aHSK/PGR/UH/02318(3);

e) aHSK/PGR/UH/02318(4).

UNIVERSITY OF HERTFORDSHIRE
SOCIAL SCIENCES,ARTS AND HUMANITIES

ETHICS APPROVAL NOTIFICATION

TO Jacqueline Kelly

CC Professor Sally Kendall

FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman

DATE 25/02/16

Protocol number: HSK/PGR/UH/02318

Title of study: An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities

Your application for ethics approval has been accepted and approved by the ECDA for your School.

This approval is valid:

From: 01/04/16

To: 31/12/17

Please note:

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

UNIVERSITY OF HERTFORDSHIRE
HEALTH AND HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Jacqueline (Jackie) Kelly

CC Professor Sally Kendall

FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman

DATE 04/05/16

Protocol number: aHSK/PGR/UH/02318(1)

Title of study: An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities

Your application to modify the existing protocol as detailed below has been accepted and approved by the ECDA for your School.

Modification: Participant modifications as described in your EC2 application dated 29/04/16

This approval is valid:

From: 04/05/16

To: 31/12/17

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

UNIVERSITY OF HERTFORDSHIRE
HEALTH AND HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Jacqueline Kelly

CC Professor Sally Kelly

FROM Rev Dr Kim Goode, Health and Human Sciences ECDA Chairman

DATE 13/7/16

Protocol number: aHSK/PGR/UH/02318 (2)

Title of study: An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities

Your application modify the existing protocol as detailed below has been accepted and approved by the ECDA for your School.

Modification: Amendments to the participant information sheets for children and young people.

This approval is valid:

From: 13/7/16

To: 31/12/17

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

University of Hertfordshire UH

HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Jacqueline Kelly

CC Professor Sally Kendall

FROM Dr Simon Trainis, Health, Sciences, Engineering & Technology ECDA Chair

DATE 2nd October 2017

Protocol number: aHSK/PGR/UH/02318(3)

Title of study: *An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities*.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Modification: As stated in the EC2 dated 25/09/2017

This approval is valid:

From: 02/10/2017

To: 31/12/2018

Additional workers: no additional workers named.

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

University of Hertfordshire UH

HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Jacqueline (Jackie) Kelly

CC Prof Sally Kendall

FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair

DATE 27/11/2018

Protocol number: **HSK/PGR/UH/02318(4)**

Title of study: An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Modification: Extension to dates to enable continued data collection.

This approval is valid:

From: 27/11/2018

To: 31/03/2020

Additional workers: no additional workers named

Please note:

If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete. You are also required to complete and submit an EC7 Protocol Monitoring Form if you are a member of staff. This form is available via the Ethics Approval StudyNet Site via the 'Application Forms' page http://www.studynet1.herts.ac.uk/ptl/common/ethics.nsf/Teaching+Documents?Openview&count=9999&restricttocategory=Application+Forms

Any conditions relating to the original protocol approval remain and must be complied with.

Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1/EC1A or as detailed in the EC2 request. Should you amend

APPENDIX THREE: University EC5 Standard Risk Assessment Document

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC5: STANDARD RISK ASSESSMENT FORM

FORM EC5 – STANDARD RISK ASSESSMENT FORM

NAME: Jacqueline (Jackie) Kelly

DATE: 26-01-16

Activity Description					
1. IDENTIFY HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS		4. ACTION NEEDED
Activities/tasks and associated hazards Describe the activities involved in the study and any associate hazards. Check sector specific/UH specific Guidance. (NB. Describe any equipment to be used and read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)	Who is at risk? e.g. participants, researchers, other people at the location, the owner / manager / workers at the location etc.	How could they be harmed? What sort of accident could occur, e.g. trips, slips, falls, lifting equipment etc., handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely?	Are there any precautions currently in place to prevent the hazard? Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc.	Are there any risks that are not controlled or not adequately controlled?	List the action that needs to be taken to reduce/manage the risks arising from your study?
Participants becoming distressed during interviews or project participation.	Participants	Emotional distress.	The Researcher will follow CRIPACC lone researcher policy (version 4 April 2015). Lone Working policy v4 150415.docx The Researcher is at all times bound by their Nursing and Midwifery Council NMC Code for Nurses and Midwives. (NMC 2015) .		The researcher will ensure copies of leaflets and contact details are made available and will carry additional copies to each interview.

			http://www.nmc.org.uk/standards/code/read-the-code-online/ Safeguards will be identified and information for access to support services will be made available. This will be noted on participant and parent consent and participation information sheets.		
Vulnerability and safety of the researcher as alone researcher in accessing family home environments.	Researcher	Personal safety risk. Researcher could also be open to accusation of inappropriate behaviour if in a 1:1 setting with a child participant, i.e. in a room in the family	Researcher will follow CRIPACC lone researcher policy (version 4 April 2015). Researcher will advise key personnel within the University, i.e. identified colleague of the date/time and location of the interview. Researcher will request and ensure that a parent/guardian, responsible adult known to the participants are present in the home for the duration of the interviews. Researcher will discuss with the participant their preferred environment in the home.		Researcher will notify the identified colleague once they have completed the interview within two hours of the expected completion time. Any changes of dates/times will also be advised to key personnel. Researcher will request and ensure that a parent/guardian, responsible adult known to the participants are present in the home

		home but on a 1:1 basis.			for the duration of the interviews. Interviews will normally be conducted in a semi-private but communal environment within the home. Both the participant and the researcher will agree the appropriate environment.
1. IDENTIFY HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS		4. ACTION NEEDED

Signed by applicant:	Signed by Off Campus Location Representative: (NB. This needs to be the person who has given permission to use the location)

APPENDIX FOUR: School reference group request flyer

Just a little TIME needed with *FREE CAKES & an Amazon Thank You VOUCHER!*

Do you have a brother or sister with intellectual disabilities?

I would welcome your help with my PhD Research project.

Hello! My name is Jackie Kelly, I am a postgraduate research student and a staff member at the University of Hertfordshire.

How can I help?

You can help by being part of a small reference group to support my studies. You would not be a participant in the study itself.

What is the Study about?

This is an exploratory study of the experience of having a brother or sister with intellectual disabilities.

What would I need to do?

Support me to check out my thoughts and ideas for the research study. For example, review information sheets and questions. Help me to think about any ethical issues.

How much time would be needed?

We would meet as a group (i.e. 5 or 6 people), on 2 or 3 occasions, for no more than 1 hour.

Can I be involved?

Yes, if you have a sibling with intellectual disabilities.
Yes, if your parents and school are happy for you to do so.

What do I get in return?

Soft drinks and cakes! will be provided when we meet and a £5 amazon voucher at the end!
You get the satisfaction of helping a student in an important project!
I would also provide a "thank you" notification that you can add to your CV, advising of your support for a research project.
You will also be credited in the final report for the research project.

Please feel free to contact me if you are able to help text or give me a call, thank you! Jackie Kelly [redacted]

APPENDIX FIVE: Email of acknowledgement and thanks re: school reference group

Friday, March 8, 2019 at 6:40:24 PM Greenwich Mean Time

Subject: Re: Amazon vouchers re: Research Support
Date: Thursday, 30 June 2016 at 16:02:07 British Summer Time
From: Kelly, Jacqueline
To: Angela [redacted]

Dear Angela

My pleasure I was very grateful and I am sure I will be in touch this is an ongoing venture over the next couple of years research takes time, so no doubt I will be seeking further support. I hope the letters are also of use as the students start putting together their CV's and University of Hertfordshire applications!

My thanks to you also for all your support.

Kind Regards

Jackie

Jackie Kelly
Head of Department Nursing and Social Work
(Children's, Learning Disability and Mental Health Nursing)
School of Health and Social Work
University of Hertfordshire
Hatfield
Hertfordshire
AL10 9AB

EA: Tara Bullworthy
Email: T.Bullworthy@herts.ac.uk
Tel:: 01707 285901

From: [redacted]sch.uk>
Date: Thursday, 30 June 2016 14:09
To: Jackie Kelly <j.2.kelly@herts.ac.uk>
Subject: RE: Amazon vouchers re: Research Support

Dear Jackie

I just wanted to send an email to say a very big 'Thank You' for dropping of the Amazon Gift Vouchers for me to distribute to the students who participated in the research group a couple of weeks ago.

Please let us know in the future, if any further support is required.

Best Wishes

Angela

From: Kelly, Jacqueline [mailto:j.2.kelly@herts.ac.uk]
Sent: 24 June 2016 10:53
To: [redacted]
Subject: Re: Amazon vouchers re: Research Support

Dear Angela

Page 1 of 3

APPENDIX SIX: Parents/Guardian information sheet and Consent Form

"An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities."

My name is Jacqueline (Jackie) Kelly, and I am a registered learning disability nurse working as a senior academic manager at the University of Hertfordshire (UH). I have been privileged to work with people with intellectual disabilities and their families as a nurse and systemic practitioner since 1987. More recently I have been working as a lecturer and senior academic at UH delivering programmes of study to nurses and professional working with and supporting people with intellectual disabilities.
I am undertaking a research project as part of a Doctor of Philosophy (PhD) research degree programme at the University, and I am contacting you through the NetMums network to canvass your interest and support in engaging with this project.

This is an invitation for your family, namely your child(ren) to be part of a research project that is seeking to explore the experience of having a sibling with intellectual disabilities.

This information leaflet outlines what is involved in more detail to help you to understand the project and decide if you agree for your family and child(ren) to participate in the project. It is important for me to seek both your consent and that of your child(ren) to their involvement.

I have attached a second leaflet for you to share with your child(ren) that explains more about the project to them. If you are happy to consider their involvement, please share and discuss this with them. I would encourage you to speak to others about the project also, and I am happy to be contacted to clarify any points or to answer any questions you may have. Please see my email and telephone details below.

Thank you for giving this your consideration.

What is the aim of the project?

This project aims to learn more about siblings' views and experiences growing up with a brother or sister with intellectual disabilities. There are a number of research projects that have looked at siblings' experience of intellectual disabilities, but many of these projects have asked for the views of parents, teachers or other professionals involved with families. There are fewer studies that ask the views, perceptions and experiences of the siblings directly, as this project aims to do.

Please be assured that the views of your child with intellectual disabilities is also very valuable, but in relation to the specific aims of this project I will be seeking the views and experiences of their brother(s) and/or sister(s).

What is involved in the project?

Once I have received the signed consent form below, I will contact you to arrange to meet your family, normally at your home or another place by agreement. This initial meeting will be an opportunity for me to introduce myself and explain more about the project, and for you and your child(ren) to introduce me to your family.

If you are happy to continue, I will ask some questions and construct a picture of the family with you and your child(ren).
I will arrange a further meeting with your child(ren) individually, usually in your home and interview them about their experience. The interview will be audio recorded, and written transcripts will be typed up at a later date.

After this I will ask your child(ren) to keep a diary/blog over a six-month period, requesting that they make two entries each month, twelve entries in total. They can make further entries, but this minimum number will help to give me enough information to inform the project. They do not have to make entries if they do not want to share particular information or feel they have nothing to say.
The diaries can be written, (paper diary), recorded, (audio or video blog) or communicated in another format e.g. pictures or drawings. I will agree the format with them when we meet and discuss the types of entries they might like to make. For example, they might record their thoughts about a significant event, a birthday, a trip, a time when they feel happy or sad.

I will arrange with you and your child to collect the diary/blog once completed.

I will provide you and your child with my email and telephone contact should there be any queries about the diary/blogs during this time. I will also contact your child(ren) on a few occasions to see how they are getting on.

For your assurance the project has full ethical approval from the University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority (HHSECDA). In addition, I have a full Disclosure and Barring Service check (DBS) for working with children and vulnerable people in my capacity as a senior academic manager and as a researcher.

What will happen to the information and diaries/blogs?

All information will be anonymised, and information will be kept securely either in a locked cabinet in the case of paper documentation or diaries, or on a secure computer or server for any electronic information. I am supported and monitored by two research supervisors at the University. My supervisors and myself will have access to the information. In addition, a transcription service will help to support me to transcribe some of the information. This is a service used to support researchers in the University, this is an established service with whom we have a confidentiality agreement. You and your child(ren)'s names will be changed and where names are necessary to aid explanations, pseudonyms will be used. Your child(ren) can decide the pseudonym they would like me to use for them.

The information will be collated and analysed, and I will produce a report at the end of the project. A copy of the report can be made available to you. Please be aware that the project will be undertaken over quite a lengthy period, so will take some time to complete. I will provide a summary of the report for your child(ren), so they have feedback on the outcomes and potential findings from the project. Further extracts all or in part and smaller elements or summaries of the project may be reproduced as journal articles or contribute to books or other publications, so the information can be shared widely and inform professionals working with siblings and their families.

What is the advantage of the being involved in the research?

Although this study may not give direct benefit to you and your family, research is often influential in guiding policy and legislation in deciding how best to support people. Therefore, your involvement may help to influence future policy and improve other families' experience. It is important that this influence is informed from the perspective of the people that it aims to help, in this instance the siblings who have brothers and sisters with intellectual disabilities. This research will help to inform professionals working with siblings to provide more effective support with the aim of improving their general wellbeing.

Children have been found to be very valuable contributors to research. This project presents your child(ren) with the opportunity to share and values their views, that will ultimately contribute to future information available to professionals, other siblings and their families.

Are there disadvantages or risks in being involved in the research?

There are no specific disadvantages or risks to your child(ren) being involved in the research. However, if a situation arises that I feel requires professional support I am obligated to refer this on but would not do so without informing you.
If sharing their experiences gives the child(ren) or you any cause for concern they can withdraw from the project at any time.
I will provide you with details advising of how and where to access support in your local area if this is needed.

If you have further questions?

Please feel free to contact me if you have any further questions. I would like to take this opportunity to thank you for reading this information sheet and for your consideration of participating in the research project.

If you and your child(ren) are happy to agree to your child(ren)'s participation, please complete and sign the tear off slip below and return in the stamped addressed envelope provided. Thank you.

Jacqueline (Jackie) Kelly

Email:-

Telephone:- 01707 286490

Please tear here

Research Project Participation Consent Form

"An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities."

I confirm that I have read the information sheet attached to this document and agree to my child(ren) participating in this research project. I have provided a contact telephone number below.

Parent/Guardian Name……..

Please state relationship to the child…….

Signature…….. Date……

Telephone Contact details……..

Only one adult consent is required but please feel free to add others if you wish to represent mutual consent.

Parent/Guardian Name……..

Please state relationship to the child…….

Signature…….. Date……

I confirm that I have read the information sheet provided for children and young people that accompanies this consent form and agree to participate in this research project.

Child (Sibling) Name……..

Signature……. Date……

Child (Sibling) Name……..

Signature……. Date……

Child (Sibling) Name…….

Signature……. Date……

Please feel free add the name and signature of any additional siblings who would like to participate. Thank you.

Researcher Name Jacqueline (Jackie) Kelly
University of Hertfordshire

Signature…….. Date……

APPENDIX SEVEN: Example of recruitment request posted on Net Mums

Do you have a child with intellectual disabilities? Do they have a brother(s) or sister(s)?

If so, then I would welcome your help with my project.

My name is Jacqueline (Jackie) Kelly, and I am a registered learning disability nurse working as a senior academic manager at the University of Hertfordshire (UH). I have been privileged to work with people with intellectual disabilities and their families as a nurse and systemic practitioner since 1987. More recently I have been working as a lecturer and senior academic at UH delivering programmes of study to nurses and professionals working with and supporting people with intellectual disabilities.
I am undertaking a research project as part of a Doctor of Philosophy (PhD) research degree programme at the University, and I am contacting you through the NetMums network to canvass your interest and support in engaging with this project.

This is an invitation for your family, namely your child(ren) to be part of a research project that is seeking to explore the experience of having a sibling with intellectual disabilities.

Project Title:- ***"An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities."***

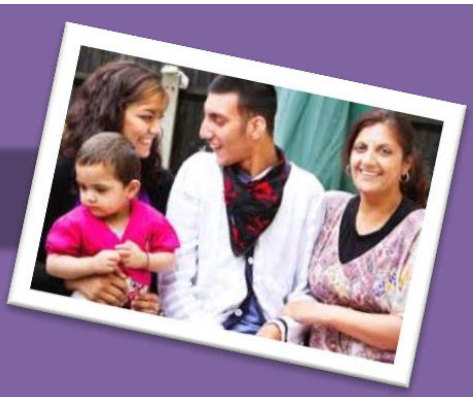
If you are interested, please contact me by email or telephone and I will send you further information.

Many thanks for giving this your consideration.

Email:- J.2.Kelly@herts.ac.uk; Telephone:-[redacted]

Jackie Kelly

APPENDIX EIGHT: Flyer to recruit participants



CAN YOU HELP?

Do you have a child with intellectual disabilities?

Do they have a brother(s) or sister(s) aged between 11 and 16 years?

This is an invitation for your family to be part of a project exploring the experience of children and young people who have a sibling with intellectual disabilities.

My name is Jackie Kelly and I am a registered learning disability nurse and academic working at the University of Hertfordshire, (UH). As part of a Doctor of Philosophy (PhD) I am undertaking a research project, "An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities".
My interest stems from my privileged career working with people with intellectual disabilities and their families as a nurse, systemic practitioner and lecturer since 1987.

What would be involved? Once you contact me, I will provide more information and answer your questions about the project. I will come to meet you. If you are still happy for your family to be involved I will arrange to meet with your child/children who are siblings and ask them some questions about their views and experiences. I will ask them to keep a blog or diary for a period of time noting their ideas and experiences they feel would be valuable to share to inform other families and professionals about being a sibling.

Please contact me by email or telephone and I will send you further information.

THANK YOU! for giving this your consideration.

Jackie Kelly
Email: - J.2.Kelly@herts.ac.uk
Telephone: - 01707 286 490

The project has full ethical approval.
University protocol number aHSK/PGR/UK/02318 (2)

APPENDIX NINE: Information booklet children and young people 11 – 13 years

"An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities."

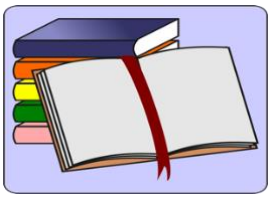
Researcher: - Jackie Kelly

Information sheet for young people asking for your help with this research project

Ethics approval protocol number aHSK/PGR/UK/02318 (2)

Experiences of having a Sibling with Intellectual Disabilities.

Hello, my name is Jackie Kelly. I work at the University of Hertfordshire. Some of you may know people who go to University, or you might be thinking of going there yourself. I am sending this information leaflet to ask for your help with a project I am doing at the University.



- As part of your work at school you might be asked to do some work, a project to find information about something.
- I am doing a project at the University that is called a research study, or a Doctor of Philosophy (PhD).
- My research study is trying to find out more about what brothers and sisters think about having a sibling with intellectual disabilities, this is sometimes called learning disabilities.

Why am I receiving this leaflet?

I have asked NetMums and Schools to help me with my project.

- They have sent information about my project to families and your parents/carers has contacted me to say that you might be like to help me.
- Your parents/carers have told me that it is ok to share this with you.

What will I have to do?

- If you would like to help, I will come to your home or somewhere else that you and your parents/adult agree is best to meet you.

- I will meet you with your family to introduce myself and tell you more about the project.

After that if you would still like to help with the project, I will arrange a time to come to talk just

to you and ask some questions. Some examples of the questions might be: -

- Can you tell me about you and some of the things you enjoy, like school or hobbies?
- Can you tell me what it is like for you having a sibling with intellectual disabilities?
- Do you think it is the same or different from having other siblings?

I will have some questions to start with, but we will talk about the things you feel are important to tell me about being a sibling.

I will ask you to keep a diary or a blog telling me about things that happen that you think might be helpful for the project. The diary can be written, typed on a computer or voice recorded. We can talk about this and agree what type of diary/blog you want to keep and what is easiest for you.

Will this be a lot of work for me?

This will not be a lot of work. It will help if you can write in diary/blog two times a month for six months. That might sound a lot, but it is just about 12 entries. You can do more if you want to, but 12 entries will give enough information to help with the project.
It is ok if you cannot think of things to say/record during this time, but we will talk about the types of things that might be helpful

I will give you and your parents/ carers my email and telephone number so you can contact me if you are not sure about the diary or anything about the project and want to speak to me about it. I will also get in touch with you by phone/text or email a few times to see how you are getting on with this. You can tell me about the best way for us to keep in touch.

Will my information be private and safe?

The law makes sure that research information is kept safe. The university will check that I keep your information safe.

I also have two people called research supervisors who will be meeting with me regularly to check that I am doing the research properly. I will talk to my supervisors about the project and your information. My supervisors are also professionals who have to keep information safe and confidential.

I will keep your name confidential, which means it will be private and safe, and I will not share this with anyone else. You can choose a made-up name if you want to, that we can use so no one else knows who you are, but you do not have to

do this. I will still make sure this is confidential and safe.

For some people when they are meeting as part of a project like this one, they feel safe to tell things that are worrying them. This is ok, but if some of those things are about you hurting someone or about someone hurting you, I will need to tell someone about it whose job it is to keep people safe, but I will always talk to you about this first.

What will happen to my diary/blog and information?

Once you have completed the diary/blog I will contact you and come to collect it.

- I will use the information you have given me along with the information from other brothers and sisters who have been part of the project to write a report.
- I will share the information with professionals, but your name will be removed.
- I may also use the information to write other reports that may be published in books or professional magazines so I can share what I have learned with people who are helpers such as nurses, doctors, social workers and teachers.

How can I help with this project?

I believe it is important to ask brothers and sisters themselves what their experiences are really like, so that is why I am asking for your help with this project.
Other projects often ask mums and dads (or other people in the family), or helpers working

with the family, like doctors, nurses, teachers and social workers, what they think. But I want to find out what you think.

Do I have to help with this project?

- No, you do not have to help with this project if you do not want to.
- I will give you a form to sign and one for your parents/carer to sign to tell me that you are happy to help me with the project.
- If you do start to help with the project and later want to stop, you can stop at any time.
- For some young people telling someone about their experiences and ideas may upset them. If you feel upset and you would like to talk to someone about this, we will tell your parents/carers, and I will give you and them information so you can contact professionals/helpers to talk to.

Why is my help important?

- Professionals or helpers who work with families and people with intellectual disabilities use the information from projects like this one when they are deciding how best to support people.
- It is important that we have the right information to make sure that siblings and all the people in the family get the right kind of help.
- This project will help siblings to tell the helpers about the support they need which might be different to what their mum, dad or other family members need.

How many people will you be asking to help with the project?

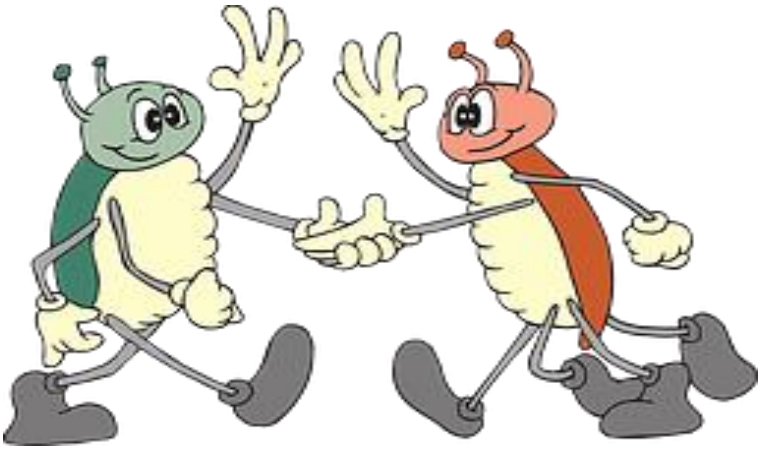
- I am hoping to be able to speak to siblings from about 15-20 families.

- The children and young people will be at secondary school or college and will be between 11 and 16 years old.

What if I have questions?

If you have any questions now or during the project, you or your parents or adult responsible for you can contact me. I have put my email and telephone number below.

J.2.Kelly@herts.ac.uk
01707 286490



Thank you for thinking about helping me with this project. I look forward to meeting you soon.

Jackie Kelly

APPENDIX 10: Information booklet children and young people 14 - 16 years

"An Exploratory Study of the Lived Experience of having a Sibling with Intellectual Disabilities."

Researcher: - Jackie Kelly

Information sheet for young people asking for your help with this research project

Ethics approval protocol number aHSK/PGR/UK/02318 (2)

Experiences of having a Sibling with Intellectual Disabilities.

Hello, my name is Jackie Kelly. I work at the University of Hertfordshire. Some of you may know people who go to University, or you might be thinking of going there yourself. I am sending this information leaflet to ask for your help with a project I am doing at the University.

- As part of your work at school or college you might sometimes be asked to do a project to find out more details and information about something.
- I am doing a project at the University that is called a research study, or a Doctor of Philosophy (PhD).
- My research study is trying to find out more about what brothers and sisters think about having a sibling with intellectual disabilities, this is sometimes called learning disabilities.

What does 'intellectual disabilities' (learning disabilities) mean?

- Having an 'intellectual disability' does not mean a person cannot have a good life, but it can mean that they need more help and sometimes need that help all of their lives.
- It means that a child develops at different times than others of the same age.
- A child may take longer to learn and do things for themselves and might need extra help with day-to-day things like getting dressed, washing or eating.
- Some children may also have problems with their health and need to spend time with doctors or in hospital.
- Sometimes children with intellectual disabilities may find it hard to understand how to behave around other people and people may need to try lots of different ways to make sure they can understand the child and their needs.

Why am I receiving this leaflet?

- I have asked NetMums and Schools to help me with my project.
- They have sent information about my project to families and your parents/carers has

contacted me to say that you might be interested in helping me.

- Your parents/carers have given me permission to share this with you.

What will I have to do?

- If you would like to help with the project, I will come to your home or somewhere else that you and your parents/adult agree is best to meet you.

- I will meet you with your family to introduce myself and tell you more about the project.

fter that if you would still like to help with the roject, I will arrange a time to come to talk just o you, to ask some questions about being a sibling of someone who has intellectual disabilities. Some examples of the questions might be: -

- Can you tell me about you and some of the things you enjoy, school or hobbies?
- Can you tell me what it is like for you having a sibling with intellectual disabilities?

- Do you think it is the same or different from having other siblings?

I will have some questions to start with, but other questions will come from the things you want to tell me about; things you feel are important to say about being a sibling of someone with an intellectual disability.

I will ask you to keep a diary or a blog telling me about things that happen that you think might be helpful for the project. This is so I can be sure I am getting lots of your ideas and experiences.

The diary can be written, typed on a computer or voice recorded. We can talk about and agree what type of diary/blog you want to keep when we meet.

Will this be a lot of work for me?

This will not be a lot of work, I will ask you to write/record in the diary/blog two times a month, for six months. So that will be about 12 entries. You can do more if you want to, but 12 entries will give enough information to help with the project.

It is ok if you cannot think of things to say/record during this time, but we will talk about the types of things that might be helpful when we meet.

I will give you and your parents/ carers my email and telephone number so you can contact me if you are not sure about the diary or anything about the project and want to speak to me about it. I will also get in touch with you by phone/text or email a few times to see how you are getting on with this. You can tell me the best way for us to keep in touch.

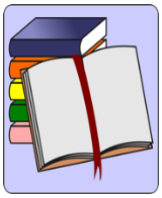
Will my information be private and safe?

The law makes sure that research information has to be kept safe. The university will check that I have arranged to keep information safe, either in a locked filing cabinet if this is paper information, or in a safe and secure place on a password safe computer. I also have two people called research supervisors who will be meeting

with me regularly to check that I am doing the research properly. I will talk to my supervisors about the project and your information. My supervisors are also professionals who are required to keep information confidential.

I will keep your name confidential, which means it will be private and safe, and I will not share this with anyone else. You can choose a made-up name if you want to, that we can use for your information so no one else knows who you are, but you do not have to do this. I will still make sure this is confidential and safe.

For some people when they are meeting as part of a project like this one, they can feel safe to tell things that are worrying them. This is ok, but if some of those things are about you hurting someone or about someone hurting you, I will need to tell someone about it whose job it is to keep people safe, but I will always talk to you about this first.



What will happen to my diary/blog and information?

Once you have completed the diary/blog I will contact you and arrange to collect it. If you have kept this on your computer or it is voice recorded in some way, we can arrange for you to send it to me. But I will still come and visit you and we can agree how to do this.

- I will use the information you have given me along with the information from other brothers and sisters who have been part of the project to write a report.
- I will share the information with professionals, but your name will be removed.
- I may also use the information to write other reports that may be published in books or professional magazines so I can share what I have learned with people who are helpers such as nurses, doctors, social workers and teachers.

How can I help with this project?

There are lots of projects that have tried to find out about brothers' and sisters' experience. These projects often ask mums and dads (or

other people in the family), or helpers working with the family, like doctors, nurses, teachers and social workers, what they think. I believe it is important to ask brothers and sisters themselves what their experiences are really like, so that is why I am asking for your help with this project.

Do I have to help with this project?

- No, you do not have to help with this project if you do not want to. I will give you a form to sign and one for your parents/carer to sign to tell me that you are happy to help me with the project.
- If you do start to help with the project and later want to stop, you can stop at any time.

- For some young people telling someone about their experiences and ideas may upset them. If you feel upset and you would like to talk to someone else, we will tell your parents/carers, and I will give you and them information so you can contact

professionals/helpers in your local area to talk to you.

Why is my help important?

- Professionals or helpers who work with families and people with intellectual disabilities use the information from research projects when they are deciding how best to support people.
- It is important that we have the right information to make sure that all the people in the family get the right kind of help.
- This project will help brothers and sisters to tell the helpers what kind of support they need which might be different to what their mum, dad or other family members need.

How many people will you be asking to help with the project?

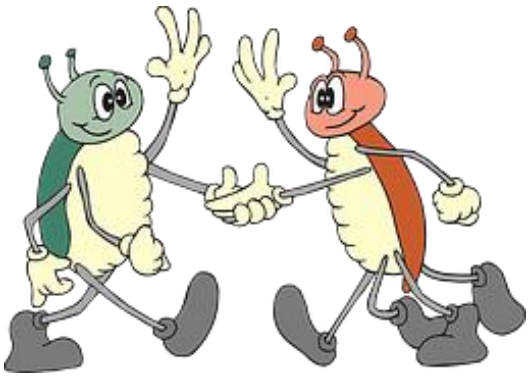
- I am hoping to be able to speak to siblings from about 15-20 families.

- The children and young people will be at secondary school or college and will be between 11 and 16 years old.

What if I have questions?

If you have any questions now or during the project, you or your parents or adult responsible for you can contact me. I have put my email and telephone number below.

J.2.Kelly@herts.ac.uk
01707 286490



Thank you for taking the time to read this information sheet and for considering helping me. If you would like to help with the project, I look forward to meeting you soon.

Jackie Kelly

APPENDIX 11: Semi-Structured Interview Schedule

Questions	**Grouped question nos.**	**Aims of questions**
1) (*Address by name*), tell me a little bit about you? 2) What School/college year are you in? 3) Which subject do you like the most? (a) What's the best thing about (*insert school subject*)? 4) Can you tell me about an activity, hobby, or clubs/groups that you enjoy in or outside of School? (a) What do you enjoy most about that?	Q. 1-4	This section consisted of general questions aiming to find out more about the sibling themselves, their school, friends, hobbies, to engage them in conversation about familiar aspects of their lives. The aim was also to put them at their ease at the beginning of the interview, engaging the importance of and interest in their broader life roles and experience, alongside being a sibling with a brother or sister with intellectual disabilities (ID).
5) Tell me a little bit about the people in your life that are important to you? (a) People who help you, that are special in your life. *(Prompt: - Parents, friends, siblings, teachers, grandparents, pastor, other relatives)*	Q. 5	This reintroduced the initial introductory meeting, using the genogram prepared in these initial meeting, as a reference point to reengage with conversation about the siblings, people in their family, including their sibling(s) with ID.

		This provided a link to the conversations where their mothers were present for reassurance with the aim of reinforcing the parental approval of the process.
It is good to hear about you and some of the things that are important to you and that you enjoy. As you know I am interested to find out what it is like for you being a brother/sister to (individuals name used here throughout). So, I would like to ask some questions about that, is that ok with you? 6) When did you notice that (*insert name*) had intellectual disabilities, (*familiar terminology used by the child(ren) will be inserted here as appropriate throughout*)? 7) Who was the person/people who spoke to you or answered your questions about that?	Q. 6 & 7.	These questions aimed to elicit what the C&YP understood by the term intellectual disabilities. To ascertain when they became aware of this, in the context of their sibling, and identify who provided them with the information about their sibling's intellectual disabilities.
8) What's it like having a brother or sister with ID?	Q. 8-10.	These questions focused on the sibling and their personal accounts of having a brother or sister with intellectual disabilities.

9) How has having a brother/sister with ID affected you? (a) In your home life? (b) In your school life? 10) Are there things you would want other people to know about how this affects you?		This also aimed to explore how this affected the siblings in their day to day lives, and what they wanted people to know and understand about that experience.
11) Can you tell me how this has affected your Mum and Dad (*insert guardian as appropriate*)? (a) Affected your other siblings, (*if relevant*)? 12) What are the things that you notice about the effects on your Mum and Dad (*insert guardian as appropriate*)? (a) What do you notice that shows you about the effects on your other siblings?	Q. 11&12	These questions aimed to explore what siblings notice and their awareness of the experience of others, particularly their parents' experiences of having a child with intellectual disabilities.
13) How do you tell other people about your sibling? (a) Your friends? (b) Other people?	Q. 13-14	This section aimed to explore how siblings describe ID to others, how they describe their own and their family experience.

14) Can you tell me things that are special about being a brother or sister to (*insert name here*)? (a) Is that different to being a brother or sister to (insert name of another sibling)? (i) How is it different? (*Asked as appropriate if there are other siblings in family*). (ii) How is that different to your friends whose brother(s) or sister(s) do not have ID?		To explore how they relate their experience of being a sibling, where they have brothers and sisters without ID, and awareness of the experience of their peers as siblings, to make any connections of similarity and difference.
15) What are the things that you do that show your brother or sister how you feel about them? 16) What do they do to show you how they feel about you? 17) What activities do you and your sibling with ID (*insert name*) enjoy together? (a) Tell me about the best part of that for you, for your sibling (*insert name*)? (b) What makes it difficult doing things together?	Q. 15-17	This section aimed to explore the interrelationship between the participants and their sibling with ID. To gain insight into how siblings interact with one another, and how they show and express their feeling about one another as siblings.

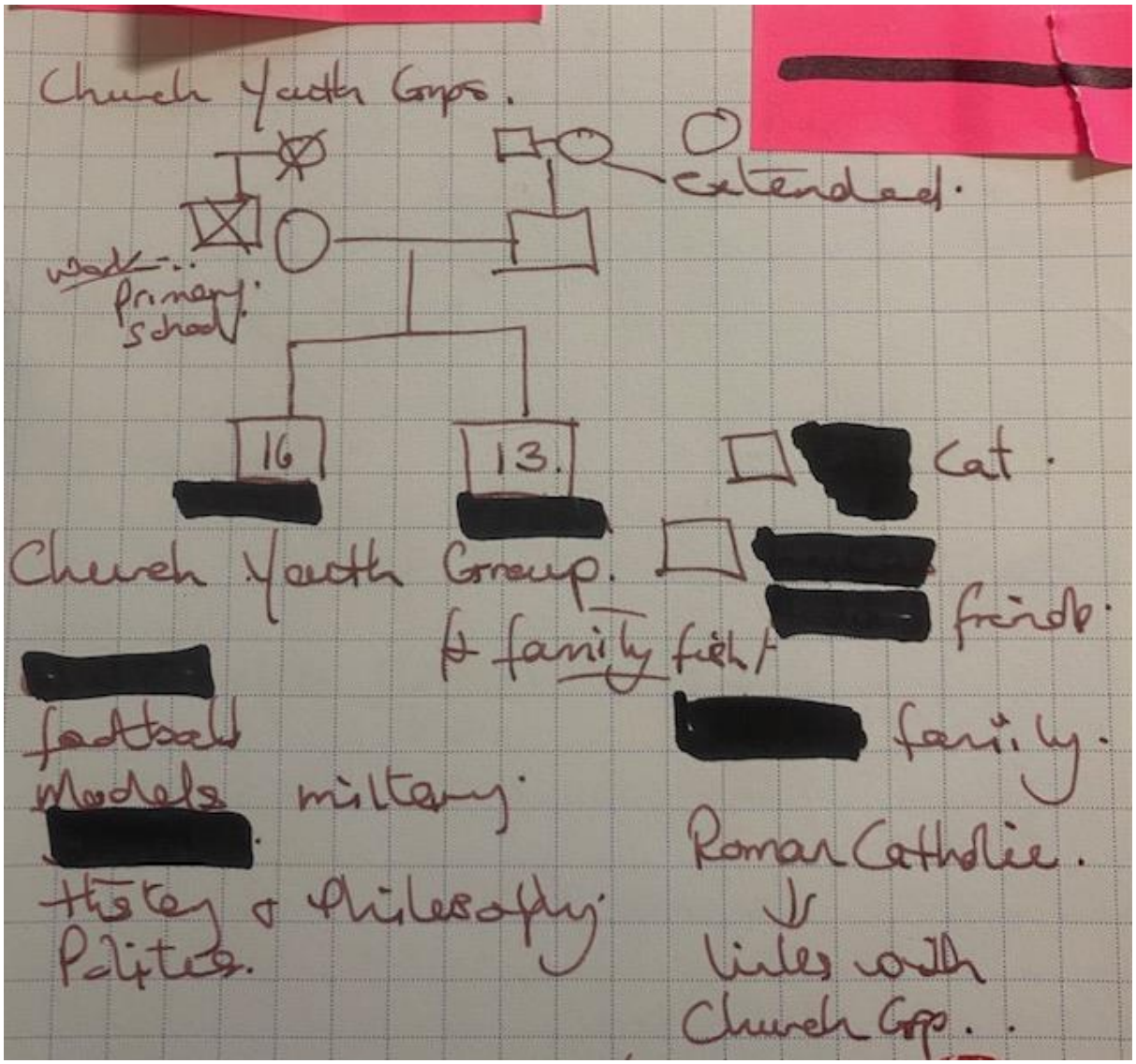
18) When I met you and your family, you told me your family beliefs/religion is (*insert religion or no belief as appropriate*). *OR* b Do you have a faith? (a) What does that mean to you and your family? (b) How does this help you with things in your life that are important to you? (c) Does it help you to think about being a brother/sister, son daughter, a part of your family? (d) How does your religion talk about ID and people in their families?	Q. 18	Religious and cultural context, this was included as it was identified from the literature review, as an aspect of context not often widely explored.
19) What are your dreams for the future? (a) What would you like to do as a job/ career when you are older? (b) What other things are important to you for your future? (c) What would you like to achieve in your personal life? (d) Would you like to have a family?	Q. 19-22	This section explored considerations and aspiration for their own future, and the aspirations for their sibling. It also sought to explore opportunity for considerations given to having a sibling with ID, their future relationship, potential caring role, or future responsibilities, as these were areas identified in much of the literature reviewed. This also aimed to explore how the future was discussed within the family.

20) Who do you talk to about your dreams for the future? *(Prompt: - may not share this if not then explore if they would like to talk about this and their view of how that might be achieved?).* *(a)* What would be different about your dreams if you brother or sister did not have ID? 21) What are your dreams for your ID sibling's future? (a) What job/career might they have when they are older? (b) What other things are important for (*insert name's*) future? 22) How do you talk about this in your family? (a) What are other things that would help you to talk about this in your family?		
23) What is the most important thing that you would like other siblings to know about being a brother or sister with ID? (a) Why is that so important?	Q. 23 - 26	This section explored how and where siblings find information about ID. What they believe is important for others to know about being a sibling,

24) Where is the best place to find out information about being a sibling of a brother or sister with ID? (a) From whom? (b) What other information would you like to have, or that you think would be helpful for siblings? 25) What is the most important thing for other people, professionals/ helpers to know about children and young people who are siblings of a brother or sister with ID? (a) What do you think is important for me to tell them from this project? 26) How do you think we should tell professionals/helpers about the things you have suggested?		for other siblings as well as professionals supporting siblings and their families.
27) Is there anything else that you expected me to ask or something that you would like to tell me about being a sibling to (*insert name*)?	Q. 27	This gave an opportunity for the sibling to raise any areas of consideration not covered in the interview.

		At the end of the interview the researcher took the opportunity to remind participants of the diary, blog completion. Answering any questions, connecting the diary activity as an ongoing part of the research data collection, and reinforcing their choice and the support available.

APPENDIX 12: Example of participant genogram sketch anonymised



APPENDIX 13: Interview transcript, participant 1 analysis process (a - d)

a) Interview transcript, participant 1 analysis process
b) Analysis of connections emergent themes participant 1
c) Abstraction of themes transcript 1
d) Transcript data analysis board image participant 1

Appendix 13 (a): Example of interview transcript analysis participant 1

Participant 1 Interview [Names used for participant and sibling are pseudonyms - to protect confidentiality]

Emergent Themes	**ORIGINAL TRANSCRIPT**	**Exploratory comments** [Descriptive comments in normal text], [*linguistic comments in italics]*; [conceptual comments [underlined] (Smith et al., 2009:84)
Birth order	**SHAFEEQ-JK MARCH 2017** **1.1 So I mean basically to start, tell me a bit about you talked** **1.2 last week with Mum, talked a little bit about the family** **1.3 and, you know, when you.., you're the older of the two** **1.4 are you…..?** 1.5 Yeah. **1.6 You're the oldest?** 1.7 Oldest. **1.8 Yeah. So just tell me a little bit about you, about, you** **1.9 know, we talked about the school you went to, what year** **1.10 you're in, the stuff you like to do, your favourite** **1.11subjects, that sort of stuff? Just a little bit about you?** 1.12 Alright. Erm So I'm just starting my GCSEs, this is my first 1.13 year and I've got about 18 months until my exam I think.	Identity in the family as the oldest sibling.

Identity encompasses a wide range of life experience and varied activities and interests	1.14 I've got some mock exams in a few months. And erm I 1.15 play a lot of sports at school. And er I prefer, for subject- 1.16 wise I prefer maths and physics rather than like chemistry and 1.17 stuff like that. My favourite is probably maths. **1.18 So you like the detail...** 1.19 Yeah. **1.20 ...the numbers and that sort of, maths and physics are** **1.21 often two things that go…** 1.22 Together, yeah. **1.23 …together don't they? Yeah. You find that. And what** **1.24 sort of sports do you enjoy?** 1.25 I play mainly football but I've done other sports in the 1.26 past like rugby, cricket. I used to do karate as well. **1.27 Wow!** 1.28 Yeah. **1.29 Bit of martial arts?** 1.30 Yeah. I don't do much anymore just because I haven't got 1.31 the time but I used to do it every weekend.	Identity in his current life experience and a timeline of events. Further identity of interests and likes and dislikes in school subjects. Describes pleasure in various sports both a diversity of interest and a focus on one area of football.

Chronological age, education, choices begins to change priorities	**1.32 And was that all through school or are they sort of clubs 1.33 and things you'd do after school?** 1.34 That was just outside school, yeah. **1.35 So and then has that changed now that you've moved? 1.36 Because you said that you moved?** 1.37 Yeah. I mean obviously I used to do karate in (*City in* 1.38 *England)* in *(County in England)* and then we moved down 1.39 to *(Town in England)* and that's when it stopped because 1.40 I became busy with schoolwork and secondary school. 1.41 But yeah, I used to play football outside of school as well 1.42 but I've stopped that now for my GCSEs, to focus on my 1.43 work and stuff like that. **1.44 So what team, do you play for a school team?**	Mentions available time as an influencing factor in participating in sport options and <u>choices. Suggest maturity and change of priorities.</u> Some sport activity enjoyed outside the school environment. Stopped sport activity due to moving to a different town. School work being busy is a focus now over some of his sporting interests.
With maturity comes increased responsibility.	1.45 Yeah, just a school team. **1.46 And you were telling me last week the position you play, 1.47 is it centre?** 1.48 Centre and midfield, yeah. **1.49 Mid-centre or centre-mid, you can tell I'm not a footie 1.50 fan. I don't know too much about it. So what do you 1.51 1.52 think are kind of the best things about school or what 1.53 do you enjoy the most about school or social life or 1.54**	<u>Academic focus is important and given priority over other interests. Sense of responsibility and maturity?</u> Still involved in sport in school. <u>Uses 'just' is there a sense of loss and compromise?</u> Part of a team.

	activities or other things, you know, what's your, what rocks **1.55 your boat?** 1.56 I guess I enjoy being part of like a team so obviously 1.57 football and sports really encourages that, <u>being like a</u> 1.58 <u>team player. It also builds your like team building skills</u> 1.59 <u>which helps in life</u> and I kind of erm, school I enjoy more 1.60 subjects this year than I did last year. I find like this year 1.61 I've been like trying to concentrate a bit more and I've 1.62 actually been enjoying the subjects. **1.63 And what do you think has changed sort of from, what** **1.64 maybe have influenced that? What, how come you're** **1.65 enjoying it more?** 1.66 Definitely because I got to choose some of the subjects 1.67 and drop some. So I used to do French and history and I 1.68 absolutely hated it. 1.69 ***[Laughs]*** **They weren't your thing?** 1.70 Definitely not. I dropped both so… **1.71 So that's kind of nice with GCSEs to be able to pick?** 1.72 Yeah. You get to, every subject that I'm doing right now I 1.73 enjoy and I wanted to do so *[pause]* school's fine. 1.74 **So that's felt kind of good? And so we talked a little bit**	
Being a team player is important in life.		Enjoys being part of a team stating the application of team building skills in sport to other areas of life. *Being a team player team building skills are important and valued attributes* <u>Linking concentration and effort to enjoyment</u> of school subjects.
Personal choice is important		Appreciates school subjects, personal choices and the opportunity to enjoy learning.
Expression of self, through likes and dislikes, personal choice helps things to be fine.		Dropped subjects that he did not like. Knows his own preferences and makes choices based on likes and dislikes. Choice and enjoyment helps school *to be 'fine'.*

Varied social relationships are important. Relaxation opportunities are important.	1.75 **about used to do karate, used to football, things outside.** 1.76 **Are there other things that you do outside, you know,** 1.77 **what do you do to relax outside of school? What sort of** 1.78 **things do you enjoy?** 1.79 I go out with my friends a lot, well when I can. I'm going 1.80 out tomorrow with my friends so, or we go out as a 1.81 family. I go out with Zahra and do things that we both enjoy. **1.82 So what sort of things would that be? What sort of** **1.83 things would you enjoy?** 1.84 I mean I just really enjoy going out to be honest and being 1.85 kind of erm out of the zone of working and stuff, kind of 1.86 just more relaxed. 1.87 **So what would you and your friends do? You can tell I'm** 1.88 **not a young teenager! What would you and your friends** 1.89 **do as something that would, to relax, so if you and your** 1.90 **mates went out on a weekend or, you know, day?** 1.91 Probably go out into *(main city)*, do a bit of shopping and 1.92 like see what events are on, like movies, bowling. 1.93 **Is that easier now you're living closer?** 1.94 Yeah it is, yeah. 1.95 **Because the travelling?**	Going out with people is important. Friends, family. Going out with his sister doing things they both enjoy. Going out is enjoyable to zone out of work. Going out is a relaxation. *Recognises the need to get 'out of the zone of working'.* Enjoying activities with friends going to the central city shopping, movies, bowling, various activity.

Opportunity for interests outside the family are important. Shared experiences with sibling is important and enjoyable. Seeing sister's enjoyment brings enjoyment for sibling.	1.96 It was like an hour train. It's only like a 20 minute train 1.97 here so… 1.98 **And you mentioned that you like going out with the** 1.99 **family and you like going out with Zahra?** 1.100 Yeah. 1.101 **What sorts of things do you like doing when you're out** 1.102 **with Zahra?** 1.103 I mean normally as a family we go out to like big places, 1.104 like parks or shopping centres and stuff like that, have a 1.105 walk around, even if we're not getting anything we just 1.106 walk around, try and get a bit of outside the house. And 1.107 then Zahra, I enjoy it as well, Zahra really enjoys err this 1.108 place called Mega Jump, like a trampoline park indoors. 1.109 So she really loves that so I enjoy going there with her. 1.110 **And would you say that's something that you both enjoy, you know, that you can enjoy as a shared activity?** 1.111 Yeah, definitely. 1.112 **And what's good about that for you?** 1.113 I mean not only is it, if I was there by myself it's also 1.114 really fun for me personally but it's she enjoys it so	Move to new town gives access to activity reducing travel time. <u>Opportunity and location to enable outside interests seems important.</u> Going out with family, *going to big places*. Are there restrictions on going to other places as a family? Getting outside the house is important. Enjoying activity Zahra enjoying activity. *Zahra enjoys it so I enjoy going there with her.* Seeking shared experiences. '*She really loves that so I enjoy going there with her"* Emphasising the importance of enjoyment for Zahra and shared enjoyment of activities. Are these activity choices defined by Zahra's enjoyment/*loves*? It's fun for me and Zahra enjoys it.

Care and understanding requires compromise. Siblings have fun together. Keeping sibling happy prioritised. Choices influenced by sibling needs, potential loss of self-identity.	1.115 much, like she gets so happy that I'm willing to do it. I'm 1.116 happy to do it anyway so it's really fun. 1.117 **So it's something you…?** 1.118 And just fun doing it together as well. 1.119 **Yeah. You can have as a shared…., it's lovely to hear** 1.120 **you say that, that's fun.** 1.121 Yeah. 1.122 **So you, is that important to you? What's important to** 1.123 **you in your relationship with Zahra?** 1.124 I mean mostly probably keeping her happy I think, like I 1.125 wouldn't want to go somewhere with her where she 1.126 wouldn't enjoy it or she wouldn't kind of like to be there. 1.127 So whenever I do something with Zahra I try to make 1.128 sure I do whatever she likes or, obviously I enjoy it as 1.229 well but I try to like make sure she's enjoying it or having 1.130 fun. 1.131 **And what happens, you're saying that you really like** 1.132 **her to be happy and you enjoy ensuring that she does** 1.133 **feel happy, and what happens in a situation where** 1.134 **there's an activity that she's not enjoying or you're not** 1.135 **enjoying? How do you work with that together?**	*'I am willing to do it'* as its fun anyway. <u>Is the use of the term *willing to* suggestive of caring, understanding but also compromise?</u> Shared activity with Zahra is good when both enjoy the same thing. Zahra enjoys it so Shafeeq is happy to do trampolining anyway and it is fun. Fun doing things together with Zahra shared activity. Important to keep Zahra happy. Would not go somewhere she does not enjoy or would not be happy. Very strong message about keeping Zahra happy. <u>Suggests compromise in terms of not doing things that would not keep Zahra happy, is self identity lessened</u>? I do whatever she likes or enjoys. I enjoy it but try to make sure she is enjoying it.

Happy approach and positivity is a valued attribute. Family is the main priority. Avoid upset and shame.	1.136 I mean Zahra kind of, to be honest like we, wherever we 1.137 go she tries to make the most of it and she's like, 1.138 because, I don't know, she's just such like a happy 1.139 person and such a positive person and I just try to stay 1.140 positive and enjoy it as I can. 1.141 **Yeah…That's a nice outlook on life.** 1.142 Yeah. 1.143 **That feels nice from what you're sort of showing.** 1.144 **You're looking happy. You talk about that relationship** 1.145 **with Zahra and obviously I met you with Mum and I** 1.146 **met your grandmother last week and Mum talked** 1.147 **about, I think Mum described herself as being a bit** 1.148 **more like dad. She's a bit of a disciplinarian.** 1.149 Definitely, yeah. 1.150 **She described herself as that and, you know "get your** 1.151 **homework done" and get things on time. But tell me a** 1.152 **little bit about the relationships in your family, the** 1.153 **other people, you know, with your grandmother, with** 1.154 **your aunt, with Mum, you know, a little bit about the** 1.155 **people in your life? What's important to you? What's** 1.156 **important about sort of your relationships with** 1.157 **people?** 1.158 Well obviously my main priority with like my	Wherever we go she tries to make the most of it. Zahra is a happy person, positive person. I try to stay positive and enjoy it as I can. Main priority is to never do anything to make family upset or ashamed. Keeping their best interests basically.

Upsetting people is bad.	1.159 relationship with my family is to never do anything that 1.160 would make them upset or ashamed. It's like keeping 1.161 their interests, best interests basically and making sure 1.162 I don't upset them or do anything bad. I think, oh do you 1.163 want me to talk about relationships between me and my 1.164 family or Zahra and my family?	
	1.165 **Whatever you interpret as that, you know, how do you** 1.166 **feel? How do you feel about your, you know, maybe** 1.167 **talk about with your relationship with Mum, what's** 1.168 **important about that relationship? How does that sort** 1.169 **of work for you, you know….?**	
Maturity and sense of responsibility. Strong partnership with parent. Deep realisation of parental investment, shared responsibility.	1.170 Me and my Mum have quite a good like friendship 1.171 relationship kind of so we get along together as friends 1.172 and mother and son. And I know she works hard so I try 1.173 to make sure I don't, well I try hard in my school and 1.174 stuff like that because she's sending me to a good school 1.175 so I need to try and like, you know, not let her down 1.176 basically.	Me and Mum have a good friendship. Get along as friends and Mother and Son. Mum works hard and I try hard in school. Mum is sending me to a good school. I need to try not to let her down. Powerful sense of responsibility. What would happen if he 'let Mum down'. Sense of nurture, care is there potential fragility?
	1.177 **Yes. yes. And what about with your grandmother?** 1.178 **Because Mum described last week that you spend a lot** 1.179 **of time with your grandmother?**	
Importance of extended family. Mutual support and care, family system working together.	1.180 Yeah, I do. Especially when growing-up as well. She, 1.181 because my Mum was at work my grandmother used to 1.182 like look after me all day. So I'm quite close to my	Mum was at work, my Grandmother looked after me every day. I am close to my Grandmother and to my Aunt as well.

Mature sense of responsibility to family/others. Compromise requires some sacrifice and loss of agency. Fragility of relationships and need to contain things.	1.183 grandmother and like my auntie as well because I spent 1.184 so much time with them at home. Like they, we all care 1.185 for each other, one another, one and the same. 1.186 **So how do you think they might describe you if I were** 1.187 **to ask them?** 1.188 Um… 1.189 ***[Laughs]*** **I'm not asking you to second-guess. What** 1.190 **sorts of things, you know, what makes you, when you** 1.191 **say, you know, you've got a nice good relationship,** 1.192 **what sort of things if other people were looking at your** 1.193 **relationship what would tell them, what would tell** 1.194 **other people about that relationship? What sorts of** 1.195 **things would they see?** 1.196 Hmm, well I think again like I said I think they also kind 1.196 of see me as a person that they can rely on and like that 1.197 they know that I care about them. They know I'd like 1.198 never do anything bad to them, so yeah. 1.199 **So it sounds like it's a very positive…** 1.200 Yeah. 1.201 **…positive family. Because you talked last week about** **1.**202 **being the man among all the women?** 1.203 *[Laughs]* Yeah.	They, we all care for each other one and the same. They *[family]* also see me as a person that they can rely on. They know I care about them. They know I'd never do anything bad to them. What would happen if something 'bad' happened. Sense of tension, fragility is there a sense of fear of breaking the equilibrium? Weight of responsibility

Strong sense of acceptance and embracing responsibility.	1.204 **Yeah? And I wondered what that feels like sometimes?** 1.205 I mean I'm fine with it and, uh, I.. it's just kind of 1.206 standard for me really. 1.207 **It is what you're used to?** 1.208 Yeah it is, yeah. 1.209 **It's the same as what you've grown up with I guess?** 1.210 Yeah. 1.211 **So you don't know anything different? Yeah. When I** 1.212 **gave you the information sheet as well I described a** 1.213 **little definition of intellectual disabilities and we talked** 1.214 **a little bit about that when we met with Mum last** 1.215 **week just to, I said to you that I have slightly different** 1.216 **leaflets for different ages and my reference group of** 1.217 **young people like yourself had shared with me it was** 1.218 **important maybe to make things a little simpler for** 1.219 **some younger children. But in the sheet that I gave you** 1.220 **I described a definition for intellectual disability, so** 1.221 **that's a word that we use to describe people who have,** 1.222 **sort of are grouped with special needs and support** 1.223 **needs, a little bit like Zahra. So I just wondered sort of** 1.224 **what, when you read that or when you hear me say the** 1.225 **word intellectual disability, what does that mean? Or** 1.226 **what sort of language or words would you use to**	It is a standard thing for me [*Acceptance, care, is there a sense of responsibility, being a man among family of women*].

Knowledge of intellectual disabilities varies. Term autism captures all autism things.	1.227 **describe, if you were trying to explain to me Zahra's** 1.228 **needs for example, what sort of words might you use** 1.229 **to describe that, or would intellectual disability fit or…?** 1.230 Yeah. I think intellectual disability does fit but I've 1.231 always grown up knowing that it's kind of, obviously 1.232 autism, I've known it's autism but I know in the category 1.233 of like learning disabilities or… 1.234 **Okay. Yes.** 1.235 Yeah. I've never called it like mental disabilities but more 1.236 learning difficulties. 1.237 **Yes, yes, and all of those words, it depends on where** 1.238 **you read things and who you're speaking to, different** 1.239 **people describe, they mean…** 1.240 Autism, yeah. 1.241 **Yeah. So when you hear learning disabilities, learning** 1.242 **difficulty as you've said, autism and intellectual** 1.243 **disability, does that all mean the same sort of thing to** 1.244 **you?** 1.245 To me I think, obviously I know there's other types of 1.246 learning disabilities but to me I think I know what all of 1.247 them are, because I know they're like autism or 1.248 Asperger's, I know that they're all different ways of 1.249 describing these, yeah, these like autism things.	Always grown up knowing intellectual disability that it's obviously autism, I've known it as Autism, I know in the category of learning disabilities Never called it mental disabilities more learning difficulties. I know there's other types of learning disabilities. I know Autism and Aspergers There are different ways of describing these like autism things. Demonstrates knowledge. <u>Is autism easier to understand/explain to others perhaps? Is a definition important?</u>

	1.250 **Yes, and when you say autism or learning difficulty or** 1.251 **whatever, what does that mean? If you were to break** 1.252 **it down, if you were trying to explain perhaps to** 1.253 **somebody younger or you were just trying to explain** 1.254 **to somebody what that means, how would you** 1.255 **describe it? How would you explain it in sort of simpler** 1.256 **terms?**	
Sibling knowledge is learned over time. Referenced to personal experience with sibling. Siblings relate learned knowledge to their own sibling and circumstance. Knowledge can be quite sophisticated. Normalising diagnosis 'autism' affects everyone we are all on a spectrum.	1.257 Well I'd say autism is a learning difficul… erm disability 1.258 that you get when you are like you're very young or 1.259 you're diagnosed with it when you're born, and what it 1.260 is it makes it hard, it makes it difficult for you to process 1.261 things and it makes it harder for you to learn. And it gives 1.262 you other things like hearing gets very sensitive and an 1.263 autistic person, there's erm I know there's something 1.264 called the autistic spectrum so I remember going up and 1.265 learning about Zahra's, where Zahra was and I think I 1.266 remember seeing like a diagram of some semicircle or 1.267 something like that with autism in the middle and OCD 1.268 and stuff like that. I'd say erm for someone with autism 1.269 it's err quite a severe part on the autistic spectrum. <u>We</u> <u>1.270 might be all on the autistic spectrum</u> but my sister or 1.271 Zahra is quite severe on that. 1.272 **Right, ok, so you have a sense that perhaps everybody** 1.273 **might have a little bit of something?** 1.274 Like some, yeah, a little bit or very light.	Autism diagnosed when you are born or very young. It makes it hard for you to process things to learn. Hearing is sensitive Something called autistic spectrum. I remember going to learn where Zahra was. Remember seeing a diagram of semicircle with autism in the middle and OCD and stuff. Someone with autism is quite a severe part of the spectrum. We might all be on the spectrum but my sister is quite severe on that. <u>Is this a shared experience, we are all on the spectrum?</u> Describes 'the spectrum' everyone may be a bit autistic. <u>Sense of normalising autism</u>

	1.275 **But when you've got lots more it's more obvious to** 1.276 **other people? Is that a fair…** 1.277 Possibly, yeah. I think so. 1.278 **…summary? And when did you first notice that Zahra**	
Age impacts on awareness of IDs for siblings. Knowledge can be helpful to enable understanding. Sibling's acceptance of IDs as their norm as young children. Begin to 'notice' as they get older. Social influence, acceptance, noticing of difference changes as sibling get older and gain more knowledge.	1.279 **had autism or learning difficulties?** 1.280 Oh obviously when, she was diagnosed very young and 1.281 I think I was about 3 or 4, maybe 5, and I never noticed 1.282 anything because I was so young but when my Mum told 1.283 me I learnt about what it was and then I realised and 1.284 understood it. 1.285 **Right, yes..** 1.286 That's when I really found out, when my Mum told me 1.287 or when she actually got diagnosed. I never noticed it 1.288 before that.	She was diagnosed very young, I was about 3,4 or 5. I never noticed anything because I was so young. When my Mum told me I learnt about it then realised, then understood. Mum told me when she *[Zahra]* got diagnosed. I never noticed before that. <u>Social construct of dis-ability?</u>
	1.289 **So you were saying kind of she was diagnosed maybe** 1.290 **when you were 3 or 4. Did you have those** 1.291 **conversations when you were that age?**	I don't really remember.
Learning to understand IDs together as a family is valued.	1.292 I don't really remember to be honest. I reckon, she was 1.293 born when I was 3 actually so probably 4 or 5 she was 1.294 diagnosed. 1.295 So I mean I guess, I think I was probably told that she 1.296 had autism when I was about 5. So at first obviously I	I was told when I was about 5. I had no idea but once explained to it as a family we learnt more about it. All of us learnt more. All of us needed to learn more to help her.

	1.297 was like “what’s autism?” because I had no idea but 1.298 once I, explained to it as a family we kind of learnt more 1.299 about it, all of us learnt more about it because all of us 1.300 needed to learn more about it and we learnt how to kind 1.301 of help her in a way. So we all learnt how to, what we 1.302 should do to help her, so as I grew up and as my Mum, 1.303 family raised me. 1.304 **So how did you learn that? Was that conversations** 1.305 **with the family? What sorts of ways? Because those** 1.306 **are the sorts of things that maybe would be helpful for** 1.307 **other people to think about how we talk to young**	We all learned how to, what we should do as I grew up.
Parents are the initial gate keepers of knowledge for siblings. Self-help is needed in families to help develop knowledge and understand IDs. Family gaining information and knowledge together is valuable. Sibling need for knowledge and information is needed as they grow to help them understand and to help their sibling.	1.308 **people and brothers and sisters about that.** 1.309 Yeah definitely, so my Mum learnt about it, she did a lot 1.310 of research about it and found out what we should do 1.311 to help her. And she, we had a lot of talks as a family and 1.312 we also ordered a lot of like guides and books and like 1.313 leaflets and things like that to read and learn. And I 1.314 guess obviously I was so young I didn’t read these books 1.315 and things. 1.316 **No, no.** 1.317 Yeah. But my Mum and my family read these like 1.318 information guides and read and they talked to me, like 1.319 as I was growing-up they like taught me how I should 1.320 kind of help her and just be.	Mum learned about it did a lot of research, found out what to do to help her *[Zahra].* <u>Mother’s response influencing the child response</u> We had lots of talks as a family. <u>Sense of togetherness valued</u> We ordered guides and books and leaflets to read and learn. <u>Knowledge, education and information is important.</u> I was so young I didn’t read these books and things. <u>Responses and actions led by adults [Mum]</u> Mum and my family read these information guides and they talked to me as I was growing up. They taught me how I should help her.

Siblings have a lot of questions. Parent [Mum] is the gatekeeper of explanations and information. Sibling's maturity and sense of caring for sister. Sibling experience may differ from peers. Needing to mature take responsibility. Influence of family structure and relationships linked to roles and responsibilities.	1.321 **What do you remember Shafeeq, do you remember** 1.322 **any times where you… can you think of any particular** 1.323 **conversations or anything where things were** 1.324 **explained to you, where you felt you needed an** 1.325 **explanation and things were explained to you? Are** 1.326 **there any particular times that you can recall?** 1.327 Well to be honest… when I was first being told about 1.328 autism and stuff obviously I was still getting my head 1.329 around it and I was still trying to understand what 1.330 autism actually was and what a, to be honest what a 1.331 learning difficulty was. Because when I was really young 1.332 I had no idea what a learning difficulty was. I just never 1.333 knew anyone with a learning difficulty. So I had a lot of 1.334 questions, I just want.. needed to find out what it was 1.335 first. So obviously my Mum explained that to me and she 1.336 kind of taught me a bit, kind of taught me about what 1.337 autism was and what learning difficulties are, like er the 1.338 autistic spectrum. And obviously when Zahra grew up a 1.339 little bit she went to meetings and stuff like that. And 1.340 I've been to a few of her like, um, oh what's it called um? 1.341 Parent evenings and stuff like that with my Mum. 1.342 **Oh okay.** 1.343 Her new school *[named removed]* she started in 1.344 September, she had a parent's evening and I went with 1.345 my Mum to talk to her teachers and her specialists and 1.346 stuff, to get a bit more insight on how she's doing at 1.347 school, mm like how she's been so…	When I was first told about Autism I was still getting my head around it trying to understand what autism was what a learning difficulty was. Age impact on understanding I had no idea what a learning difficulty was. I never knew anyone with a learning difficulty. Mum explained to me taught me a bit about what autism was and what learning difficulties are. When Zahra grew up a bit she *[Mum]* went to meetings and stuff like that. I've been to a few parent evenings and stuff with my Mum. Sense of responsibility, sense of maturity. Does this differ for peers? Impact of family structure? Differentiated role of sibling in partnership with parent? Supporting Mum.

	1.348 **So what was that like?**	Went to parent evening me and my Mum, sister did not go. Taking on parental role and responsibility. Support role for Mum.
Siblings take on parenting type role. Sibling role influenced by family structure [Single parent/Mum].	1.349 Well the most recent one, yeah. I went and we, yeah, 1.350 just me and my Mum, my sister didn't go, and we went 1.351 and we talked to each teacher like individually. We 1.352 talked to her form tutor and like it was kind of like the 1.353 first time I've seen Zahra at school really, because it's a	
Sibling maturity. Care and concern for sibling. Siblings demonstrate strong sense of empathy and care for sibling/sister.	1.354 big change for her going to this new school, so I'd never 1.355 really experienced like the first part of her big change 1.356 before. So it was really like different for me because I 1.357 erm, when we were talking to these teachers we 1.358 realised that she was struggling and stuff like that and 1.359 like finding it hard and getting frustrated because it was 1.360 a massive change and...	We realised that she was struggling. *Empathic understanding of the difficulties of change for his sister.* Recognition of potential frustration and challenges for his sister. Understanding the impact of change for his sister. [Does this break the sense of containment, maintaining a happy environment always. Life realities illicit concern for his sister?]
External expertise and support is important and valued by families.	1.361 **Of course.**	Good insight from specialists. <u>Value of knowledge and expert insight.</u> *<u>I've noticed.</u>* <u>I</u>'m growing up as well. <u>Is there a sense that he is growing up too quickly and perhaps his needs are not noticed?</u> We help her and teachers help her. <u>Shared support and expert input is valuable.</u>
Siblings take early responsibility for their sibling/sisters care. Potential loss of self. Loss of agency.	1.362 Yeah. But it was a good insight from specialists and stuff. 1.363 And like I learned, I've noticed <u>as I'm growing-up as well</u> 1.364 like her vocal and her speech is improving quite a lot and 1.365 we kind of like helped her with that but also her teachers 1.366 helped her with that.	
	1.367 **And do you see…, what difference do you see in her** 1.368 **going to *(named school)* as opposed to the previous** 1.369 **schools say? Because you and Mum both mentioned** 1.370 **that last week when we met and…**	
	1.371 I think it's much better for her at [Named school], the	Specialist school is better she was not learning so well in mainstream.

Sibling experience is different, may attend specialist school. Freedom to do what you want is better than a systematic approach and control. Siblings with IDs can experience social challenges and isolation. Siblings demonstrate empathy to their siblings with IDs. Sibling maturity and need to be aware of social challenges e.g. finding the right support early in life. Strong sense of caring for sibling with IDs. Mature ability to 'notice' and adapt to their needs. Impact on sibling self-expression/agency needing to adapt to sibling with IDs 'mood' and behaviour.	1.372 autistic specialist school because in mainstream schools 1.373 she was kind of not learning as well. She was so focused 1.374 on what was going on around her and like she was, like 1.375 obviously in normal school they have like assemblies 1.376 and stuff where you have to be quiet and like it was very 1.377 systematic and very controlling I think, but in this 1.378 autistic school she's kind of free to do whatever she 1.379 wants. And obviously at first it was very hard because at 1.380 her mainstream school everyone talked to her and 1.381 everyone was like "oh Zahra", you know, looking after 1.382 her but everyone else at her new school is autistic so she 1.383 found it very different and weird because she was like 1.384 "why is no-one like talking to me?" But I think she's 1.385 getting better now like as time goes on. 1.386 **What changes did you observe in Zahra at that time?** 1.387 **You talked about it being a very big change and this** 1.388 **maybe being the first time you were aware of a big** 1.389 **change like that for her. What sorts of things did you** 1.390 **notice about changes?** 1.391 She was kind of a bit more down I think and getting tired 1.392 very easily, a bit frustrated like I said. So she'd come 1.393 home, the first time she came home she was crying and 1.394 we had no idea what went wrong and she said like "it's 1.395 so different, it's big change", so I mean I've noticed, at 1.396 first I noticed that she was tired, she was frustrated, she 1.397 was getting angry easily but you had to be careful. But 1.398 yeah, she's alright now.	Being free to do what she wants. [Is Shafeeq free to do what he wants?] Normal school very systematic and controlling. Is systematic and control challenging? *She is free to do what she wants.* It was hard for her… in mainstream school everyone talked to her in social school no one was talking to her. Strong empathic appreciation of his sister's experience. Demonstrates care. Suggests the difficult balance of finding the appropriate educational support environment. Observed change in his sister's behaviour noticed her frustration and upset, crying. We had no idea what went wrong. I've noticed she was tired, frustrated, getting angry easily. *You had to be careful [cautionary tone in his voice].* Trying to support her, tell her it's ok, *reassurance is the key.*

Care for sibling is important. Sibling needs to take responsibility. Reassurance can help siblings with IDs Relationship of trust between siblings Sibling with IDs is vulnerable. A need for things to be ok. A sense of containing things. Sense of maturity, recognising sibling's naivety. Importance of Trust in families. Vulnerability of sibling with IDs, trusting anyone. Sibling aware of stranger danger. Trust. Sense of sibling responsibilities now and in the future? Power imbalance, agency for both siblings. Parent is gateway for information.	1.399 **And how did you manage, how do you manage that as** 1.400 **a family? How did you manage the support?** 1.401 I guess trying to support her really and like, you know, 1.402 tell her it's all going to be okay, like reassurance I think 1.403 is key, especially with like an autistic person, they look 1.404 for reassurance. So if you tell them it's all going to be 1.405 okay they'll know like "oh he said it's going to be okay 1.406 like". I think that helped her. 1.407 **So what do you think that, that's obviously something** 1.408 **that Zahra really trusts what you say?** 1.409 Yeah. 1.410 **And believes what you say?** 1.411 I think she's very naïve which is why I think I need to look 1.412 after her a lot, especially in the future because I mean 1.413 things could happen and she's very trusting. So if 1.414 someone says "oh I'll take you here, I'll take you home" 1.415 or something, she's going to believe him. She's going to 1.416 believe that person. So we've taught her as she's grown 1.417 up to like, you know, not believe strangers, not listen to 1.418 these people but, you know, trust her family and trust 1.419 these people. But I know like it's just she trusts me and 1.420 like believes that I say, so I just kind of need to be careful 1.421 that… 1.422 **She has a very, obviously she's got a very strong** 1.423 **relationship with you?**	Reassurance is important for autistic people. If you tell her it's going to be ok it is reassuring. <u>Sense of the vulnerability of his sister and her reliance on him for reassurance. A need for things to be "ok" is there a worry about what will happen if his sister is not ok, if things are sometimes not ok?</u> I think she's very naïve and that's why I need to look after her, especially in the future. Mature awareness of his sister's vulnerability and her need for his support now and in the future. We have taught her as she's grown up not to believe strangers. <u>Key issue of vulnerability for his sister now and in the future. Strong sense of her need for care and his responsibilities in this regard. Mentions himself not the family.</u> *She trusts me, believes what I say.* <u>Is there a sense of power and imbalance of agency for him differentiated from that of his sister</u> Parent (Mum) gatekeeper and guide for information and modelling behaviours. Strong relationship with his sibling.

Sibling relationships are strong. Leadership and role modelling responsibilities for siblings. Loss of personal 'self' agency, 'need to be good influence'. Maturity, strong sense of being responsible for his sibling. Courage and sense of fear. Awareness of burden of 'big' responsibility.	1.424 Yeah. My Mum's told me many times before as well and 1.425 she kind of like copies me in a way. It's like if she sees 1.426 me like doing something she'll, next time she'll do it 1.427 because she thinks like "okay this is what he's doing so 1.428 like this must be like right". So I kind of like obviously 1.429 need to be careful what I do and make sure like I'm 1.430 setting a good influence on her because she's going to 1.431 cope what I do, so I just kind of make sure I'm showing 1.432 her the right things to do. 1.433 **So how does that make you feel as the big brother?** 1.434 I mean quite responsible and like, um, I know I can do it 1.435 <u>but I just feel like it's a big responsibility.</u> 1.436 **You mentioned when you were talking about that** 1.437 **you've said that, you know, you watch what you do** 1.438 **because you know she's going to copy you or take her** 1.439 **lead from you and some, you know, and actually I'm** 1.440 **just wondering whilst listening to you say that, do you,** 1.441 **how do you feel, is that, how is that different maybe** 1.442 **from your friends who have brothers and sisters who** 1.443 **don't have a learning difficulty or autism? Maybe if** 1.444 **they're older brothers or sisters, so you're an older** 1.445 **brother so your younger sister is looking to you and** 1.446 **copying you as you say. How do you think that would** 1.447 **be with some of your friends who've got perhaps** 1.448 **brothers or sisters younger where they're older?**	She copies me. I need to be careful what I do make sure I am setting a good example. <u>Role model of sibling is highlighted strong message of responsibility. Realises his influence and need to be good, set the example.</u> *Showing her the right things to do.* Feels quite responsible. I know I can do it but *I just feel like it's a big responsibility*. [<u>Powerful statement] in terms of his maturity and courage with a sense of the weight of responsibility.</u> Zahra's taught me to care for a sibling more not be rude to her.

The experience of caring for siblings with IDs teaches siblings to be caring to others. Positive reflection of sibling relationships differs positively from his peers. Sibling relationships are different from peers. Envy for the norm to argue and be challenged. Envy from peers for the closeness and care of this sibling relationship.	1.449 Well I think Zahra's actually taught me kind of to like 1.450 care for my, like for a sibling more and not be rude to a 1.451 sibling and stuff like that. Because I've never been rude 1.452 to her because obviously, but I've seen obviously like my 1.453 friends who have brothers and sisters like shouting at 1.454 their sister, they'll tell them to go away or shut up, that 1.455 I've never done to Zahra. So I mean personally because 1.456 I'm so used to having Zahra as a sister I kind of, I find it 1.457 a bit weird that they would be like that because I would 1.458 never be like that. 1.459 **And how would you say in terms of, you know, as you** 1.460 **said having a sister like Zahra has changed some of the** 1.461 **ways, and that sounds…** 1.462 Positive, yeah. 1.463 **…positive in terms of you've reflected it quite** 1.464 **positively, that you would never do that and you look** 1.465 **at your friends. And are there other ways that you feel** 1.466 **that, you know, people coming to visit or looking in at** 1.467 **the family would see influences of Zahra in the family?** 1.468 **How does having Zahra as part of the family impact on** 1.469 **you and on Mum and grandmother and your aunt?**	I've seen my friends who have brothers and sisters shouting telling them to go away or shut up. That I've never done to Zahra. <u>Positive difference of sibling relationship from his peers. Is there some envy here of and from others? As his experience though positive is different?</u> *I find it a bit weird that they would be like that.* <u>Sense of what is the norm for sibling relationships is care not being rude, is there a sense of loss of the normal challenge from siblings.</u> *Positive.* Parent (Mum) as the gatekeeper.
Parent as gatekeeper. Patience and understanding.	1.470 Yeah. My Mum taught me from a very young age as I'm 1.471 growing-up that with an autistic person or with an 1.472 autistic sibling you have to be <u>very patient</u> and very 1.473 understanding, so as a family we try to be really 1.474 <u>understanding</u> and patient with Zahra. So for example	*You have to be very patient, very understanding.* <u>Is there a sense of needing to contain things, avoid confrontation/outburst, perhaps set aside his or family needs, a loss of self agency and that of the family to be "*patient.., understanding..,*</u>

Loss of personal agency and that of the family. Having a sibling with IDs fosters the development of positive qualities in siblings and families, understanding, care, patience. Siblings need space to be themselves. Siblings are open about having a sibling with IDs, it is not something to hide. Can feel conflicted at times, space for self and space for being with sibling.	1.475 when we go out for dinner sometimes she'll be 1.476 distracted with her iPad but we wait for her because we 1.477 have to be patient. You can't rush her, can't like rush an 1.478 autistic person because they want to go at their own 1.479 pace. And I think as a family we've all learnt, I think it's 1.480 actually a good thing because it's good in school, good 1.481 in work, good in everything, to be more patient and 1.482 understanding. So I think having Zahra here it's kind of 1.483 made us all like, you know, realise that we need to be 1.484 patient, need to be understanding, we know she's 1.485 autistic like, you know, just a bit more caring and like, 1.486 you know, like understanding. 1.487 **You talked about your friends and, you know, that you** 1.488 **see them perhaps not behaving in the positive way that** 1.489 **you behave with Zahra. And I just wondered how do** 1.490 **you talk about Zahra to your friends? Do you talk about** 1.491 **having a sister who has learning difficulties or autism** 1.492 **with your friends?** 1.493 To be honest as friends we don't really talk about 1.494 families much but if they say "have you got a sister?" 1.495 I've said "yeah, she's, I've got a sister, she's 11, she's got 1.496 autism". So I'm very open with it, I'm not saying, I'm not 1.497 hiding it or anything, I'm perfectly fine with it, but all my 1.498 friends know I've got a sister with autism, so it's fine. 1.499 **And how does Zahra respond when your friends are here?**	*distracted.., wait for her.., can't rush her.., go at their own pace.."* *You can't rush her, ..they want to go at their own pace.* Have to be patient is there a sense that the family are containing everything. What would happen if they were not patient? Patience framed in the context of understanding and care. Friends we don't really talk about families. Is this a place to be yourself and not a sibling? I'm very open with it, I'm not hiding it, *I'm perfectly fine with it* my friends know I have a sister with autism *so it's fine Is there an underlying difficulty in sharing this? A defence mechanism in repeating the word 'fine'? Is it always fine?.*

Pride in sibling with IDs showing confidence to others.	1.500 Very excited. 1.501 **Yeah?** 1.502 Yeah. So my friend stayed the night once and she was 1.503 very excited, very happy to meet him and she's shaking 1.504 his hand saying "hello, what's your name? My name's 1.505 Zahra". Very, you know, confident and very excited that 1.506 there's a new person here. 1.507 **Yes. I very much enjoyed meeting her last week. She** 1.508 **was really keen to come and be introduced and that** 1.509 **was lovely that, you know, she felt confident to come** 1.510 **to say hello to someone that she'd never met before?** 1.511 Yeah. She was very open. 1.512 **Yeah, she was. Very open. I felt very privileged and** 1.513 **very humble. And if you, so obviously if you're saying** 1.514 **you've got a friend coming over and that's somebody** 1.515 **that you know very well and you've talked to them** 1.516 **about having a sister and they come and they meet** 1.517 **Zahra. If it's maybe not people that are as close, how** 1.518 **do you talk to people about Zahra if you have to talk to** 1.519 **people to explain her learning difficulties or her** 1.520 **autism? How do you talk to people about that?** 1.521 Again I'm quite open with it. I don't mind telling people 1.522 I've got an autistic sister and thankfully most, like 1.523 everyone I've told is pretty respectful and that, and	My friend stayed the night once [was this only once] She's confident and very excited. <u>Suggested sense of pride in his sister's confidence and positive experience with his friend.</u> I don't mind telling people I have got an autistic sister. *And thankfully most..respectful.* <u>Use of word most suggest not always the same positive experience with others.</u>

Siblings care for their sibling and expect others to do so. Being respectful is important. Societal acceptance, ethical values and respect is important to siblings. How others treat their sibling with IDs. Cultural values influence expected behaviours of self and society.	1.524 they're perfectly fine about it. They don't find it weird 1.525 or different. I think that's a good thing that no-one is, 1.526 everyone's respectful and everyone is like kind. No- 1.527 one's been mean to Zahra so that's alright. Even Zahra's 1.528 friends from her mainstream school, when they came 1.529 over once they were very nice to her, like they all like 1.530 her and everything so… 1.531 **And you talked Shafeeq about things that you enjoy, so** 1.532 **your friends, going to London, you know, going out** 1.533 **shopping or, you know, to the cinema or other,** 1.534 **bowling, other activities and things. So you're a young** 1.535 **person of 15 now?** 1.536 15, yeah. 1.537 **And Zahra's 11? She's got a birthday…** 1.538 Coming up, yeah. 1.539 **…coming up soon. She told me that last week. So when** 1.540 **you think about the things that you do with your** 1.541 **friends and you think about you as a young teenage** 1.542 **person, and you think about Zahra and the things that** 1.543 **she does with her friends, what sorts of things does** 1.544 **Zahra enjoy doing with her friends or with you? You** 1.545 **talked about as a family the things that you enjoy** 1.546 **but…?** 1.547 Zahra really enjoys I mean just being outside the house, 1.548 going out, going places, new places. She enjoys cinema,	It's a good thing that everyone is respectful and kind. <u>Strong sense of positive expectation of societal ethics and values, maybe be linked to expected family/Muslim cultural values?</u> Zahara likes being outside the house, a bit of adventure.

Siblings enjoy the same things. Some social restrictions with friendships. Care and desire to involve siblings and expectation of friends to do the same. Positive role model to others.	1.549 bowling, everything like that as well. I think she just likes 1.550 the, instead of, it doesn't matter where we go really, she 1.551 just likes the idea of going out, bit of an adventure like, 1.552 you know, just getting out of the house, yeah. 1.553 **So she enjoys those family outings?** 1.554 Yeah, definitely. 1.555 **And you said when some of her, when in her previous** 1.556 **school some friends came over, what sorts of things** 1.557 **does she enjoy doing with her friends?** 1.558 Her room is round the corner, it's absolutely pink. 1.559 *[Interviewer laughs]* She plays a lot with toys and she's 1.560 very into Minecraft as well, so her and her friends play 1.561 it or they play with toys or have a bit of play outside and 1.562 stuff like that. 1.563 **So when you have your friends come over would Zahra** 1.564 **also have friends come over regularly to visit?** 1.565 I mean not at the same time. I mean if my friend came 1.566 over Zahra would obviously come and meet him and 1.567 everything but after she met him she'd want to get 1.568 involved a bit, which is perfectly fine, I don't mind. So if 1.569 like we're going to go play outside, play football, she'd 1.570 come outside to watch or she'd come and play on the 1.571 swings or have a run around and stuff like that. She likes 1.572 the feeling of being involved, which I know I need to	Her room is absolutely pink. She plays with toys and Minecraft. <u>Activity of 11 year olds and their friends.</u> Friends not over at the same time. If my friend came *Zahara would obviously come to meet him*. <u>Use of word 'obviously' would this be obvious in every family for siblings?</u> She'd want to get involved a bit *I don't mind.* *She likes the feeling of being involved which I know I need to include her that's perfectly fine.*

Willingness to share experiences. Finding personal space can be difficult if involving sibling all the time. Siblings sometimes compromise more than their sibling with IDs. Different rules for them and their siblings. Siblings defend their sibling with IDs. Siblings challenge others and choose relationships with people sharing similar values of care and respect in their friendships.	1.573 include her in things so that's perfectly fine. 1.574 **And what about when her friends come to visit, does** 1.575 **she, you like to include her, does she like to include** 1.576 **you?** 1.577 Not really to be honest. *[Laughter]* She just kind of wants 1.578 to do her own thing with her friends, like "oh my friends 1.579 are here now so I'm going to go play with them" and like 1.580 she's not too bothered about me when her friends 1.581 come. 1.582 **So when you think about, you've talked a lot about,** 1.583 **and you can correct me if I'm misinterpreting anything** 1.584 **that you're saying, but you talked a lot about you feel** 1.585 **that most people that you talk to about Zahra or talk** 1.586 **to about autism or having a sister who has learning** 1.587 **difficulties that people are respectful?** 1.588 Yeah, definitely. 1.589 **That sounds to me like something that's quite** 1.590 **important to you?** 1.591 Yeah. I mean I'd never accept anyone being rude about 1.592 my sister or rude about someone with autism. And I 1.596 think my friends are very like nice people and respectful 1.597 people, for example if we saw like an autistic person at 1.598 school being made fun of, we'd definitely step in to 1.599 defend him or something like that. And even if I wasn't	<u>Care and a willingness to share experiences with his sister.</u> <u>Emphasises that all is ok with the use of the words *obviously and perfectly fine*? Is there something about a lack of choice and where is his own space ?</u> She wants to do her own thing with her friends. She's not too bothered about me when her friends come. <u>Do different rules apply for both siblings?</u> I'd never accept anyone being rude about my sister or someone with autism. My friends are very nice people we'd step in to defend someone. It's not like I influence my friends, they have that view.

	1.600 there, it's not like I influence my friends, they also have 1.601 that view. 1.602 **They share…** 1.603 Yeah. 1.604 **…your perceptions? And if you thought there were** 1.605 **things that you would want other people to know how** 1.606 **you're affected by having a sister with autism etc.,** 1.607 **what sorts of things do you think would be important** 1.608 **for other people to know about being a brother of a** 1.609 **sister who has autism or learning difficulty, the words** 1.610 **that you've used to describe Zahra's needs?**	<u>Strong sense of positive moral compass choice of friends with shared values.</u>
Being patient and understanding is key to being a sibling to someone with IDs. Values of a sibling are patience, understanding, suiting them, encouraging them, doing things at their pace, keeping them happy. Sense of containment keeping the sibling with IDs happy is prioritised, potential fear of not keeping them happy and consequences. A need to contain self-expression and emotions.	1.611 Yeah. I'd definitely say the first thing that's absolutely 1.612 key if you have an autistic brother or sister is to be 1.613 patient and understanding. Like you have to be kind and 1.614 patient and understanding with the autistic person. You 1.615 have to kind of suit their needs and try and help them 1.616 and encourage them in doing things, and not rush them, 1.617 not force them, kind of let them go at their own pace 1.618 and keep them happy, definitely. That's absolutely key. 1.619 Keep them happy. 1.620 **And what do you think that that does for you Shafeeq** 1.621 **in you talk and if I may say so very maturely about lots** 1.622 **of things in terms of your life and the things that you** 1.623 **enjoy, and so kind of are there things that you feel that** 1.624 **are special about being a brother to Zahra?**	If you have an autistic brother or sister you need to be patient and understanding, kind. You have to suit their needs, encourage them, not rush or force them do things at their pace and keep them happy. That's absolutely key. Keep them happy. <u>A sense of his insight and the need to keep them happy is this at any cost? A sense of need to hold this together a degree of containment. Would things be out of control if this were not achieved?</u>

Pride in being unique as a sibling. Separation from others being different [viewed positively]. Pride in self as a sibling. Normalising experiences. Sibling acceptance of their reality their version of normal. Pride in difference.	1.625 I think it's kind of unique and a bit different because not 1.626 many people can say "I've got an autistic brother or 1.627 sister". So I mean it's quite different, like I've seen how 1.628 my other friends act with their brothers and sisters but 1.629 I mean I'm so used to having an autistic sister that it's 1.630 kind of standard for me and like normal. Like I'd be like 1.631 this normally because that's how I've been taught to act 1.632 when I was growing-up. So for me having an autistic, it's 1.633 like normal for me. I don't really know what it's like not 1.634 having an autistic sister personally, yeah. 1.635 **This is your life?** 1.636 Yeah. 1.637 **Literally. There used to be a programme called that!** 1.638 **This is your life. I'm just looking at my papers to remind** 1.639 **me now because you're, see I knew I would get drawn** 1.640 **into the things that you would interest me and that's** 1.641 **really good. If as I said that I was to sit and observe,** 1.642 **how would I see, you've talked about you, if your** 1.643 **friends come over, spending time with Zahra, you** 1.644 **would enable her to be part of your time with your** 1.645 **friends and you talked a lot about patience and respect** 1.646 **being important. But maybe the other way round, if I** 1.647 **were to sort of see you and Zahra enjoying activities** 1.648 **together, how would I see Zahra express how she feels** 1.649 **about you?**	It's kind of unique not everyone can say I have an autistic brother or sister. Sense of pride and setting them apart. Seen how other friends react. Further pride in himself as a brother. Its standard for me and like normal. I don't really know what its like not having an autistic sister. This is normal for me. Acceptance that this is reality, he knows no different and highlights how this sets him apart.

Keeping sibling happy is paramount. Worry of not containing a 'happy' existence. Siblings are proud of and love their sibling with IDs. Closeness of sibling relationship interdependence and reciprocated care and love. Realisation siblings with ID have resilience and can cope with unexpected situations.	1.650 I mean I always, even if we're not going out I always try 1.651 to like maybe keep her happy, make her laugh or like, 1.652 you know, make sure she's happy. And I think if we were 1.653 like going out or we were playing at the park or 1.654 something, you'll see her like laughing, playing very, in a 1.655 happy good mood because she enjoys going out. She 1.656 enjoys spending time with me. Like I was ill, I was like 1.657 really ill last week from school. 1.658 **Oh dear.** 1.659 Yeah. Because I had jabs on last Friday so on Monday I 1.660 was really ill and I stayed home and this is, I was going 1.661 to put this in the diary because this is the first time I've 1.662 really experienced this. Like I was in so much pain and 1.663 like really ill, I was lying down on the bed and Zahra saw 1.664 me like that and she started crying and like was so upset 1.665 because I was upset. So I kind of, I didn't know what to 1.666 do really to be honest because I've never experienced 1.667 that like. And then when I told her I'm staying home on 1.668 Monday the first thing she said is "will you play with 1.669 me?" 1.670 **Ah. Yes. And you told me you have quite long school** 653 **days?** 1.671 Yeah, definitely. 1.672 **So it would be unusual for Zahra for you to be home?**	I always try to keep her happy make her laugh, make sure she's happy. <u>Is he worried about what will happen if he doesn't make her happy?</u> She enjoys spending time with me. <u>Sense of pride, expression of love.</u> I was in so much pain really ill and Zahra saw me and started crying. She was so upset because I was upset. I didn't know what to do I've never experienced that. <u>Sense this was a time Shafeeq appreciated how much his sister cares about him and not the other way around.</u>

	1.673 For a long time, yeah. 1.674 **For a long time during the week? Yes. That would be a** 1.675 **great thing to put in the diary. It sounds like, because** 1.676 **that's a first experience.** 1.677 Yeah. 1.678 **I hope it's the last experience you have of being ill and** 1.679 **feeling like that. So I wondered, there's something that** 1.680 **I had, I didn't talk to your Mum about last week but,** 1.681 **you know, things about are there, you talked about,** 1.682 **you've described lots of things o using a phrase, you** 1.683 **know "as a family we do this" or "as a family we've** 1.684 **always tried to learn about autism or we've tried to** 1.685 **discuss it and we feel that, you know, we need to be** 1.686 **patient etc." Are there, do you think there are** 1.687 **particular characteristics about your family? Is there** 1.688 **sort of, you know, a cultural, um, are there sort of rules** 1.689 **or cultural, important things or is there a religious** 1.690 **thing that is part of the family, you know, what are the** 1.691 **kind of aspects of your family that mean that you** 1.692 **would think in that way? So are there religious beliefs** 1.693 **that you think influence how you behave as an** 1.694 **individual and as a family, you know, culture, I think** 1.695 **Mum, as I said Mum last week when we met** 1.696 **described herself very much as 'dad' and I know that** 1.697 **Mum works very hard. You've talked about that again** 1.698 **today. So are there characteristics, that's the word I'm** 1.699 **looking for, you heard me struggling for that. Are there**	

	1.700 **characteristics in your family that you think, you know,** 1.701 **are important about how you as a family have** 1.702 **responded to having Zahra in your life?**	
Culture and religion influence values and approach in family. Culture is integrated into care in families. Having a sibling with IDs brings families together, shared caring role. Age and experience over time are factors that enable siblings to develop coping strategies and better understand the needs of and relationship with their sibling with IDs. Parents {Mum} as gatekeeper parent response influences sibling response.	1.703 Well I think our culture especially is all about respect, 1.704 especially respect for elders. And our religion as well, it's 1.705 mainly about being a good person, being a good human 1.706 to other people. So I think we've just kind of integrated 1.707 that into Zahra and like focused our attention on Zahra 1.708 a bit to like, you know, care for her a bit more. And like, 1.709 you know, make sure she's not in danger, make sure 1.710 she's happy, just we as a family like I say we've all kind 1.711 of come together to, you know, focus a bit on her, to 1.712 make sure she grows up and, you know, improves a little 1.713 bit. Because when she was younger she had a struggle 1.714 even talking, like she couldn't, she didn't know how to 1.715 structure a sentence so we all focused our attention on 1.716 helping her with that and now she can talk a lot more, 1.717 you know, have a communication, have a, what's it 1.718 called? A conversation with someone, which I think 1.719 we've all helped her with. And I just, I think we, the one 1.720 thing I remember learning as a kid is about patience and 1.721 understanding. Those are the two words my Mum 1.722 always said to me, like even when I was like really young 1.723 and I didn't understand autism and was frustrated by 1.724 like what was happening, she would just tell me 1.725 patience and understanding. I think we've all kind of 1.726 learnt that, even as adults them lot, they've just learnt 1.727 that and they've taught me that. So I think that's the one 1.728 thing I remember really.	Our culture especially is about respect and our religion as well. Respect for our elders. Being a good person a good human to other people. Influence of culture and religion Integrated our culture into how we care for Zahra. As a family we have come together. Make sure she grows up and improves a little bit. Seems to suggest that family values and culture inextricably linked. She didn't know how to structure a sentence , we focused on that and now she can talk a lot more. Communication, have a conversation. I remember learning as a kid about patience and understanding. Having to consider and support his sister suggests that this has heightened his personal qualities of patience and understanding. I was young I didn't understand autism and was frustrated. That's the one thing I remember really Mum telling me patience and understanding.

	1.729 **And when you say those, and you've used those words** 1.730 **quite a lot in our conversation, patience and** 1.731 **understanding, so that's obviously something as you** 1.732 **say you've grown with?** 1.733 Yeah. 1.734 **When you said that in your culture and in your religion** 1.735 **that those also are characteristics that you feel are part** 1.736 **of that, so what would you describe as your culture?**	
Culture influences family behaviours. Asian families respect their elders, people with IDs.	1.738 I'm not too sure to be honest but I mean my grandma's 1.739 from Pakistan and we're mainly I think an Asian family. 1.740 So I think in Pakistan and Asia elderly people are so 1.741 highly respected, like you'd never do anything to wrong 1.742 an elderly person. So I think as a family we care for each 1.743 other quite a lot, and especially with Zahra.	We are mainly an Asian family. In Pakistan and Asia elderly people are so highly respected. You'd never do anything wrong Families care for each other, especially Zahra.
	1.744 **And in terms of religion, what would you describe as** 1.745 **the religion that is the family religion?**	
Religion is important in framing siblings values and who they are as people, not just as siblings. Moral, ethical and social compass is influenced by religion and culture.	1.746 Well we're all Muslims so we follow Islam and there's 1.747 lots of rules in Islam and stuff like that. But personally I 1.748 think Islam's quite a peaceful religion and the main thing 1.749 I stress is about, in Islam is about being a good person, 1.750 being a good human. So I try and like just base my life 1.751 on being a good person and not trying to wrong people. 1.752 **And what does that mean, what's your perception of**	We are all Muslims and we follow Islam. There are lots of rules in Islam. Islam is a peaceful religion. It's about being a good person a good human. I base my life on being a good person and not trying to wrong people. <u>Strong social ethical and moral compass influenced by religious teachings of Islam and Asian culture.</u>

	1.753 **what does that mean to Zahra…** 1.754 To Zahra? 1.755 **…having that culture and religion? I'm not asking you** 1.756 **to guess but, you know, how do you see her being part** 1.757 **of that?**	
Siblings with IDs can be carefree. Siblings have more responsibility cannot be as carefree. Loss of childhood, loss of freedom loss of 'carefreeness'. Religion and culture is important to siblings with IDs too.	1.758 I think she's a bit more carefree. She can't, is a bit in her 1.759 own world. She doesn't understand it as much as we do 1.760 but she definitely knows it exists I think because we've 1.761 taught her from a young age a little bit about like, less 1.762 about the ideas, more about the like just what you 1.763 should do. So about being kind and not being rude to 1.764 people, just teaching her how to be a good person rather 1.765 than be like a scholar or anything, yeah. 1.766 **So you mentioned a little while ago, you talked about** 1.767 **the responsibility that you felt I think you mentioned** 1.768 **and you talked a little bit about you think about the** 1.769 **future and some of the things that maybe you might** 1.770 **need to do and support Zahra, so you said you've** 1.771 **grown up with it?** 1.772 Yeah. 1.773 **And I just wonder in terms of what are your dreams for** 1.774 **the future? What sorts of things do you think about in** 1.775 **terms of jobs, careers, you know? What's important for** 1.776 **you about your future?**	*Zahra is more carefree,* [Is there some potential envy that he cannot be carefree?] a bit in her own world. She doesn't understand it as much as we do. She definitely knows it exists, we've taught her from a young age. <u>Realises the difference in his sister's engagement with the 'rules' but she engages with the principle to be a good person.</u> <u>Sense of pride in the family culture.</u> Teaching her to be a good person rather than a scholar.

Keeping sibling {with IDs} happy is priority. Pressure to do well, o to a good University, get a good job, linked to future caring role. Acceptance of reality, maturing early, burden of responsibility at young age. Looking for choice but this is framed in the context of his future caring role. Identifying with parental role. Insight, acceptance and maturity. Underlying concern with weight of current and future caring responsibility.	1.777 Well I mean for Zahra I think keeping her happy and I 1.778 just kind of need to try hard and go to a good university, 1.779 get a good job so I can provide for her and look after her. 1.780 I know I'm going to have to care for her for all my life 1.781 but I'm completely fine with that. I just know that I need 1.782 to kind of work my way so I can provide for her and keep 1.783 her happy. And personally I don't know what I want to 1.784 do yet to be honest. I haven't really given much thought 1.785 about it. I think in the summer we have a careers talk, 1.786 so yeah. 1.787 **Okay. So you were saying that you like maths and** 1.788 **physics and you'll be thinking about, so no thoughts?** 1.789 **And that's not unusual. You're 15, you've got plenty of** 1.790 **time to decide on that. But I'm interested when you** 1.791 **talk about, you know, you're fine with that, about** 1.792 **caring for Zahra for your life etc. How did you, how has** 1.793 **that come about that you have that sense of the future for you and Zahra?** 1.794 I kind of just realised really and like saw how much my 1.795 Mum looks after her and how much she relies on us. I'm 1.796 just thinking when I'm grown up my Mum might not be 1.797 around so I have to be the person there that she can like 1.798 100% rely on. And I know I can do it, I just need to make 1.799 sure I get a good job and stuff like that. 1.800 **How do you feel about that? It sounds, you talk a lot**	Keeping Zahra happy. He needs to try hard and go to a good University so he can provide for her. *I know I am going to have to care for her for all my life but I'm completely fine with that.* Is he worried to say that he is not 'completely fine' with some of this responsibility? Needing to have mature and responsible outlook at a young age. I don't know what I want to do yet haven't given it much thought. Seems to suggest his path is laid out to care for his sister how he does this will be through hard work, University and providing for her. I realised how much my Mum looks after her and when I'm grown up I have to be the person that she [Zahra] can 100% rely on. Huge insight and maturity at 15 recognising the needs of his family. *I know I can do it* Is there a suggestion of underlying question if he can do it? Presents a total acceptance of his responsibility for his sister now and in the future.

	1.801 **about responsibility and you very much come across as** 1.802 **a young man who carries that responsibility?**	Mum taught me the right thing from a young age and I know that's what I need to be like.
Being a sibling nurtures and requires greater maturity and social responsibility.	1.803 I mean my Mum's taught me to be like that from a young 1.804 age so I kind of know that that's the right thing and I 1.805 know like that's what I need to be like. If Zahra wasn't 1.806 around then I probably wouldn't be as responsible I 1.807 think because I wouldn't have to care this much about 1.808 anybody, I wouldn't have to like look after and attend to	If Zahra wasn't around I wouldn't be as responsible. I wouldn't have to care as much about anybody.
	1.809 people as much. I think having to look after Zahra and 1.810 care for her and care about her needs has made me a 1.811 more responsible person because I know I have that 1.812 responsibility.	I think having to look after Zahra has made me a more responsible person.
	1.813 **Would you say that that's made you think about that** 1.814 **from a younger age than you might have otherwise?**	
Acceptance of responsibility.	1.815 To be honest I haven't really thought about it much. It's 1.816 kind of just there and I know that that's, that it is what 1.817 it is.	That is what it is. Demonstrates absolute acceptance of his responsibilities at a young age.
	1.818 **Yeah. You've talked a lot about sort of growing-up with** 1.819 **that. And when you think about, we've talked a little** 1.820 **bit about sort of your, you know, your dreams etc., for** 1.821 **the future and you said that if you didn't have Zahra** 1.822 **maybe you wouldn't feel that way but it is what it is is** 1.823 **your phrase and I think that's a good phrase. What are** 1.824 **your dreams for Zahra's future? So what sorts of things** 1.825 **do you think that she might do when she's older? What**	

	1.826 **do you think are important for her? What things will be** 1.827 **important for her?**	
Sibling with IDs freer to be spontaneous.	1.828 She's very quick on deciding what she wants to do. She's 1.829 kind of already decided she wants to be, the most recent 1.830 thing that she wants to do is she wants to be a movie	She's quick deciding what she wants to do. Most recent thing she wants to be a movie director.
Mature but potentially unrealistic about future for sibling with IDs. Unrealistic that we are all happy all the time.	1.831 director now. So I mean I, for me I just want her to be 1.832 happy so whatever makes her happy, if being a nurse, 1.833 being a teacher, being a movie director or doing nothing 1.834 makes her happy, as long as it makes her happy then it's 1.835 fine.	For me ..whatever makes her happy being a nurse, a teacher a movie director or nothing, its fine. <u>Is he suggesting that all responsibility rests with Shafeeq and none with his sister.</u>
	1.836 **So she makes her mind up quite quickly you said?** 1.837 Yeah, definitely. 1.838 **Does that change quickly?**	
Sibling [with IDs} freer with choices/options.	1.839 I mean she can change her mind, yeah. So she was 1.840 obsessed with purple and now she's obsessed with pink, 1.841 or she said she wanted to be a teacher, now she's so 1.842 keen on being a movie director. And I mean her mind is 1.843 going to change but <u>I think whatever she wants to do</u> 1.844 <u>she can do really.</u>	She can change her mind quickly. Whatever she wants to do she can do really. <u>Is there a potential sense of acceptance that this is not true given his sister's needs?</u>
	1.845 **She's only 11?** 1.846 Yeah. 1.847 ***[Laughs]*** **And she's got…**	

Caring responsibility potentially conflicts with undecided career choice and future.	1.848 I'm 15 and I don't know what I want to do! 1.849 **Absolutely. And when you think about, sort of talk** 1.850 **about the future as a family, how do you talk about** 1.851 **those things as a family? You've described a lot of** 1.852 **things about as a, when you talk about your respect** 1.853 **and you talk about all sorts of things you use that** 1.854 **phrase quite a bit that "as a family we do this" so…**	
Family work together as a team. Has to keep her happy. String sense of caring and awareness of vulnerability of sibling with IDs	1.855 I mean I use that phrase as a family because we have to 1.856 work as a team and work together. But I mean we all 1.857 kind of see it as whoever's here, whoever's with Zahra, 1.858 whoever's looking after Zahra has to keep her happy and 1.859 has to ensure she's living a happy life. And just look after 1.860 her and take care of her, <u>not let her get in dangerous</u> 1.861 <u>situations, not let her be in danger and just, hopefully</u> 1.862 <u>just give her a very happy life.</u> 1.863 **That's sort of started to answer my next question. It** 1.864 **would have been if, you know, what do you think is the** 1.865 **most important thing or the most important things for** 1.866 **other siblings to know about being a brother or sister** 1.867 **of somebody who has autism or a learning difficulty,** 1.868 **whether it's the same as Zahra or as you've said there's** 1.869 **lots of things or something different? What do you** 1.870 **think is the most important thing that you would like** 1.871 **other siblings to know?**	As a family we have to work as a team to work together. Whoever's looking after Zahra has to keep her happy. Look after her not let her get into dangerous situations.

Sibling being happy is paramount. Families protect siblings with IDs going into hospital for being depressed and sad must be avoided. Siblings understand that society can be cruel and misunderstand or upset siblings with IDs. Fear of failure of family if sibling is not happy or is exposed to societal norms of upset. Need to protect sibling {with IDs} is strong.	1.872 Keep them happy. Never do anything to make them 1.873 upset or make them scared or sad. Definitely try to keep 1.874 them content and happy and enjoying life. 1.875 **Why do you think that's so important?** 1.876 I think that it's very easy for autistic people to get caught 1.877 up in everything and get upset and get fed up. Like I was 1.878 watching a programme about autism and it was talking 1.879 about a boy who just got so depressed and so upset that 1.880 he had to go to hospital and stuff like that. And I think 1.881 that you have to keep her happy and just keep her 1.882 enjoying life. Never wanting, I'd never want her to be 1.883 sad. I never want her to be like upset. 1.884 **When you say you'd never want her to be sad or upset,** 1.885 **what do you think about if she were sad or upset?** 1.886 I mean she hasn't, I haven't experienced many times 1.887 where she is sad but like for example if she's crying or 1.888feels scared or has a bad day or gets, her autism school 1.889 are so, there's other autistic kids. When she first went 1.890 to the school one of the other autistic kids said 1.891 something to her and she got really upset through it and 1.892 she was like crying and, because she's never 1.893 experienced that before. So I mean I just don't want to 1.894 see her upset to be honest. 1.895 **You talked about on Monday when you weren't very** 1.896 **well and she was upset?**	Keep them happy, never make them upset. Is there a suggestion of a distorted sense of reality here? Is this degree of happiness possible? It is easy for autistic people to get upset and fed up. I watched a programme about autism as boy got so upset he went into hospital. You have to keep her happy. Never wanting. *I's never want her to be sad.* An inference that keeping his sister happy will prevent her going to hospital. I haven't experienced many times where she is sad. At her School other autistic kids said something. To her and she got upset. I don't want to see her upset to be honest. Zahra being upset is to be avoided always.

		I was really upset, in pain and ill.
Siblings have loving relationships and show love and share empathy with one another.	1.897 Yeah. I had no idea. I was like, because I was really upset 1.898 and I was really in pain and just really ill, so she saw me 1.899 like that and her just seeing me like that had such a big 1.900 impact on her, it kind of like amazed me and kind of 1.901 shocked me a bit because I've never like thought that 1.902 she would be like that.	Seeing me like that had a big impact on her. It amazed me, shocked me I never thought she would be like that.
	1.903 **And how did that make you feel? Because you said it's** 1.904 **really important that people know that, you know, you** 1.905 **don't want her to be upset but how did it make you** 1.906 **feel?**	
Sibling relationships are strong, empathic and emotional responses are interrelated in their individual and shared experiences. Siblings want to protect their sibling {with IDs} but reality is they cannot always succeed.	1.907 A little bit upset initially because like just seeing her like 1.908 that is a bit weird and a bit upsetting because I had no 1.909 intent to make her feel like that obviously. But the fact 1.910 that she got like that in such a quick moment of time 1.911 because I was upset, because I was, that shows how 1.912 much of an influence I have on her.	A little bit upset seeing. Her like that is weird and upsetting. I had no intent to make her feel like that obviously. *I was upset,* [so she was upset] *shows how much of an influence I have on her.* <u>Did this reinforce his sense of responsibly to keep everything calm and keep his sister happy. Using the phrase *'I had no intent,'* is there a reality that he cannot always protect her from life experiences?</u>
	1.913 **But what does that say to you about your relationship** 1.914 **with Zahra?**	
Sibling relationships are interrelational, caring and strong.	1.915 I think she looks up to me quite a lot and she like cares 1.916 about, because <u>I've cared about her, she cares about</u> 1.917 <u>me</u>.	She looks up to me quite a lot, she cares about me. <u>Realises he is cared about by his sister, as he cares for her.</u>
	1,918 **Yeah, I think so. And if you, so you talked about when** 1.919 **you first, you said you don't sort of remember when**	

Knowledge and information is important for siblings to understand their brother or sister. Parents are primary gatekeepers of information and role models of behaviour. Information specifically for and accessible to siblings is valued.	1.920 **you first knew that Zahra had autism, it's just always** 1.921 **been…** 1.922 Yeah, like been there. 1.923 **…it is how it is? What do you think is kind of the best** 1.924 **place to find out information about, so have you read** 1.925 **anything before about brothers and sisters in the** 1.926 **information that you've had about being a brother to** 1.927 **somebody with autism, or where do you think would** 1.928 **the place to find information?** 1.929 I mean I haven't been taught really about how to be a 1.930 brother of someone with autism. I've just been taught 1.931 how to be a family member with someone with autism. 1.932 So just like my Mum researched, she passed that 1.933 information on to me and I researched, and me and my 1.934 Mum learnt in the same way. So it's not been like a thing 1.935where it's different for the siblings to be honest. For me 1.936 it's just been the same, I've been treating her the same 1.937 as my Mum has. 1.938 **Yes. Obviously my work and the research that I'm** 1.939 **trying to look at is to talk to brothers and sisters just to** 1.940 **find out their thoughts and for them to share as you** 1.941 **very kindly are, share their experiences and their** 1.942 **thoughts and ideas. Why do you think that might be an** 1.943 **important thing to do? Obviously I'm very grateful for** 1.944 **you agreeing to talk to me. Why do you think it might**	Mum researched information, passed it on to me. It wasn't different for the siblings. I've treated her the same as my Mum has. <u>Parents {Mum] as gatekeepers and role models.</u> No-one's ever really done research on what it's like to be a sibling.

	1.945 **be important? Or do you think it's important and if you** 1.946 **do, why?** 1.947 Because no-one's ever really done research on what it's 1.948 like to be a sibling. Like when I was younger I never 1.949 found anything on how to be sibling. I just learnt how to 1.950 be like a family, have someone with autism, just like my 1.951 Mum did. So I mean I think it's good that this research is 1.952 going on because it kind of gives a bit of insight into, you 1.953 know, people that have young autistic children on how 1.954 to act and how to act if you're a sibling. Because I think 1.955 it's a bit more on a personal level, like I learnt through 1.956 how to live with an autistic person but I think if there's 1.957 actually information on how to be a sibling I think that's 1.958 a bit more personal and it's a bit more easy to 1.959 understand. 1.960 **Oh that's really interesting. If you, so you've talked** 1.961 **about talking to your friends or talking to your, you** 1.962 **know, or the siblings, if there were other people like** 1.963 **me, so professionals or, you know, schoolteachers or** 1.964 **helpers or other people who are going to be supporting** 1.965 **young people who are brothers and sisters of siblings,** 1.966 **do you think there are things that's important for them** 1.967 **to think about? What sorts of things are important for** 1.968 **professionals and people that are working with** 1.969 **siblings, with brothers and sisters to think about? If you** 1.970 **were to give them advice perhaps, what might, what** 1.971 **sorts of things might you say they should be thinking** 1.972 **about?**	When I was younger I never found anything on how to be a sibling. I just learned with the family just like Mum did. Research is good to give insight into how to act if you are a sibling. I think it's a bit more on a personal level, I learned through living with a sibling, but If there's information on being a sibling I think this is more personal and it's a bit more easy to understand. <u>A sense that something focused for siblings would be helpful.</u>

Knowledge is important but must be contextualised to personal experience. Relationships with the person, their sibling, their family is important for any intervention or knowledge exchange for families. Personal connections are important to aid understanding.	1.973 I think really kind of understand the situation like on a 1.974 personal level instead of like what's the fact. I think get 1.975 to know the person like you have, get to know the 1.976 person and get to know the siblings. I think that's 1.977 probably the best way to do it. And I think the siblings, 1.978 like in this process when you get to know the siblings I 1.979 think they feel a bit more comfortable and a bit more, 1.980 they think it's a bit more, like I said it's a bit more on a 1.981 personal level. I think it's just, I think it's just more easy 1.982 to talk about if it's on a personal level. And if a 1.983 professional understands, because like for example like 1.984 teachers, not with autism but teachers with school talk 1.985 about what's going on, they never know about the 1.986 student personally. So I think having a personal 1.987 connection with the student or with the sibling makes 1.988 them find it easier to talk about and easier to 1.989 understand I think. 1.990 **Yes? And is there anything that you think that you sort** 1.991 **of expected that I might ask you or…?** 1.992 I think, I haven't thought about it much to be honest. 1.993 The one thing I had in my mind that you were going to 1.994 ask is what is it like living with her or what is it like having 1.995 an autistic sister. That was the only question I really 1.996 thought about to be honest so… 1.997 **And do you feel I've asked that in my own way?**	Advice for professionals is to get to know the person and the siblings. I think siblings, like in this process, when you get to know them, feel more comfortable. More easy to talk about on a personal level. Having a personal connection with the student [for teachers] or with the sibling makes it easier for them to talk and to understand. I thought you were going to ask what it is like living with her.

	1.998 Yeah. I think so, yeah. 1.999 **Hopefully!** 1.1000 In multiple questions, yeah. 1.1001 **In multiple *[laughs]*, multiple questions. Sorry about** 1.1002 **that! And so that's it. Is there anything else that you** 1.1003 **think whilst we've had the conversation or that as** 1.1004 **we've been going along and talking that's occurred to** 1.1005 **you that you think "oh that's something that's** 1.1006 **important" or "it's really important that {Researcher's** 1.1007 **name] makes sure that that's kind of a message that's** 1.1008 **in the research for other people to know about"?** 1.1009 Not really to be honest. I think I've talked about pretty 1.1010 much everything I've thought about and everything 1.1011 that I know really. 1.1012 **Yeah, okay. That's been really helpful to me and as I** 1.1013 **said I deviated all over the place because you've given** 1.1014 **me so many interesting things and been so honest** 1.1015 **and, you know, you talk a lot about being respectful** 1.1016 **and being kind and I have to say thank you. I feel very** 1.1016 **respected and it's very kind of you to give your time** 1.1017 **after a long week, especially when you've not been** 1.1018 **well on Monday. So thank you ever so much. So yeah,** 1.1019 **we talked about keeping the diary.** 1.1020 Yeah.	I've talked about everything I thought of, that I know.

	1.1021 **So would you, what's the best way for you to keep** 1.1022 **that? Is that in a written diary or on, you've got a** 1.1023 **laptop computer?** 1.1024 Yeah, a laptop. 1.1025 **Is that your best, is that your preferred…?** 1.1026 I think either writing it down or on computer, like not 1.1027 vocal. I think I'd prefer to have it written down or 1.1028 written down on a laptop, either way. 1.1029 **Well really Shafeeq any way that suits you, that's fine.** 1.1030 **And we talked last week that, you know, I know** 1.1031 **you're a busy young 15 year old young man with lots** 1.1032 **of things going on, but I'm ever so grateful for your** 1.1033 **contribution to this. And the diary as we said, I don't** 1.1034 **know whether you've got any questions about that** 1.1035 **but it was, you've described Monday was a good** 1.1036 **situation to reflect on?** 1.1037 Yeah. I think all the questions I had were answered in 1.1038 the leaflet. Everything I needed to know was in that 1.1039 so… 1.1040 **Yeah. So that's what I'll say from here is that, that's** 1.1041 **our conversation for today but if there's anything that** 1.1042 **you think about that you think occurs to you…**	Writing the diary or on the computer. All the questions about keeping the diary were answered in the leaflet.

	1.1043 Just write it down. 1.1044**…you think it will be useful, yeah, write it down or** 1.1045 **we've got, we've decided that email will be our** 1.1046 **contact?** 1.1047 Yeah, email's quite easy. 1.1048 **So, you know, I'll kind of give you an email once a** 1.1049 **month. I'm not going to bother you, I know as I say** 1.1050 **you're very busy but just to say that I'm thinking of** 1.1051 **you and just seeing how things are going for you with** 1.1052 **keeping a little diary. And it is as you said as things** 1.1053 **occur, so something happened on Monday, you** 1.1054 **weren't thinking about putting something in the** 1.1055 **diary but a situation happened and it's little things** 1.1056 **like that. It's whatever you feel would be important?** 1.1057 To be honest before you first came to meet me I was 1.1058 told, my Mum told me about the diary and all about 1.1059 what was going to happen and I just kind of thought to 1.1060 myself about the diary, like I don't know what to write 1.1061 because nothing happens. But on Monday I 1.1062 experienced something new, so yeah, I'll see if 1.1063 1.1063 anything else happens. 1.1064 **Yeah. And that's, you know, as I say or if you, now** 1.1065 **that we've had a conversation maybe other things will** 1.1066 **occur to you that you think it would be important?**	My Mum told me all about the diary before you came to meet with me. I just thought to myself like I don't know ow what to write. On Monday I experienced something, so I'll see if anything else happens. Maybe I'll notice things now. <u>Engaging in the research process could potentially help Shafeeq to notice things more from the perspective of a sibling?</u>
Involving siblings in research discussions may enhance 'noticing'. Siblings are willing to share personal experience to help other siblings.		

	1.1067 Yeah. Maybe I'll notice things now, yeah. 1.1068 **Yeah. I think it's really valuable Shafeeq and again as** 1.1069 **I said thank you for that. But it's any little thing that** 1.1070 **you think and it doesn't have to be a big thing. That** 1.1071 **sounds like quite a big experience for you both on** 1.1072 **Monday?** 1.1073 Yeah that is, definitely, yeah. 1.1074 **So really important to hear that but it doesn't have to** 1.1075 **be a big thing. It can be something small that you,** 1.1076 **you've described as you said you've grown up with** 1.1077 **Zahra and are very experienced at being a brother** 1.1078 **supporting your sister but it would be useful for us to** 1.1079 **understand things that maybe you can share with** 1.1080 **people who are not so experienced. So, you know,** 1.1081 **don't feel limited by what you can, we can turn this** 1.1082 **off anyway now. Thank you.**	

Appendix 13 (b): Analysis of connections emergent themes participant 1

Analysis of Connections from Emergent Themes – Interview 1

1.6 Birth order

1.12 Identity encompasses a wide range of life experience and varied activities and interests

1.30 Chronological age, education, choices begins to change priorities

1.44 With maturity comes increased responsibility.

1.57 Being a team player is important in life.

1.66 Personal choice is important

1.70 Expression of self, through likes and dislikes, personal choice helps things to be fine.

1.81 Varied social relationships are important.

1.85 Relaxation opportunities are important.

1.96 Opportunity for interests outside the family are important.

1.106 Shared experiences with sibling is important and enjoyable.

1.110 Seeing sister's enjoyment brings enjoyment for sibling.

1.115 Care and understanding requires compromise.

1.118 Siblings have fun together.

1.124 Keeping sibling happy prioritised.

1.127 Choices influenced by sibling needs, potential loss of self-identity.

1.136 Happy approach and positivity is a valued attribute.

1.158 Family is the main priority.

1.159 Avoid upset and shame.

1.162 Upsetting people is bad.

1.170 Maturity and sense of responsibility. Strong partnership with parent.

1.172-1.176 Deep realisation of parental investment, shared responsibility.

1.180-1.185 Importance of extended family. Mutual support and care, family system working together.

1.197 Mature sense of responsibility to family/others.

1.198 Compromise requires some sacrifice and loss of agency.

Fragility of relationships and need to contain things.

1.205 Strong sense of acceptance and embracing responsibility.

1.245 Knowledge of intellectual disabilities varies. Term autism captures all autism things.

1.259 Sibling knowledge is learned over time. Referenced to personal experience with sibling.

1.265 Siblings relate learned knowledge to their own sibling and circumstance. Knowledge can be quite sophisticated.

1.269 Normalising diagnosis 'autism' affects everyone we are all on a spectrum.

1.280 Age impacts on awareness of IDs for siblings.

1.282 Knowledge can be helpful to enable understanding.

1.282 Sibling's acceptance of IDs as their norm as young children.

1.287 Begin to 'notice' as they get older.

1.282-1.289 Social influence, acceptance, noticing of difference changes as sibling get older and gain more knowledge.

1.295 Learning to understand IDs together as a family is valued.

1.309 Parents are the initial gate keepers of knowledge for siblings.

1.312 Self-help is needed in families to help develop knowledge and understand IDs.

1.317-1.320 Family gaining information and knowledge together is valuable.

1.317-1.320 Sibling need for knowledge and information is needed as they grow to help them understand and to help their sibling.

1.334 Siblings have a lot of questions.

1.335 Parent [Mum] is the gatekeeper of explanations and information.

1.340 Sibling's maturity and sense of caring for sister.

1.340 Sibling experience may differ from peers. Needing to mature take responsibility.

1.345-1.347 Influence of family structure and relationships linked to roles and responsibilities.

1.349-1.353 Siblings take on parenting type role.

1.352 Sibling role influenced by family structure [Single parent/Mum].

1.358-1.360 Sibling maturity. Care and concern for sibling.

1.360 Siblings demonstrate strong sense of empathy and care for sibling/sister.

1.362 External expertise and support is important and valued by families.

1.363 Siblings take early responsibility for their sibling/sisters care. Potential loss of self. Loss of agency.

1.371-1.378 Sibling experience is different, may attend specialist school.

1.384 Freedom to do what you want is better than a systematic approach and control.

1.391-1.398 Siblings with IDs can experience social challenges and isolation.

1.391-1.398 Siblings demonstrate empathy to their siblings with IDs.

1.391-1.398 Sibling maturity and need to be aware of social challenges e.g. finding the right support early in life.

1.395 Strong sense of caring for sibling with IDs. Mature ability to 'notice' and adapt to their needs.

1.397 Impact on sibling self expression/agency needing to adapt to sibling with IDs 'mood' and behaviour.

1.401 Care for sibling is important.

1.401-1.406 Sibling needs to take responsibility.

1.404 Reassurance can help siblings with IDs.

1.405-1.406 Relationship of trust between siblings.

1.403-1.404 Sibling with IDs is vulnerable.

1.405-1.406 A need for things to be ok. A sense of containing things.

1.411 Sense of maturity, recognising sibling's naivety.

1.418 Importance of Trust in families.

1.411-1.421 Vulnerability of sibling with IDs, trusting anyone.

1.417 Sibling aware of stranger danger.

1.411/1.417 Trust. Sense of sibling responsibilities now and in the future?

1.411-1.417 Power imbalance, agency for both siblings.

1.424 Parent is gateway for information.

1.427-1.430 Sibling relationships are strong.

1.429-1.430 Leadership and role modelling responsibilities for siblings.

1.430 1.432 Loss of personal 'self' agency, 'need to be good influence'.

1.434-1.435 Maturity, strong sense of being responsible for his sibling. Courage and sense of fear.

1.435 Awareness of burden of 'big' responsibility.

1.499-1.451 The experience of caring for siblings with IDs teaches siblings to be caring to others.

1.453 Positive reflection of sibling relationships differs positively from his peers.

1.453-1.458 Sibling relationships are different from peers.

1.449-1.458 Envy for the norm to argue and be challenged. Envy from peers for the closeness and care of this sibling relationship.

1.470 Parent as gatekeeper.

1.472-1.474 Patience and understanding.

1.474-1.482 Loss of personal agency and that of the family.

1.483-1.486 Having a sibling with IDs fosters the development of positive qualities in siblings and families, understanding, care, patience.

1.493 Siblings need space to be themselves.

1.495 Siblings are open about having a sibling with IDs, it is not something to hide.

1.497-1.498 Can feel conflicted at times, space for self and space for being with sibling.

1.505 Pride in sibling with IDs showing confidence to others.

1.523 Siblings care for their sibling and expect others to do so. Being respectful is important.

1.527-1.530 Societal acceptance, ethical values and respect is important to siblings. How others treat their sibling with IDs.

1.521-1.530 Cultural values influence expected behaviours of self and society.

1.547 Siblings enjoy the same things.

1.565-1.573 Some social restrictions with friendships.

1.565-1.573 Care and desire to involve siblings and expectation of friends to do the same. Positive role model to others.

1.573 Willingness to share experiences.

1.577-1.581 Finding personal space can be difficult if involving sibling all the time.

1.591 Siblings sometimes compromise more than their sibling with IDs. Different rules for them and their siblings.

1.591 Siblings defend their sibling with IDs. Siblings challenge others and choose relationships with people sharing

1.596 Similar values of care and respect in their friendships.

1.613 Being patient and understanding is key to being a sibling to someone with IDs.

1.613 -1.618 Values of a sibling are patience, understanding, suiting them, encouraging them, doing things at their pace, keeping them happy.

1.619 Sense of containment keeping the sibling with IDs happy is prioritised, potential fear of not keeping them happy and consequences.

1.613-1.619 A need to contain self-expression and emotions.

1.625 Pride in being unique as a sibling.

1.627 Separation from others being different [viewed positively].

1.626 Pride in self as a sibling.

1.629-1.634 Normalising experiences.

1.632-1.634 Sibling acceptance of their reality their version of normal.

1.633 Pride in difference.

1.651 Keeping sibling happy is paramount. Worry of not containing a 'happy' existence.

1.655-1.656 Siblings are proud of and love their sibling with IDs.

1.662-1.669 Closeness of sibling relationship interdependence and reciprocated care and love.

1.668-1.669 Realisation siblings with ID have resilience and can cope with unexpected situations.

1.703 Culture and religion influence values and approach in family.

1.704-1.706 Culture is integrated into care in families.

1.707 Having a sibling with IDs brings families together, shared caring role.

1.718-1.728 Age and experience over time are factors that enable siblings to develop coping strategies and better understand the needs of and relationship with their sibling with IDs.

1.721-1.725 Parents {Mum} as gatekeeper parent response influences sibling response.

1.738-1.743 Culture influences family behaviours.

1.738-1.743 Asian families respect their elders, people with IDs.

1.746-1.751 Religion is important in framing siblings values and who they are as people, not just as siblings.

1.746-1.751 Moral, ethical and social compass is influenced by religion and culture.

1.758 Siblings with IDs can be carefree.

1.758-1.765 Siblings have more responsibility cannot be as carefree. Loss of childhood, loss of freedom loss of 'carefreeness'.

1.760 Religion and culture is important to siblings with IDs too.

1.777 Keeping sibling {with IDs} happy is priority.

1.778-1.779 Pressure to do well, go to a good University, get a good job, linked to future caring role.

1.778-1.779 Acceptance of reality, maturing early, burden of responsibility at young age.

1.780-1.786 Looking for choice but this is framed in the context of his future caring role.

1.797 Identifying with parental role.

1.794-1.798 Insight, acceptance and maturity.

1.794-1.799 Underlying concern with weight of current and future caring responsibility.

1.805 -1.812 Being a sibling nurtures and requires greater maturity and social responsibility.

1.811-1.812 Acceptance of responsibility.

1.828 Sibling with IDs freer to be spontaneous.

1.829-1.835 Mature but potentially unrealistic about future for sibling with IDs.

1.834 Unrealistic that we are all happy all the time.

1.829-1.835 Sibling [with IDs} freer with choices/options.

1.780-1.786; 1.848 Caring responsibility potentially conflicts with undecided career choice and future.

1.856 Family work together as a team.

1.858 Has to keep her happy. [Containment]

1.860-1.861 Strong sense of caring and awareness of vulnerability of sibling with IDs

1.862 Sibling being happy is paramount.

1.876-1.883 Families protect siblings with IDs going into hospital for being depressed and sad must be avoided.

1.890-1.894 Siblings understand that society can be cruel and misunderstand or upset siblings with IDs.

1.893 Fear of failure of family if sibling is not happy or is exposed to societal norms of upset. Need to protect sibling {with IDs} is strong.

1.897-1.902 Siblings have loving relationships and show love and share empathy with one another.

1.901-1.902 Sibling relationships are strong, empathic and emotional responses are interrelated in their individual and shared experiences.

1.907-1.912 Siblings want to protect their sibling {with IDs} but reality is they cannot always succeed.

1.911-1.912 Sibling relationships are inter-relational, caring and strong.

1.929-1.937 Knowledge and information is important for siblings to understand their brother or sister.

1.932 Parents are primary gatekeepers of information and role models of behaviour.

1.947-1.949 Information specifically for and accessible to siblings is valued.

1.955 Knowledge is important but must be contextualised to personal experience.

1.974-1.982 Relationships with the person, their sibling, their family is important for any intervention or knowledge exchange for families.

1.986-1.989 Personal connections are important to aid understanding.

1.1061-1.1067 Involving siblings in research discussions may enhance ‘noticing’.

1.1057-1.1063 Siblings are willing to share personal experience to help other siblings.

Appendix 13 (c): Abstraction of themes of transcript 1

Abstraction & Subsumption of Emergent Themes from Transcript 1 [Working from right to left]

Emerging Super-ordinate themes	Sub Themes	Transcript Emergent Themes Grouped through abstraction/subsumption – created by hard copy cut and visualising process.
1 Sibling age, life stage and experience impacts experiences.	• Birth order [older/younger siblings]. • Age influence on understanding and potential stressors. • Impact of social construct of Intellectual disability.	1.6 Birth Order 1.30 Age, Education choice changes priorities. 1.44 With maturity comes increased responsibility. 1.280 Age impacts on awareness of ID for siblings. 1.287 Begin to notice as they get older. 1.282-1.289 Social influence, acceptance, noticing of difference changes as sibling get older and gain more knowledge. 1.718-1.728 Age and experience over time are factors that enable siblings to develop coping strategies and better understand the needs of and relationship with their sibling with IDs. [7 Refs]
2 Valuing the sibling relationship, positive accounts.	• Empathic sibling relationships. • Valuing sibling. • Valuing the sibling role and relationship. • Pride in self; in sibling and their achievements. • Genuineness, love, care and compassion.	1.106 Shared experiences with sibling is important and enjoyable. 1.110 Seeing sister's enjoyment brings enjoyment for sibling. 1.118 Siblings have fun together. 1.282-1.286 Sibling's acceptance of IDs as their norm as young children. 1.340 Sibling's maturity and sense of caring for sister. 1.358-1.360 Sibling maturity. Care and concern for sibling. 1.360 Siblings demonstrate strong sense of empathy and care for sibling/sister. 1.391-1.398 Siblings with IDs can experience social challenges and isolation. 1.401 Care for sibling is important. 1.405-1.406 Relationship of trust between siblings. 1.427-1.430 Sibling relationships are strong. 1.493 Siblings need space to be themselves. 1.505 Pride in sibling with IDs showing confidence to others. 1.547 Siblings enjoy the same things. 1.625 Pride in being unique as a sibling. 1.626 Pride in self as a sibling. 1.633 Pride in difference. 1.655-1.656 Siblings are proud of and love their sibling with IDs.

			1.662-1.669 Closeness of sibling relationship interdependence and reciprocated care and love. 1.668-1.669 Realisation siblings with ID have resilience and can cope with unexpected situations. 1.797 Identifying with parental role. 1.860-1.861 Strong sense of caring and awareness of vulnerability of sibling with IDs. 1.897-1.902 Siblings have loving relationships and show love and share empathy with one another. 1.911-1.912 Sibling relationships are inter-relational, caring and strong. 1.986-1.989 Personal connections are important to aid understanding. [25 Refs]
3	Coping strategies and managing sibling with ID relationships in the family.	• Self-expression and potential for emotional containment. • The '*Happy*' Sibling. • Normalising experiences.	1.124 Keeping sibling happy prioritised. 1.199 Fragility of relationships and need to contain things. 1.136 Happy approach and positivity is a valued attribute. 1.405-1.406 A need for things to be ok. A sense of containing things. 1.159 Avoid upset and shame. 1.162 Upsetting people is bad. 1.613 -1.618 Values of a sibling are patience, understanding, suiting them, encouraging them, doing things at their pace, keeping them happy. 1.613-1.619 A need to contain self-expression and emotions. 1.619 Sense of containment keeping the sibling with IDs happy is prioritised, potential fear of not keeping them happy and consequences. 1.629-1.634 Normalising experiences. 1.651 Keeping sibling happy is paramount. Worry of not containing a 'happy' existence. 1.777 Keeping sibling {with IDs} happy is priority. 1.862 Sibling being happy is paramount. 1.876-1.883 Families protect siblings with IDs going into hospital for being depressed and sad must be avoided. 1.834 Unrealistic that we are all happy all the time. 1.858 Has to keep her happy.[Containment] 1.893 Fear of failure of family if sibling is not happy or is exposed to societal norms of upset. Need to protect sibling {with IDs} is strong. [17Refs]
4	Sibling 'agency'.	• The maturity of siblings.	1.127 Choices influenced by sibling needs, potential loss of self-identity. 1.197 Mature sense of responsibility to family/others.

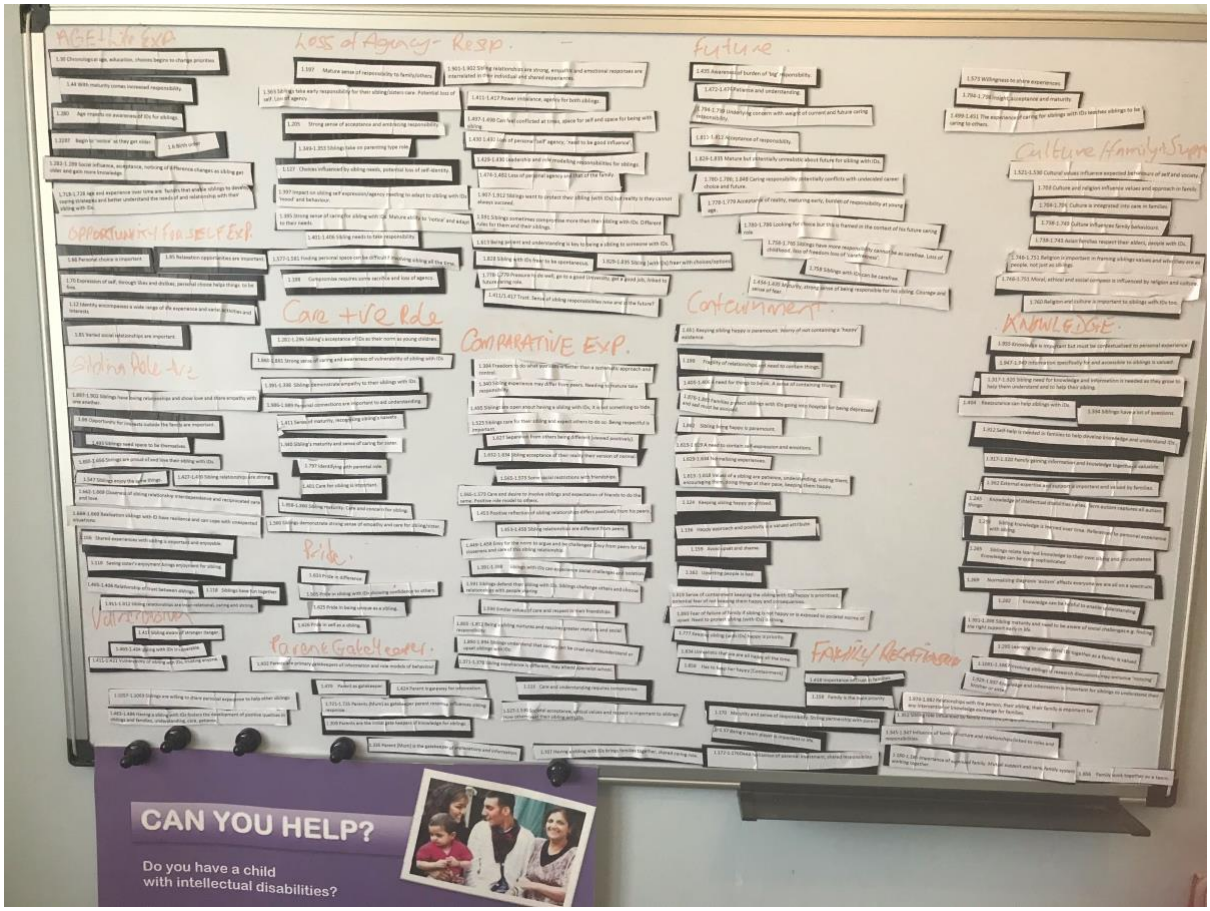
	• A need for selflessness. • Loss of agency. • Responsibility and compromise for siblings. • Role dynamics with siblings and other family members, [the sibling as parent and protector]. • Power and agency for siblings and their sibling with ID. • The relationship of trust and vulnerability for siblings with ID and for self.	1.198 Compromise requires some sacrifice and loss of agency. 1.205 Strong sense of acceptance and embracing responsibility. 1.349-1.353 Siblings take on parenting type role. 1.363 Siblings take early responsibility for their sibling/sisters care. Potential loss of self. Loss of agency. 1.395 Strong sense of caring for sibling with IDs. Mature ability to 'notice' and adapt to their needs. 1.397 Impact on sibling self-expression/agency needing to adapt to sibling with IDs 'mood' and behaviour. 1.401-1.406 Sibling needs to take responsibility. 1.403-1.404 Sibling with IDs is vulnerable. 1.411/1.417 Trust. Sense of sibling responsibilities now and in the future? 1.411-1.417 Power imbalance, agency for both siblings. 1.411-1.421 Vulnerability of sibling with IDs, trusting anyone. 1.417 Sibling aware of stranger danger. 1.429-1.430 Leadership and role modelling responsibilities for siblings 1.430 1.432 Loss of personal 'self' agency, 'need to be good influence'. 1.474-1.482 Loss of personal agency and that of the family. 1.497-1.498 Can feel conflicted at times, space for self and space for being with sibling. 1.577-1.581 Finding personal space can be difficult if involving sibling all the time. 1.591 Siblings defend their sibling with IDs. Siblings challenge others and choose relationships with people sharing 1.613 Being patient and understanding is key to being a sibling to someone with IDs. 1.778-1.779 Pressure to do well, go to a good University, get a good job, linked to future caring role. 1.828 Sibling with IDs freer to be spontaneous. 1.829-1.835 Sibling [with IDs} freer with choices/options. 1.901-1.902 Sibling relationships are strong, empathic and emotional responses are interrelated in their individual and shared experiences. 1.907-1.912 Siblings want to protect their sibling {with IDs} but reality is they cannot always succeed. [26 Refs]
5 Imagining the future, growing up and responsibilities.	• The impact of current and future responsibilities. • Visualising my future as a sibling? • Visualising my sibling's with ID future?	1.434-1.435 Maturity, strong sense of being responsible for his sibling. Courage and sense of fear. 1.435 Awareness of burden of 'big' responsibility. 1.472-1.474 Patience and understanding. 1.758 Siblings with IDs can be carefree. 1.758-1.765 Siblings have more responsibility cannot be as carefree. Loss of childhood, loss of freedom loss of 'carefreeness'. 1.780-1.786 Looking for choice but this is framed in the context of his future caring role. 1.778-1.779 Acceptance of reality, maturing early, burden of responsibility at young age.

		1.780-1.786; 1.848 Caring responsibility potentially conflicts with undecided career choice and future. 1.794-1.798 Insight, acceptance and maturity. 1.811-1.812 Acceptance of responsibility. 1.829-1.835 Sibling [with IDs} freer with choices/options. [11 Refs]
6 Sibling self-identity and expression.	• The need and value of outside interests. • The importance of friendships and acceptance. • Comparative experience to peers; [‘*the same and different’].* • Realities; social impacts and acceptance of sibling with ID by peers/others. • Seeking shared values in relationships.	1.66 Personal choice is important. 1.85 Relaxation opportunities are important. 1.70 Expression of self, through likes and dislikes, personal choice helps things to be fine. 1.12 Identity encompasses a wide range of life experience and varied activities and interests. 1.81 Varied social relationships are important. 1.96 Opportunity for interests outside the family are important. 1.115 Care and understanding requires compromise. 1.340 Sibling’s maturity and sense of caring for sister. 1.371-1.378 Sibling experience is different, may attend specialist school. 1.384 Freedom to do what you want is better than a systematic approach and control. 1.391-1.398 Siblings with IDs can experience social challenges and isolation. 1.453 Positive reflection of sibling relationships differs positively from his peers. 1.453-1.458 Sibling relationships are different from peers. 1.495 Siblings are open about having a sibling with IDs, it is not something to hide. 1.499-1.451 The experience of caring for siblings with IDs teaches siblings to be caring to others. 1.523 Siblings care for their sibling and expect others to do so. Being respectful is important. 1.547 Siblings enjoy the same things. 1.565-1.573 Some social restrictions with friendships. 1.565-1.573 Care and desire to involve siblings and expectation of friends to do the same. Positive role model to others. 1.591 Siblings defend their sibling with IDs. Siblings challenge others and choose relationships with people sharing 1.596 Similar values of care and respect in their friendships. 1.627 Separation from others being different [viewed positively]. 1.632-1.634 Sibling acceptance of their reality their version of normal. 1.794-1.798 Insight, acceptance and maturity. 1.805 -1.812 Being a sibling nurtures and requires greater maturity and social responsibility. 1.890-1.894 Siblings understand that society can be cruel and misunderstand or upset siblings with IDs. [27 Refs]

7	Family dynamics and behaviours influence/impact sibling experience.	• Family context and relationships. • Empathic relationships with parents and wider family. • The parent as gatekeeper. • The influence of cultural context. • The influence of religious beliefs.	1.57 Being a team player is important in life. 1.158 Family is the main priority. 1.170 Maturity and sense of responsibility. Strong partnership with parent. 1.172-1.176 Deep realisation of parental investment, shared responsibility. 1.180-1.185 Importance of extended family. Mutual support and care, family system working together. 1.309 Parents are the initial gate keepers of knowledge for siblings. 1.335 Parent [Mum] is the gatekeeper of explanations and information. 1.345-1.347 Influence of family structure and relationships linked to roles and responsibilities. 1.352 Sibling role influenced by family structure [Single parent/Mum]. 1.418 Importance of Trust in families. 1.424 Parent is gateway for information. 1.470 Parent as gatekeeper. 1.483-1.486 Having a sibling with IDs fosters the development of positive qualities in siblings and families, understanding, care, patience. 1.521-1.530 Cultural values influence expected behaviours of self and society. 1.703 Culture and religion influence values and approach in family. 1.704-1.706 Culture is integrated into care in families. 1.707 Having a sibling with IDs brings families together, shared caring role. 1.721-1.725 Parents {Mum} as gatekeeper parent response influences sibling response 1.738-1.743 Culture influences family behaviours. 1.738-1.743 Asian families respect their elders, people with IDs. 1.746-1.751 Religion is important in framing siblings values and who they are as people, not just as siblings. 1.746-1.751 Moral, ethical and social compass is influenced by religion and culture. 1.760 Religion and culture is important to siblings with IDs too. 1.856 Family work together as a team. 1.932 Parents are primary gatekeepers of information and role models of behaviour. 1.974-1.982 Relationships with the person, their sibling, their family is important for any intervention or knowledge exchange for families. [26 Refs]
8	Valuing knowledge and information.	• The importance of contextualised information. • Accessibility of information, age	1.245 Knowledge of intellectual disabilities varies. Term autism captures all autism things. 1.259 Sibling knowledge is learned over time. Referenced to personal experience with sibling. 1.265 Siblings relate learned knowledge to their own sibling and circumstance. Knowledge can be quite sophisticated. 1.269 Normalising diagnosis ‘autism’ affects everyone we are all on a spectrum. 1.282 Sibling’s acceptance of IDs as their norm as young children.

	appropriate and timely. • Valuing lived experience, families and siblings as sources of knowledge.	1.295 Learning to understand IDs together as a family is valued. 1.312 Self-help is needed in families to help develop knowledge and understand IDs. 1.317-1.320 Family gaining information and knowledge together is valuable. 1.317-1.320 Sibling need for knowledge and information is needed as they grow to help them understand and to help their sibling. 1.334 Siblings have a lot of questions. 1.362 External expertise and support is important and valued by families. 1.391-1.398 Sibling maturity and need to be aware of social challenges e.g. finding the right support early in life. 1.404 Reassurance can help siblings with IDs. 1.573 Willingness to share experiences. 1.955 Knowledge is important but must be contextualised to personal experience. 1.947-1.949 Information specifically for and accessible to siblings is valued. 1.1061-1.1067 Involving siblings in research discussions may enhance 'noticing'. 1.929-1.937 Knowledge and information is important for siblings to understand their brother or sister. 1.1057-1.1063 Siblings are willing to share personal experience to help other siblings. [19 Refs]

Appendix 13 (d): Transcript data analysis board image participant 1



APPENDIX 14: Interview transcript, participant 8 analysis process (a - d)

a) Interview transcript, participant 8 analysis process
b) Analysis of connections emergent themes participant 8
c) Abstraction of themes transcript 8
d) Transcript data analysis board image participant 8

Appendix 14 (a): Interview transcript, participant 8 analysis process

Participant 8 Interview Helene and Ellie [Names used for participant and sibling, or others are pseudonyms to protect confidentiality.

Emerging Themes	Original transcript interview 27-11-17	Exploratory Comments - Descriptive comments in normal text; *linguistic comments in italics*; conceptual comments underlined
	8.01 Hello. 8.02 Hello. **8.03 That all sounded a bit, was a bit mad, wasn't it, little bit crazy.** 8.04 Yeah. **8.05 Never mind, we're here now. So you've just come from your tuition?** 8.06 Yes. **8.07 So where is that that you go then?** 8.08 Just down the road for maths tutoring. **8.09 Oh right, so what were you doing this evening?** 8.10 Algebra. **8.11 Ah! I used to like algebra, I don't know why.** 8.12 It depends whether it's hard or easy. **8.13 Okay, so how was this evening's session?**	

	8.14 Alright actually. **8.15 Alright…** 8.16 Yes. **8.17 …not too bad, not too bad, okay, good, good. Well, it's really nice** **8.18 to see you…** 8.19 You too. **8.20 …so I think it's been nearly a month, he's alright, don't worry, that's** **8.21 Fluff the dog saying hello. It's been nearly a month I think since we** **8.22 first met…** 8.23 Yes. **8.24 …because I've been away for a couple of weeks etc, so thank you** **8.25 very much for seeing me, and I know it's been a busy day for you.** **8.26 So just to start off Helene, when I came before we talked a little** **8.27 about you, and met with mum, met with your sister, we talked a little** **8.28 bit about the family, so maybe just for the purposes of settling us** **8.29 into our conversation, tell me a little bit more about the family, so** **8.30 who's in your family, so we know we've got mum, Claire and dad,** **8.31 Adam, tell me about you, tell me about your sister, a little bit about** **8.32 you and what school you go to, those sorts of things, so tell us first** **8.33 about your family?** 8.34 So we have 5 people, well 4 people and 1 dog. **8.35 people and 1 dog, here he is making himself known.**	
8.36-8.39 Family are important	8.36 Yeah, Fluff, Adam, Claire, Helene and Ellie, and mum's a [**** *******] 8.37 and dad works for *******, and me and Ellie both go to school and	Family important.

	8.38 Ellie goes to [names school *1] which was my primary school, and then 8.39 I now go to [names school *2] which is literally just over the fence. **8.40 Yes, what's it called?** 8.41 [names school *2]. **8.42 [names school *2], [names school *2], how do you spell that?** 8.43 Well, it's like [names school *2] but everyone calls it [names school *2]. **8.44 Oh, [names school *2], oh, okay.** 8.45 Yes. **8.46 So tell me a little bit about the school that you're in, what year 8.47you're in?** 8.48 I'm in Year 8. **8.49 Okay, and tell me a little bit more about sort of subjects you like, 8.50 what's the best thing about school, what do you enjoy?**	
8.51 – 8.52 Enjoys hobbies, varied subjects, sport.	8.51 I like dance and PE, so I'm on the sporty side. The main like topic in PE 8.52 I like is football, I really like football. **8.53 Is that a hobby, sporting activities, do you play football for school 8.54 or outside of school?** 8.55 Yes, both, yeah, fun. **8.56 So what position do you play?** 8.57 Mainly up front or midfield.	Enjoys dance, PE, football.

	8.58 Right, so a bit in attack? 8.59 Yes. **8.60 Yeah, do you enjoy scoring goals?** 8.61 Yes. **8.62 And do your friends enjoy football?**	
8.63 – 8.64 Shared interests with friends.	8.63 Yeah, we actually like run a club together on Tuesday lunchtimes which 8.64 is fun. **8.65 Oh, tell me a little bit about that? So who does that with you?**	Shared interests with friends
8.66 Pride in achievements.	8.66 So on the, in Year 8 I'm the captain of the football team so, and then 8.67 there's a vice-captain, so me and the vice-captain we like run a like club 8.68 or it, which is good. **8.69 Wow, and do you try to get other people interested?** 8.70 Yeah. **8.71 So how that's, so if you're in Year 8, so you'll have the Year 7s 8.72 coming behind you…** 8.73 Yes, yeah, mhmm. **8.74 …so how do you get the younger people involved in football?**	I am the Captain, pride in achievements
8.75 Enjoying sport, girls [friends] playing football	8.75 Well there are actually quite a lot of Year 7s girls who play football, we 8.76 have about 10 who come and then about 13 Year 8s, which is pretty 8.77 good.	A lot of girls play football, its pretty good

	8.78 So what do you enjoy most about school or your social activities, **8.79 and, what do you do for fun?**	
8.80 – 8.82 Sibling enjoys socialising, being creative.	8.80 I like like socialising and like I said, playing sports. Probably my favourite 8.81 academic subject would probably be English because I'm quite creative, 8.82 I like poetry and things like that, yeah. **8.83 Yes, so creative and sporty?** 8.84 Yes. **8.85 So there's lots of sides to you?** 8.86 Yeah. **8.87 So when we came and I met you a few weeks ago with mum and** **8.88 with Ellie, and Fluff, we talked a little bit about you, about the family,** **8.89 so the other people, the wider people, grandparents etc., that are in** **8.90 the family, tell me if you were to, if we were having a conversation** **8.91 who are the people in your life that you would say are sort of** **8.92 important in your life?** 8.93 So obviously the main family here. **8.94 That you've already introduced.**	Like socialising Favourite academic subject English. '*I'm creative'*
8.95 – Support for the family from extended family and friends.	8.95 And then grandma and grandpa, which is mum's parents, and then dad's 8.96 parents, grandma, granddad and nana, and we also have like, it's not 8.97 official but it's like we kind of think it is, so we have, me and Ellie have 8.98 Godparents which is Sally and Keith, and then God-brother, which is 8.99 Evan. **8.100 Yes, so Sally and Keith are Godparents to both of you?** 8.101 Yes.	Extended family, godparents and family friends important.

	8.102 Oh wow! So that's a very special relationship… 8.103 Which is nice, yeah. **8.104 …very special relationship, so what about you talked about being** **8.105 captain of the football team and having a vice captain, tell me a** **8.106 little bit about your friends, who are the people that you enjoy** **8.107 spending time with that are not your family, who's special to you?** 8.108 Shall I name them? **8.109 Yes, course, whatever you're happy to share.**	
8.110 -8.14 Siblings value family/ friendships.	8.110 [names friend *1], she's a really good friend of mine, she doesn't really 8.111 play football but she does do dance with me, which is good. [names 8.112 friend *2], she's, she doesn't really do any sports with me but we're just 8.113 really good friends, and then I have like my friendship group in my class, 8.114 so it's me and then five other people which is like our friendship group. **8.115 Right, and have you been friends for long with these, with [friend** **8.116 *1] and…**	Friendships valued, lots of friends sharing interests '*dance'*
8.117 – 8.118 School is a source of building friendships accessing social networks for sibling.	8.117 Three of them I met when I came to secondary school and then two of 8.118 them were in my primary school. **8.119 Right, so they've been friends for a long time.** 8.120 Quite a long time, yeah. **8.121 So have you always lived in the [names town] area, Helene?** 8.122 I used to live in [names a city] but I don't remember that because I was 8.123 about 1 or 2, and then when I was 2 I think we moved here, because 8.124 Ellie was born here, I remember that, and I went in one night and then	School opportunity to meet friends

8.124 -8.127 Arrival of sister is celebrated. 8.129 Affection for sister '*so cute*'	8.125 I saw mummy lying on the mattress and then I went downstairs with 8.126 grandma and then I came up and there was this little baby cuddling into 8.127 daddy. **8.128 Marvellous!** 8.129 So cute! **8.130 How exciting was that!** 8.131 Yeah, very. **8.132 Yeah, and that's kind of nice because that leads me, and it's nice** **8.133 to hear about you and some of the things that you enjoy sort of** **8.134 doing and you know that one of the reasons that I'm coming to** **8.135 chat to you is to chat to you because you have a sister…** 8.136 Yes. **8.137 …Ellie, but also that Ellie has special needs is the word I would** **8.138 use, what sort of words, we talked a little bit with mum about this** **8.139 didn't we…** 8.140 Yeah. **8.141 I know that Ellie has Down's Syndrome and Ellie is Ellie…** 8.142 Yes. **8.143 …when you explain to people, if you use a word to describe some** **8.144 of her needs, extra needs that maybe she needs extra support** **8.145 with, what sort of ways do you describe that as a family, or would** **8.146 you describe it to someone?**	'*Ellie was born here, I remember that'* Arrival of new baby sister Expresses affection for sister Expresses excitement at birth of sister

8.147– 8.148 Diagnosis and terminology 'Down's syndrome' comfortably used to describe sibling with ID's additional needs.	8.147 I just say Down's Syndrome, I don't really have any problem with saying 8.148 that. **8.149 You use, okay, yeah, so that's the term that everybody would use 8.150 in the family to say that Ellie has Down's Syndrome?** 8.151 Yeah. **8.152 Okay, and what sort of things does she need help and support 8.153 with that maybe are a little bit different to somebody, because 8.154 Ellie's 9 is she?** 8.155 Yes. **8.156 That are maybe a little bit different to someone else who's 9?**	'*I just say Down's syndrome'*, comfortable with using diagnosis terminology
8.157 – 8.159 Recognises difference in capabilities for sister with ID.	8.157 Obviously like academically she's not as strong as the other kids in her 8.158 Year, but she, she does like pick-up quite well. She likes reading, like 8.159 English more than maths. **8.160 Okay, so similar to you.**	Sister '*obviously*' academically not as strong as the other kids She likes reading
8.161 Sibling recognises sibling with ID skills/strengths.	8.161 Yeah, but she is good at maths, at the moment she learns like coins 8.162 and notes and she's pretty good at that, which is good. **8.163 And she's doing a production she's telling me just a few minutes 8.164 ago, her performance coming up.**	She is good at maths
8.165 – 8.168 Pride expressed in sibling with ID achievements.	8.165 Yeah, performance, so she did a performance on the weekend and 8.166 then she won an award for it which she means she goes to perform it 8.167 at like another bigger concert with like 200 people, it should be good 8.168 fun.	Performance at the weekend, pride in sister's accomplishments

8.173 - 8.174 Sibling as a role model, trailblazer for sibling with ID '*following in the footsteps*'	**8.169 Yeah, it should be fun, she sounds very excited about it, I've had** **8.170 a little pre-performance so I feel very privileged to have seen it** **8.171 before everybody else, or a little bit of it, with actions and** **8.172 everything which was really nice.** 8.173 It's also good because I did it last year as well, so like now <u>she's</u> 8.174 <u>following in the footsteps</u>.	*'I did it last year…'she's following in the footsteps'.*
	8.175 There you are! So that's the drama and enjoying that, so dance **8.176 and drama and those sorts of performing things seem to run in** **8.177 the family. So when you said that Ellie has Down's Syndrome and** **8.178 therefore has some extra needs to support, but she goes to a** **8.179 mainstream school mum said…** 8.180 Yeah. **8.181 …which is the same primary school that you went to, so when you** **8.182 became aware that Ellie had Down's Syndrome who were the** **8.183 people who sort of spoke to you about that or were there any** **8.184 questions that you had, what sort of questions did you ask and**	
8.186 Acceptance of ID 8.188 Valuing being a sibling, normalising experience of having a sibling with ID '*just thought about it as having a sister'*	**8.185 who were the people who answered some of your questions?** 8.186 To be honest I think <u>I just grew-up with it, like it was normal to me</u> so I 8.187 didn't really like think about it as having a sister with special needs, I 8.188 just <u>thought about it as having a sister, so I didn't really understand it</u>, 8.189 and then I don't really remember like when someone told me she had 8.190 Down's Syndrome, I think it was just somehow I don't know….	*I grew up with it* [having sister with Down's syndrome] it was normal Just about having a sister I didn't understand
8.192 Siblings do not always have things explained to them, <u>[lack understanding parents protecting them, age/life stage impact]</u>	**8.191 You don't remember a conversation or anything?** 8.192 I don't remember anyone saying like sit down and we'll have a talk. **8.193 Yeah, yeah, so tell me a little bit about what it's like having a sister.** 8.194 It's great.	Don't remember anyone saying sit down and we'll talk

8.196 – 8.200 Siblings enjoy hobbies/activities together, have fun.	**8.195 What sorts of things do you guys enjoy together?** 8.196 We like like making arts and like hanging round and making like little 8.197 movies together, which is fun. She loves chilling out, a lot, and on 8.198 weekends we like do a lot of things together, like I said make movies, 8.199 and we like sometimes make-up mini dances and things like that which 8.200 is fun. **8.201 So what's it like when you make a movie, what do you do when** **8.202 you do that?** 8.203 We just like think of a storyline like say we did Cinderella once for 8.204 example, and then we just got costumes from the costume box and 8.205 then just dressed up as that. **8.206 Do you video it and play it back to mum and dad and things?** 8.207 Yeah, yeah. **8.208 Yeah, that sounds very exciting, that's very creative, the both of** **8.209 you enjoying dance and drama.** 8.210 Yeah.	Like making art, movies together On weekends we do things together..which is fun
8.213 – 8214 Sibling recognises sibling with ID talents and interests.	**8.211 Wow, wow! And so what would you say are Ellie's favourite things** **8.212 to do?** 8.213 Hairdressing, dance, drama, and playing with her friends, yes, that's 8.214 the main things. **8.215 So very similar to some of the things that you said that you enjoy.** 8.216 Yeah.	Sibling with ID enjoys hairdressing, dance, drama, playing with her friends.

	8.217 So having a sister who does have Down's Syndrome and having 8.218 different needs and extra support needs, what do you think is, are 8.219 the any ways you think that that's been very different, have you 8.220 got friends who've got brothers or sisters as well?	
8.223 – 8 225 Families network with other families with children with ID.	8.221 What, with Down's Syndrome? **8.222 With or without.**	Family meets with other families with children with Down's syndrome
8.227 Different experience of being a sibling to their peers, [peers are younger siblings Helene older].	8.223 I know there's one boy in the Year below who my parents know their 8.224 parents so we're like friends, and sometimes we meet up and then Ellie 8.225 and his name's Thomas, they play together. **8.226 And Thomas has Down's Syndrome as well?**	Most of my friends have older siblings
8.232 Protecting self, sibling, family narrative.	8.227 Yeah, yeah but most of my friends have siblings, mostly older to be 8.228 honest. All my, yeah, all my friends in my friendship group they have 8.229 older siblings. **8.230 Okay, and do you think that you talk to, do you talk to your friends 8.231 about having a sister? Presumably they know?**	Explaining to friends '*we don't talk about like what it's like we just say oh she's really cute..'* [is there a reluctance to say more, protecting self, sibling?]
	8.232 Yes, well when like Ellie sees them they're like, oh Ellie, she's so cute, 8.233 and that's when we like talk about it, but we don't talk about like what 8.234 it's like, we just say like oh she's really cute and things like that. **8.235 Does anybody ever ask you to explain some of the differences?** 8.236 Not really, no.	
8.240 Normalising experience of being a sibling with sister with ID.	**8.237 And if you were asked what do you think you might say? How 8.238 would you explain the extra support that perhaps Ellie might need 8.239 or how would you explain to other people?**	*'I wouldn't say it was a bad thing..there's up sides and there's*

	8.240 I wouldn't say it was a bad thing because it's not. I'd say it's really great 8.241 and there's up sides and there's also down sides but that happens with 8.242 every sibling, so. **8.243 Yes, and I'm sure your friends will tell you things like that in terms** **8.244 of having brothers or sisters. So are there things that you notice** **8.245 that having a brother or sister, or in your case a sister, with** **8.246 Down's Syndrome or special needs that maybe affects other** **8.247 people in the family, what sorts of ways does that affect perhaps** **8.248 mum and dad or other people in the family?**	*also down sides but that happens with every sibling'* normalising sibling relationship
8.249 – 8.251 Recognising differences in day to day experiences for them and their sibling with ID. [Sibling insight/taking responsibility, normalising as older sibling? 8.252 – 8.255 Siblings demonstrate insight into sibling with ID attributes. 8.256 – 8.260 Families find innovative, individualised ways to support sibling with ID to alleviate anxieties, [use sensory tools / responses]. 8.261- 8.262 Family stressors, sibling with ID needs support at times to manage emotions/anxieties.	8.249 Sometimes it's like quite hard to get her to concentrate, which is 8.250 sometimes hard when she's doing homework or, I don't know, trying to 8.251 do an activity or something like that, but of course then there's up sides 8.252 as well. She's very creative and funny, which is, yeah. **8.253 So what sorts of things does mum and dad do to help Ellie to** **8.254 concentrate or to focus on some of those things where…** 8.255 Well, she's very sensory so she used to, and she still kind of is but she's 8.256 kind of moved on to other things now, she used to have that whole 8.257 drawer there filled with feathers, and she just used to stroke her face 8.258 with them, obviously not bird feathers like feathers out of like arts and 8.259 crafts kits, but she'd just stroke her face with them and now she has 8.260 like make-up brushes which she just like, just like wipes on her face 8.261 and she really likes that, so that like calms her down and makes her 8.262 more concentrated, if you know what I mean? **8.263 Okay, okay, yes, so Ellie seeks those things out to do herself…** 8.264 Yeah. **8.265 …so that sounds like she recognises some of those things help** **8.266 her to relax.**	'*Hard to get her to concentrate'*. Sibling recognising difference for sibling with ID She' very creative and funny '*she'' very sensory'* '*feathers she just used to stroke her face and now has make up brushes'* '*so that like calms her down*' suggests there are times when Ellie needs calming down.

	8.267 Mmm. **8.268 And what do you see when she brings out her creative side, what 8.269 sorts of things does she share with the rest of the family, how 8.270 does everybody react and enjoy that?**	
8.271 Recognising sibling with ID 'happiness', the narrative of positivity and happiness seems to be prioritised, [potential containment/avoidance of more rounded perspective of daily life].	8.271 She likes, when she's happy she's like put some music on and I'm going 8.272 dance, and then she just like dances for like half-an-hour straight and 8.273 that's what she does when she's happy, and yeah, and then sometimes 8.274 she does like art and say oh, I'm going to do some drawing, and then 8.275 she gets pen on the sofa and then it's oh great! **8.276 And then there's lots of washing to be done?**	*When she's happy she puts on music, dances, does art, drawing* Valuing sibling's talent, [prioritising being happy, what happens when she's not happy?]
	8.277 Yes! **8.278 And who helps if there are things have to be tidied up, because 8.279 you said that some of your friends have brothers or sisters that 8.280 are older, with you having a younger sibling sometimes, tell me a 8.281 little bit about what it's like being the big sister?**	
8.282 – 8.283 Siblings take on responsibility in the family.	8.282 Well, I have to help, obviously, yeah, she does tidy up quite well to be 8.283 honest, yeah. **8.284 So what sorts of things do you do to help out?**	'*I have to help'* [as a big sister]
8.285 – 8.287 Siblings support sibling with ID – share time together [care, maturity, sense of deprioritising self]	8.285 Sometimes like when I do my homework we sit together and do like, 8.286 she does hers and I do mine, and then when she's like how do I do 3+4 8.287 or something like that then I'm like 1, 2 and I help her like that. **8.288 Okay, okay, so do you think there are, how would that be different 8.289 to having a brother or sister who didn't have Down's Syndrome?**	'*when I do my homework we sit together and do like, she does hers and I do mine'* shared time as siblings, supporting sister with ID
8.290 – 8.291 Unconditional acceptance of their context, maturity.	8.290 I don't know, I think, I do know obviously but I haven't really experienced 8.291 it…	

8.293 Potential loss of sibling relationship. 8.300 Normalising relationship, all siblings argue they are no different. 8.301 – 8.302 Inequalities in sibling relationship, differs from peers. 8.307 – 8.310 Care, compensating in sibling relationship, protection of self, sister, family narrative; sibling resilience.	**8.292 Quite right.** 8.293 …so I can't say like what it would be for a fact, but… **8.294 I guess what I was thinking about was you talked about some of** **8.295 your friends having brothers or sisters and I know you said they** **8.296 don't have younger siblings but you talked about some of the** **8.297 things that you said was oh well, you know, I'm sure that's what** **8.298 being a sister is like, are there things that you notice that are** **8.299 different?** 8.300 There are similarities, all siblings like they fight and argue and it's no 8.301 different for us, obviously, but I do notice like when I go round to my 8.302 friends' houses they argue a lot more, like we don't argue that much. **8.303 So how would you describe that, do you think that's because** **8.304 you're the big sister or do you think that's because you are sisters** **8.305 who are just different with one another, what would you put that** **8.306 down to if you had to explain that?** 8.307 I think it's kind of both, she's more not, I don't know how to explain it, 8.308 like aware when to make an argument so that makes it more like, it 8.309 makes it easier because we argue less I guess, and then also I don't 8.310 really like getting arguments, it just doesn't really… **8.311 That's not part of you, not part of your…** 8.312 Yeah, no, not really. **8.313 …personality in terms of who you are.** 8.314 No. **8.315 So you talked about the fact that people say your sister is cute…**	*'I don't know, I do know obviously, but haven't; experienced it'*. Unconditional acceptance of sister and her sibling experience [is there a potential sense of loss as the unknown or being a sibling with brother or sister who does not have Down's syndrome '*I do know obviously'*?] Similarities and difference '*all siblings fight and argue it's no different for us'* Friends argue more with their siblings. Suggests she might like to argue more, or believe she is missing something potentially a more equal sibling relationship? *'She's more not…aware when to make an argument'* [compensating as an older sibling, caring for her sister with ID and recognising differing needs. Might Helene be holding back, protecting self, sister, family narrative?]

	8.316 Yes. **8.317 …when you meet her, and she is, and I would agree, she's very** **8.318 cute, I've enjoyed meeting her immensely, but if somebody asked** **8.319 you about Down's Syndrome and asks you to explain some of the,** **8.320 if you just said Ellie's got Down's Syndrome, as you said that's** **8.321 how you explain things, how would you explain it to somebody** **8.322 who didn't understand, perhaps a friend or somebody at school?**	
8.323 Maturity [at 12 yrs.], knowledge, understanding Down's syndrome. 8.324 '*ups and downs'* sibling adaptability, loss and gain, a different sibling relationship.	8.323 I would say <u>it's one more chromosome and it makes her cute, cuter,</u> <u>8.324 and she's lovely, and there's up sides and down sides</u>. **8.329 Yes, so what would you describe as the ups and downs?** 8.330 So the ups are that she's funny and she's cute and she's very creative, 8.331 and we get the disabled badge so we can park closer…	*'it's one more chromosome and it makes her cute, cuter, and she's lovely, and there's up sides and down sides'* Up and down sides to having a sibling with ID. '*She's funny, cute, creative and we get disabled badge'*
8.334 – 8.335 normalising sibling relationship. 8.337 Compassion, understanding, recognises sibling with ID experiences difficulties.	**8.332 You mentioned that last time when I was here, that's a very big** **8.333 plus.** 8.334 Yes, very big. And down sides like I say, we argue a bit but that's like 8.335 all siblings. **8.336 But that's sisters perhaps, yes…** 8.337 And she finds it a bit difficult sometimes… **8.338 So I've seen the two of you together, so you're very loving sisters** **8.339 together, she's very, very fond of you, that's very, very obvious,** **8.340 so how do you together, if people were just watching you, like I** **8.341 had observed you, how do you show how you feel about one** **8.342 another, how would people observe you and see your relationship,** **8.343 how do you show, how does she show how she feels about you,** **8.344 how do you show how you feel about her?**	*'Down sides we argue a bit…like all siblings* *'She finds it difficult sometimes'* <u>acknowledges difficulties though wider narratives seems to contradict that there are any real difficulties.</u>

8.345 – 8.349 Sibling with ID affectionate. 8.348 - 8.349 Pride in sibling with ID abilities.	8.345 She hugs me a lot, when like we're around either her friends or my 8.346 friends, she comes like she's like Helene and she squeezes me really 8.347 tight, which is really cute, and she's also like quite shy in front of other 8.348 people, but in a good way, so she's not like doesn't want to talk, she 8.349 like smiles and then…	*Hugs me, squeezes me, is cute, quite shy, smiles.* Pride in sibling's attributes
	8.350Yes, but she is only 9.	
	8.351 Yes.	
	8.352 Mhmm, and what's the best part about being Ellie's sister?	
8.353 Values being a sister, cares for sibling with ID.	8.353 Everything! Like I said she's creative and she's very cute and kind.	
	8.354 What's the best part for you Helene, what's the best part about **8.355 being a big sister?**	'*Everything*' [when asked what's best part of being a sibling]
8.356 -8.359 Sibling as role model. Power imbalance in sibling relationship.	8.356 She kind of follows like what I do, so it feels like I'm like the leader of 8.357 like the sister family kind of thing, which is, like she doesn't ever like 8.358 say oh I'm the leader, she's always like okay, I'll follow you, which is 8.359 really cute.	'*She's creative, cute, kind* *'follows what I do, so feels like I'm the leader'* sense of power/agency in the sibling relationship, sibling with ID not giving the same challenge potentially
	8.360 And how does that feel being the big sister and being the leader?	
8.361 – 8.363 Sibling have fun enjoy shared activities.	8.361 Fun because like we have two of these beanbags so we just, on the 8.362 weekends we like get them out and then pile them on top of each other 8.363 and then I jump on and then she jumps on me, so that's like, yeah.	Fun activities enjoyed together.
	8.364 So are there other things, you talked about doing, making movies **8.365 together and perhaps creating dances together, what other sorts** **8.366 of activities do you guys enjoy together?**	
	8.367 Making dens, we do that quite a lot, yeah.	

	8.368 So it's back to that creative and adventure with both of you. 8.369 Yes. **8.370 Is there anything that makes it difficult to do things together?**	
8.371 – 8.372 Sibling with ID expresses needs through behaviours. Sibling insight, interpreting cues, e.g., opt out behaviours/ challenges. 8.377 Need to interpret sibling with ID communication and adapt. Can experience challenges.	8.371 Sometimes she gets a bit tired which means she lies on the sofa and 8.372 she refuses to get up, which is, yeah. **8.373 So what happens at those times?** 8.374 She lies on the sofa and she goes *[sigh]* I don't want to do any more, I 8.375 want to watch TV, and then I'm like are you sure, and she's like, yes, 8.376 I'm like even if we make the den even bigger, she's like yes, so she's 8.377 very like, <u>once she says something there's no changing her mind.</u>	'*she gets a bit tired.refuses to get up'* sibling with ID self-expression, <u>suggests there may be more interactive challenges than suggested in the narrative above.</u>
8.380 Care and compassion, recognises impact of ID and potential challenges for sister with ID.	**8.378 Okay, and are there times where perhaps mum or dad want her to 8.379 do something and she's finding it hard to change her mind?** 8.380 Sometimes yeah, like homework when she can't do it she just gives up, 8.381 yeah. **8.382 So what are the ways that mum or dad get around encouraging 8.383 Ellie to do some of the things that she finds more difficult?**	'*once she says something there's no changing her mind'*. '*when she can't do it she just gives up'*
8.384 – 8.388 Parents need to develop strategies to manage difficulties, parents as role models/ gatekeepers.	8.384 Sometimes like I said they give her like sensory things which kind of 8.385 brings her back. **8.386 Yes, like the feathers or the brushes that you spoke about.** 8.387 Yeah, or the brushes or things like that, or sometimes they just let her 8.388 rest for 5 minutes and then back on and she's all good.	They give her sensory things [when she finds things difficult]. Sensory strategies used by parents to support more difficult interactions situations. Parents managing more difficult situations.

8.394 Faith is not a priority for the family. 8.395 – 8.398 Sibling identifies with parents, shared interests. 8.400 Shared interests with Dad valued. 8.402 – 8.407 Protecting one another, containment, of frightening narratives [volcano as potential metaphor for ID?]	**8.389 Okay, I've got a slightly different question that I just wanted to ask** **8.390 you. When I met with you we talked about did the family have a** **8.391 faith or a belief or whatever, so how would you describe your** **8.392 family having a, what sort of a belief or value base would you think** **8.393 you'd describe your family having?** 8.394 We're not religious in that aspect but we like do believe in like certain 8.395 things like it's mainly <u>me, mum and dad</u> like because we get it more, 8.396 and I don't think many 9 year olds get like, like politics and things like 8.397 that, but that's what we like discuss, like the latest politics and the things 8.398 on the news, things like that. **8.399 Yes, and what's your big topic of the moment?** 8.400 Probably talking about the, oh we talk about, me and dad we talk about 8.401 sports lots, because we're both football fans, but at the moment we're 8.402 like keeping an eye on the volcano in, where is it, In… **8.403 [Topical news item] I think, isn't it…** 8.404 Yeah. **8.405 So you keep an eye on current affairs and those sorts of things?** 8.406 Yeah, but we don't really dwell on them that much, just like keep track 8.407 of what's happening. **8.408 So you're both football fans you and dad?** 8.409 Yes. **8.410 Do you both support the same team?** 8.411 [Names football team].	'*We're not religious'* '*me, Mum and Dad because we get it more'* Shared activities and experiences with parents Me and Dad talk about sport News items '*keeping an eye on the volcano in..* *'we don't dwell on them [*news items*] that much''* <u>Sense of protecting one another from frightening news, containment, does this link to the family narrative of ID?</u>

	8.412 Oh, you're both [names team]? Where does the [name of team] supporter	
8.414 8.418 Family heritage and extended family connections important for family identity.	**8.413 come from then, living in [names town]?** 8.414 Well actually my mum's parents support [names town] because they 8.415 were raised and born in [names town] and they live in [names town] 8.416 now, and my dad's parents they support, what's it called, [names town], 8.417 so I think dad grew up in, no, it wasn't, did he, I think he grew up in 8.418 [names town] I think, I'm not…	Family interests, sports, football team linked to places of origin <u>family connections valued.</u>
8.421 Choices restricted for sibling? Following parents' interests, [linked to ID narrative, choices restricted, sibling taking cues from parents?]	**8.419 So dad started as a [names team] supporter and you've joined 8.420 forces?** 8.421 Yes, <u>I have no other choice</u>, *[Laughter]*. **8.422 Oh, I see!** *[Laughter]* **That's often the case in families I find, that's 8.423 true.** 8.424 Yes.	Shared football team and interests with Dad. <u>Jovial reflection of no choice in choosing the same football team as Dad. Does this resonate with limited choice more broadly in the family?</u>
8.435 – 8.438 Understanding sibling with ID needs/ capabilities, potential exclusion of sibling with ID?	**8.425 So you talked about being quite politically aware and thinking 8.426 about current affairs etc, so as a family you talked very positively 8.427 about having a sister with Down's Syndrome and talked about 8.428 mum and dad and having a friend with Thomas, Thomas's parents 8.429 etc., and supporting Ellie etc, so in all the things that you think 8.430 you believe in and that political and current affairs approach 8.431 Helene, how do you think that's helped, or does it help or influence 8.432 how you think about people with disabilities, with special needs, 8.433 what sorts of things would you say you think are important when 8.434 you think about people who have different and special needs?** 8.435 I don't really think it affects the way like we teach or tell Ellie things 8.436 because I don't, it's not we don't want to get her involved, it's just even	'she's not really interested in those sorts of things'. Maturity of

8.443 Awareness of social justice, use of language impacting others. 8.450 – 8.453 Siblings experience brings insight of ID, social conscience, sense of responsibility.	8.437 if we tell her things she's like okay, can I watch Peppa Pig now, like 8.438 she's not really interested in those sort of things. **8.439 Yes, and what do you think about how we should be, generally 8.440 people should be thinking about people with Down's Syndrome or 8.441 people with special needs, what sort of things do you think are 8.442 important?** 8.443 Don't use certain words that would offend people because although it 8.444 may not hurt you or the people you think it will hurt, it does sometimes. **8.445 And how do you think you might have thought about those things 8.446 if you didn't have a sister, I know that's something you've got to 8.447 imagine because you have got a sister with Down's Syndrome…** 8.448 I think this would be… oh, sorry. **8.449 No, that's fine, just…** 8.450 I think it would be for everyone, like I don't think, like obviously I wouldn't 8.451 do it, or at least I hope I don't, or wouldn't, but I don't think I would take 8.452 it into account or like think or dwell on it as much because I couldn't 8.453 really relate to it. **8.454 Right, so you maybe think differently because you can relate to 8.455 somebody having different needs and needing to think 8.456 differently?** 8.457 Yeah, mhmm. **8.458 Okay, I just wondered if that was the case by some of the things 8.459 that you've shared.** 8.460 Yeah, yeah.	understanding of sister's needs and capabilities. Describes differentiated experience of relationships in the family for sibling with ID and others, potential exclusion of Ellie from some shared experiences. *'don't use certain words that would offend people'* powerful advocate for using appropriate language and not offending people with ID and their families, sense of social awareness, justice, fairness and care '*but I don't think I would take it into account or like think or dwell on it as much because I couldn't really relate to it*' Maturity, social conscience aware experience aids understanding of ID.

	8.461 Tell me a little bit more about you, what sort of thing do you, so 8.462 you enjoy your football, you enjoy your dance, you enjoy that 8.463 creative side, so what are Helene's dreams for the future, what 8.464 sorts of things do you think about you know, what sort of job you 8.465 might have, what your future might look like, tell me a little bit 8.456 about, you're only 12…	
	8.457 Yes.	
8.459 Sibling ambitions for the future.	**8.458 …so it's a long way off, yes.**	
	8.459 Yes, footballer or dancer, or I don't really know, that's as far as I've got 8.460 really.	Footballer or dancer, ambitions for the future.
8.462 – 8.466 Ambitions change with age and insight over time.	**8.461 That's as far as you've thought.**	
	8.462 I used to want to be a firefighter but not really anymore.	Firefighter..but not anymore
	8.463 But not now, what was attractive about being a firefighter?	
	8.464 I used to watch Fireman Sam, so that was kind of…	
	8.465 It goes with what you're watching.	Ambition changes with age, experience and overtime
	8.466 …for me, yes.	
8.473 – 8.474 Sibling ambitions for the future.	**8.467 Are there other things that you think are important for your future, 8.468 what sort of things, I know you haven't quite decided and I hope 8.469 you haven't because it's a long way off, you've got lots of time, 8.470 what sorts of things do you generally think about when you're 8.471 older, what are your dreams and ambitions and things you'd like 8.472 for yourself for the future, that you'd like to achieve personally?**	

	8.473 I'd like to, I'd like to go to university I think, I think, I'm not sure but I 8.474 think, and I want to study more dance because we only have dance 8.474 lessons twice a fortnight, and I want to do more of that. **8.475 So you'd like to do a bit more?** 8.476 Yeah.	'*go to university…study more dance'* ambitions for the future
8.477 – 8.480 Sibling sees future with a family.	**8.477 And do you think in the future, and I know you're only 12, would 8.478 you like to have a family yourself, do you see yourself having a 8.479 family in the future?** 8.480 I think so, yeah, I can actually, yeah, I think so.	Sibling sees future with a family
8.488 Future framed in context of family experience, recognise potential of having child with ID, acceptance and uncertainty, conflicted.	**8.481 Yes, what do you think that that would be, bring for you?** 8.482 A [names colour of dog] *[names breed of dog]*, oh, what would it bring 8.483 for me? Oh… **8.484 A [names colour of dog] [names breed of dog].** 8.485 Yeah, I'd have a [names colour of dog] [names breed of dog]… **8.486 You'd definitely have a [names colour of dog], Fluff, you're going 8.487 to be, we're going to have another one of you.** 8.488 Yeah, Fluff, we're going to have another one of you, call it Fluff 2.0, and 8.489 then I think it will be good.. <u>obviously it's quite rare to have someone 8.490 with Down's Syndrome so I don't really think it would be, so it'll be quite 8.491 different because I don't really know how to like handle it, but eventually 8.492 I would be but I wouldn't know at first, but that's all parents</u>… **8.493 Yes, yeah, yes, of course.** 8.494 …no one knows how to.	'*obviously it's quite rare to have someone with Down's Syndrome so I don't really think it would be, so it'll be quite different because I don't really know how to like handle it, but eventually I would be but I wouldn't know at first, but that's all parents'* <u>visualising future as a parent, considering potential of having a</u>

	8.495 No, no one, there's no book on telling you how to be a parent. 8.496 Yeah. **8.497 So who do you talk to about those things, do you talk about, as a 8.498 family, you said you're very politically aware and talk about all 8.499 sorts of things, and especially football with dad…** 8.500 Yeah.	child with down's syndrome, acceptance but may suggest a degree of uncertainty and anxiety. [potentially the family narrative evident here]
8.504 – 8.507 Sibling uncertain of sibling with ID future [age impact 9 yrs.]	**8.501 …but what do you talk about in terms of the future when you think 8.502 about oh, when I grow-up I might do this or, who do you talk about 8.503 those things with?** 8.504 I don't really talk about that much, like Ellie says every day she wants 8.505 to be something different and then at the end of the day she's like oh 8.506 no, I'm going to be a hairdresser, so Ellie wants to be a hairdresser. I 8.507 don't really know, like I don't know.	*'Every day she wants to do something different'* [Ellie's future] don't know uncertainty?
8.513 – 8.514 Sibling has ambitions for sibling with ID future/ career.	**8.508 So what are your, Ellie thinks she'd like to be a hairdresser so I 8.509 asked you about your dreams, what are your, do you have any 8.510 dreams or thoughts about the things that you, and it doesn't mean 8.511 about what she's going to be, but things that you'd like for Ellie 8.512 when she's older, when she's grown up?** 8.513 I can imagine her up on a stage, I really can, and if not, backup is 8.514 hairdressing. **8.515 Right, okay, so a lot of actresses have to have a backup, so you 8.516 think that creative side is going to come to the fore and be her 8.517 strength?** 8.518 Yeah.	*'I can imagine her on the stage… backup hairdressing'.* Sibling imagines future for sibling with ID

8.530 – 8.534 Powerful reflection for other siblings, insight of ID '*down and upsides'*. [Family narrative of positive projection '*everything is meant to happen for a reason'*, vulnerability, protecting from reality things do not always work out]. 8.537 – 8.541 idealised picture, positive narrative of being a sibling, though questions of uncertainty, reassurance it will be ok.	**8.519 And you know that the work that I'm doing, the project that I'm** **8.520 looking at is about sharing information from the voices of young** **8.521 siblings…** 8.522 Yeah. **8.523 …about what it's like to be a brother or sister with somebody who** **8.524 has Down's Syndrome or other types of special needs, so what do** **8.525 you think are the most important things that siblings should know** **8.526 about being a sister, in your case, for somebody with an** **8.527 intellectual disability, a special need or Down's Syndrome, what's** **8.528 the most important things that you would want to tell them if they** **8.529 were sitting her instead of me?** 8.530 Don't worry because there's nothing to worry about, everything works 8.531 itself out in the end and everything's meant to happen for a reason, so 8.532 obviously there are down sides but everything has down sides to it, and 8.533 then of course there are up sides, so just don't worry about it to be 8.534 honest. **8.535 Okay, why do you think that's something that's so important for** **8.536 them to be aware of?** 8.537 Because I feel like if you were like first receiving the news that you had 8.538 a sister with Down's Syndrome you would worry a bit because you'd be 8.539 like what's going to happen in the future, what's going to happen to me, 8.540 what's going to happen to him or her, so, but you don't need to because 8.541 it's all going to be fine. **8.542 Yes, when you're 12 you will be still enjoying one another's** **8.543 company as you two are, and if we had to decide, so if we were** **8.544 supporting our future, you or I, brothers or sisters who have** **8.545 somebody who has a special needs in their family, where's the** **8.546 best place to go to find that information, if we needed to put**	*Don't worry because there's nothing to worry about, everything works itself out in the end and everything's meant to happen for a reason, so obviously there are down sides but everything has down sides to it, and then of course there are up sides, so just don't worry about it'* Powerful sentence advice to others, does this project her own thoughts about life with her sister? *8.537 'I feel like if you were like first receiving the news that you had a sister with Down's Syndrome you would worry a bit because you'd be like what's going to happen in the future, what's going to happen to me, what's going to happen to him or her, so, but you don't need to because it's all going to be fine'* Unexpressed concerns for the future? Drawing on

8.550 – 8.553 Valuing sibling knowledge and lived experience, this offers support for other siblings to share experience of ID, help strategies for coping with future. 8.558 – 8.560 External groups ID networks valued by families. 8.562 – 8.564 Groups/networks provide opportunities for sibling with ID to develop friendships.	**8.547 information somewhere about don't worry and, to share some of 8.548 the things that you think are important, where would be the best 8.549 place to find that out, who'd be the best people to link in with?** 8.550 Other families who've like gone through it, preferably like families who 8.551 have someone with Down's Syndrome but who's grown-up so they 8.552 experience the whole package, and obviously it's not going to be the 8.553 same for everyone but at least they'll have some experience. **8.554 What opportunities have you or the family had to do that, to link 8.555 with other families to think about the future, has that happened?** 8.556 I think so, I can't really remember, when I was younger I think, I don't 8.557 know how but we've just eventually met other families with, oh yeah, 8.558 [names special needs/down's syndrome group], Ellie used to go to 8.559 [names special needs/down's syndrome group] and she met loads of 8.560 her friends there, so she… **8.561 What's [names special needs/down's syndrome group], Helene?** 8.562 I think it's like an organisation for people with Down's Syndrome and 8.563 it's like it's mainly for kids who're like 4 or 5 and it teaches them shapes 8.564 and the basic things, like that, and she met lots of her friends there. **8.565 Was somewhere local here in [names town] or was it a…** 8.566 I think it was down in [name of town], I don't know, we, it's all over the 8.567 place. **8.568 But still quite local to you in [name of county]?** 8.569 Yeah. **8.570 Okay, okay. So helpful to have that and helpful to link with the 8.571 family, so things like [names special needs/down's syndrome**	<u>current experience 'it is going to be fine'</u> '*Other families who have gone through it..preferably grown up so they experience the whole package'* Helpful for siblings, sibling with ID and families to get support from other families, learn from their experience External specialist groups, networks are helpful for siblings with ID and their families '*an organisation for people with Down's Syndrome.. she met lots of her friends there'* networks help sibling with ID meet friends.

8.574 – 8.575 Specialist support valued by families, mainstream not always helpful.	**8.572 group], how do you feel about organisations like that, do they have** **8.573 a place in helping families?** 8.574 I think it's good because it helped us a lot because it taught her like the 8.575 basic things before school because in nursery, she went to two 8.576 nurseries and they didn't really teach her that much, so I think at that 8.577 point we went there to [names special needs/down's syndrome group] 8.578 and then they really helped her learn a lot of things.	Specialist networks help sibling with ID develop skills. Mainstream not always helpful.
8.581 Mum as facilitator accessing support for family.	**8.579 That sounds like an excellent thing, so was it mum that found out** **8.580 about that, or…** 8.581 Yeah, I think she researched it or she might have got it from a friend.	Mum enabling access to specialist support. networks for the family
8.586 Maturity, recognising need for credible sources of information.	**8.582 And is there any other information or things that you think that** **8.583 you didn't have that you think oh, that would be really helpful or I** **8.584 think that that would be very important again, and helpful for** **8.585 siblings?** 8.586 If you're going to go on Google and Google it don't, don't because 8.587 Google usually gives you the worst-case scenario and that could get 8.588 you worked up.	'*Google usually gives you the worst-case scenario'* Maturity of sibling experience, recognising the importance of accessing accurate information
8.590 – 8.591 Siblings are accepting of the individuality of their family's experience. Demonstrates maturity, resilience.	**8.589 Right.** 8.590 Let it like flow and see what happens and what is meant to be is meant 8.591 to be. **8.592 Okay, and for professionals, so I told you when we met that I** **8.593 started as a nurse but now I'm working in a university and doing** **8.594 this research, so for people like me who are professionals or other** **8.595 people that come in to help families, so I'm sure when you were** **8.596 born and when Ellie was born you had a health visitor and you** **8.597 have doctors and nurses and physios and other people who come** **8.598 along and help with families, not just with families who have**	'*what is meant to be is meant to be*' powerful statement of acceptance and resilience of sibling and the family

	8.599 brothers or sisters who have Down's Syndrome but where people **8.600 have special needs and need extra help, so for those sorts of** **8.601 professional people again thinking about the messages you said** **8.602 you'd like to give the young people, the brothers and sisters** **8.603 themselves, is there anything you think the professionals need to** **8.604 know particularly when they're thinking about siblings, when** **8.605 they're thinking about brothers and sisters, so rather than what** **8.606 they're thinking about Ellie, when they're thinking about you?**	
8.607 – 8.610 Siblings recognise difference in sibling relationship, manage expectations, sense of loss and maturity.	8.607 It's not going to be the same as with a sister who, or with a sister or 8.608 brother or sibling who doesn't have Down's Syndrome because they 8.609 function differently, so don't like, don't have expectations because they 8.610 could go over or they could go under.	siblings with Down's syndrome '*function differently'* Siblings have to manage expectations avoiding over and under estimating
	8.611 Okay, and are there things that I, if I was coming to visit your family **8.612 are there things that I should be thinking about for you as well as** **8.613 mum and dad and Ellie, if I was coming in as a professional to** **8.614 support your family in any way?** 8.615 I don't know. **8.616 If I tell you the reason I'm asking that question, when we were** **8.618 talking when we first met and we were saying that sometimes lots** **8.619 of things come in, if Ellie had health problems or things that she** **8.620 would need help, or if mum needed help finding places like [names** **8.621 special needs/down's syndrome group] and various things like** **8.622 that, and I just wondered what sort of things you remember or** **8.623 what sort of support you had as a sibling, did anybody come to** **8.624 talk to you about it, and if they did or they didn't, was that helpful?**	
8.625 Sibling age impacts understanding.	8.625 Well obviously I was only 3 so I didn't really get it…	Age impacts understanding
8.626 – 8.628 Resilience, loss of agency, siblings normalise their	**8.626 Yeah, [?? 37:19] thinking.**	

family experience. '*I grew up with it'.* 8.632 Sibling can be forgotten, ID issues not discussed. Vulnerability, protection within the family, unspoken narratives parents with children, children with parents. 8.637 – 8.638 Siblings value information and opportunity to talk about ID and their experiences. 8.648 – 8.650 Siblings value sibling with ID, their individuality, normalising differences [everyone is different]	8.626 Yeah, so I didn't really, if anyone did talk to me, which if they did I don't 8.627 really remember because it was 9 years ago now, but I think it was just 8.628 kind of normal, I grew up with it, so. **8.629 Yes, you make a very good point, you were only 3, I guess I was** **8.630 wondering over time now you're 12 are there things that you** **8.631 know…** 8.632 I've never really had a talk about it, I've just kind of learnt stuff I guess. **8.633 Yeah, would you recommend anything like that? People like you** **8.634 perhaps coming to talk to, rather than people like me coming to** **8.635 talk, would that be useful, I'm just wondering in terms of the** **8.636 project what would I recommend?** 8.637 I guess so, yeah, because it's like face-to-face and you like know what 8.638 you're saying and things like that. **8.639 Okay, okay, so is there anything else that you think, as I said I've** **8.640 explained what the project tis, I'm trying to find out what young** **8.641 people think so that we can tell other young people who may read** **8.642 things in the future what to think as brothers and sisters, what** **8.643 sorts of things might be important or helpful for them, so are there** **8.644 any really strong message or things that I haven't asked you that** **8.645 you though, I think Jackie's going to ask me that or it's important** **8.646 that I tell her that, are there any things that you expected me to** **8.647 ask you that I didn't that you think's important?** 8.648 I think some people would like ask what are they going to be into or 8.649 things like that, and really like, you can't really tell, it's like anyone really, 8.650 you don't know what their passion's going to be or anything like that. **8.651 Yes, okay, and anything else that you think that would be** **8.652 important that we make sure that is in this project, so things that** **8.653 I haven't put in that you think I should think about it?**	'it was just kind of normal, I grew up with it..' Having a sibling with ID is normal experience. Grounded and realistic perspective '*Never had a talk..just learnt stuff*' Siblings would value face to face conversation and talking about ID and their experiences '*it's like anyone really, you don't know what their passion's going to be or anything like that*' Acceptance of ID and uniqueness of each individual.

	8.654 I think that's it. **8.655 Okay. Is there anything that you think is useful? When I met with 8.656 you the fact that you agreed to have the interview and talk to me, 8.657 you said that you thought it was a good idea, so what sorts of 8.658 things would you think for brothers or sisters in the future that we 8.659 should have for them when, maybe not when they're 3, but when 8.660 they're a bit older?**	
8.661 – 8.665 Siblings can offer insight, value opportunity to share experience to inform/support other siblings.	8.661 Well like you said, like maybe someone like me or someone who's 8.662 experienced it to come and talk to them maybe, if they wanted that, or 8.663 if they just wanted to like let it just go how it's going to go then they 8.664 would do that, but if they wanted to talk to someone and know what it 8.665 could be like or something like that then. **8.666 Yeah, and where would be the best place to do that?**	Siblings would value the opportunity to talk to other siblings if they have questions, this should not be pressured.
8.667 Siblings value choice in how and where they access support.	8.667 Where they want to do it, whatever they feel comfortable in I guess. **8.668 Yeah. I think you're very wise.** 8.669 Thank you. **8.670 And that's very interesting that you share that. Did you have 8.671 anything you wanted to ask me?** 8.672 It's just about I think, how long would I do it for, so how long does the 8.673 erm project… **8.674 For the diary?** 8.675 Yeah.	Giving siblings choice where they get support, feeling comfortable is important.

	8.676 We do that, we said when we met before we'd do it for about 6 **8.677 months if that's okay?** 8.678 Yeah. **8.679 And that doesn't have to be every day or every week, I said when** **8.680 we met that a couple of times a month or 3 times a month I would** **8.681 ask 2 or 3 times a month because that would give me a few of your** **8.682 thoughts to put together, otherwise I won't have anything to read,** **8.683 but you don't have to…** *8.684 [Interruption]* **8.685 But it's entirely up to you and how often that you write in it, and** **8.686 when we discussed before what you might write in the dairy, it's** **8.687 really about some of the things like we've talked about today,** **8.688 thoughts that occur to you, things that you think are important, so** **8.689 you've suggested to me, I think, today and tell me if I've** **8.690 interpreted that incorrectly, that you think it would be useful** **8.691 perhaps for young people like you to talk to other young people,** **8.692 so share your experience, which is what we're trying to do in a** **8.693 different way, so again if there are things that you think are** **8.694 important experiences or things that you feel are important to** **8.695 share, then those are the types of things that I'd be interested in** **8.696 hearing about, because I'm not 12, as you know, so what you think** **8.697 about as a young 12 year old person who has a sister, like Ellie** **8.698 who has some slightly different needs, it's important that I** **8.699 understand what it's like from your perspective, so that's what** **8.700 that's about, yeah?** 8.701 Yes. **8.702 Okay. Thank you for that, I'm going to turn these off now.** 8.703 Okeydokey, thank you	

Appendix 14 (b): Analysis of connections emergent themes participant 8

Analysis of Emergent Themes Interview 8 Helene/ Ellie [Analysis date 11-01-23]

8.36-8.39 - Family are important

8.51 - 8.52 Enjoys hobbies, varied subjects, sport.

8.63 – 8.64 Shared interests with friends.

8.66 - Pride in achievements.

8.75 - Enjoying sport, girls [friends] playing football.

8.80 – 8.82 Sibling enjoys socialising, being creative.

8.95 – Support for the family from extended family and friends.

8.110 -8.14 - Siblings value family/ friendships.

8.117 – 8.118 - School is a source of building friendships accessing social networks for sibling.

8.124 - 8.127 - Arrival of sister is celebrated.

8.129 - Affection for sister '*so cute*'

8.147 – 8.148 - Diagnosis and terminology 'Down's syndrome' comfortably used to describe sibling with ID's additional needs.

8.157 – 8.159 - Recognises difference in capabilities for sister with ID.

8.161 - Sibling recognises sibling with ID skills/strengths.

8.165 – 8.168 - Pride expressed in sibling with ID achievements.

8.173 - 8.174 - Sibling as a role model, trailblazer for sibling with ID '*following in the footsteps*'

8.186 - Acceptance of ID

8.188 - Valuing being a sibling, normalising experience of having a sibling with ID '*just thought about it as having a sister*'

8.192 - Siblings do not always have things explained to them, [lack understanding parents protecting them, age/life stage impact]

8.196 – 8.200 - Siblings enjoy hobbies/activities together, have fun.

8.213 – 8.214 - Sibling recognises sibling with ID talents and interests.

8.223 – 8.225 - Families network with other families with children with ID.

8.227 - Different experience of being a sibling to their peers, [peers are younger siblings Helene older].

8.232 - Protecting self, sibling, family narrative.

8.240 - Normalising experience of being a sibling with sister with ID.

8.249 – 8.251 - Recognising differences in day to day experiences for them and their sibling with ID. [Sibling insight/taking responsibility, normalising as older sibling?

8.252 – 8.255 - Siblings demonstrate insight into sibling with ID attributes.

8.256 – 8.260 - Families find innovative, individualised ways to support sibling with ID to alleviate anxieties, [use sensory tools / responses].

8.261- 8.262 - Family stressors, sibling with ID needs support at times to manage emotions/anxieties.

8.271 - Recognising sibling with ID ‘happiness’, the narrative of positivity and happiness seems to be prioritised, [potential containment/avoidance of more rounded perspective of daily life].

8.282 – 8.283 - Siblings take on responsibility in the family.

8.285 – 8.287 - Siblings support sibling with ID – share time together [care, maturity, sense of deprioritising self]

8.290 – 8.291 - Unconditional acceptance of their context, maturity.

8.293 - Potential loss of sibling relationship.

8.300 - Normalising relationship, all siblings argue they are no different.

8.301 – 8.302 - Inequalities in sibling relationship, differs from peers.

8.307 – 8.310 - Care, compensating in sibling relationship, protection of self, sister, family narrative; sibling resilience.

8.323 - Maturity [at 12 yrs.], knowledge, understanding Down’s syndrome.

8.324 - ‘*ups and downs’* sibling adaptability, loss and gain, a different sibling relationship.

8.334 – 8.335 normalising sibling relationship.

8.337 - Compassion, understanding, recognises sibling with ID experiences difficulties.

8.345 – 8.349 Sibling with ID affectionate.

8.348 - 8.349 Pride in sibling with ID abilities.

8.353 - Values being a sister, cares for sibling with ID.

8.356 - 8.359 - Sibling as role model. Power imbalance in sibling relationship.

8.361 – 8.363 - Sibling have fun enjoy shared activities.

8.371 – 8.372 - Sibling with ID expresses needs through behaviours. Sibling insight, interpreting cues, e.g., opt out behaviours/ challenges.

8.377 - Need to interpret sibling with ID communication and adapt. Can experience challenges.

8.380 - Care and compassion, recognises impact of ID and potential challenges for sister with ID.

8.384 – 8.388 - Parents need to develop strategies to manage difficulties, parents as role models/ gatekeepers.

8.394 - Faith is not a priority for the family.

8.395 – 8.398 - Sibling identifies with parents, shared interests.

8.400 - Shared interests with Dad valued.

8.402 – 8.407 - Protecting one another, containment, of frightening narratives [volcano as potential metaphor for ID?]

8.414 - 8.418 - Family heritage and extended family connections important for family identity.

8.421 - Choices restricted for sibling? Following parents' interests, [linked to ID narrative, choices restricted, sibling taking cues from parents?]

8.435 – 8.438 - Understanding sibling with ID needs/ capabilities, potential exclusion of sibling with ID?

8.443 - Awareness of social justice, use of language impacting others.

8.450 – 8.453 - Siblings experience brings insight of ID, social conscience, sense of responsibility.

8.459 - Sibling ambitions for the future.

8.462 – 8.466 - Ambitions change with age and insight over time.

8.473 – 8.474 - Sibling ambitions for the future.

8.477 – 8.480 - Sibling sees future with a family.

8.488 - Future framed in context of family experience, recognise potential of having child with ID, acceptance and uncertainty, conflicted.

8.504 – 8.507 - Sibling uncertain of sibling with ID future [age impact 9 yrs.]

8.513 – 8.514 - Sibling has ambitions for sibling with ID future/ career.

8.530 – 8.534 - Powerful reflection for other siblings, insight of ID '*down and upsides'*. [Family narrative of positive projection '*everything is meant to happen for a reason'*, vulnerability, protecting from reality things do not always work out].

8.537 – 8.541 - idealised picture, positive narrative of being a sibling, though questions of uncertainty, reassurance it will be ok.

8.550 - 8.553 - Valuing sibling knowledge and lived experience, this offers support for other siblings to share experience of ID, help strategies for coping with future.

8.558 – 8.560 - External groups ID networks valued by families.

8.562 – 8.564 - Groups/networks provide opportunities for sibling with ID to develop friendships.

8.574 – 8.575 - Specialist support valued by families, mainstream not always helpful.

8.581 - Mum as facilitator accessing support for family.

8.586 - Maturity, recognising need for credible sources of information.

8.590 – 8.591 - Siblings are accepting of the individuality of their family's experience. Demonstrates maturity, resilience.

8.607 – 8.610 - Siblings recognise difference in sibling relationship, manage expectations, sense of loss and

maturity.

8.625 - Sibling age impacts understanding.

8.626 – 8.628 - Resilience, loss of agency, siblings normalise their family experience. '*I grew up with it'.*

8.632 - Sibling can be forgotten, ID issues not discussed. Vulnerability, protection within the family, unspoken narratives parents with children, children with parents.

8.637 – 8.638 - Siblings value information and opportunity to talk about ID and their experiences.

8.648 – 8.650 - Siblings value sibling with ID, their individuality, normalising differences [everyone is different]

8.661 – 8.665 - Siblings can offer insight, value opportunity to share experience to inform/support other siblings.

8.667 - Siblings value choice in how and where they access support.

Appendix 14 (c): Abstraction of themes transcript 8

Abstraction and Subsumption of Emergent Themes from Transcript 8 [working from right to left]

Emergent Superordinate Themes.	**Sub Themes**	**Transcript Emergent Themes Grouped through abstraction/subsumption – created by hard copy and visualising process**
1. Coping, maturity, agency, loss and power.	• Sibling as role model for sister with ID • Parents develop family coping strategies, manage behaviours. • Family dynamics, different dyads, triads, [parents; siblings, sibling and parents, sibling with ID and parents, while family.. • Exclusion of sibling with ID • Sibling deprioritising self • Maturity, knowledge and understanding of ID, Down's syndrome. • Sibling identifies with parents, protective family narrative. • Diagnosis use of language • Family stressors, managing difficult behaviours. • Protecting, self, sibling with ID, family, parents protecting sibling. • Narrative of happiness.	8.36-8.39 Family are important 8.147 – 8.148 Diagnosis and terminology 'Down's syndrome' comfortably used to describe sibling with ID's additional needs. 8.173 - 8.174 Sibling as a role model, trailblazer for sibling with ID '*following in the footsteps*' 8.256 – 8.260 Families find innovative, individualised ways to support sibling with ID to alleviate anxieties, [use sensory tools / responses]. 8.282 – 8.283 Siblings take on responsibility in the family. 8.285 – 8.287 Siblings support sibling with ID – share time together [care, maturity, sense of deprioritising self] 8.293 Potential loss of sibling relationship. 8.307 – 8.310 Care, compensating in sibling relationship, protection of self, sister, family narrative; sibling resilience. 8.323 Maturity [at 12 yrs.], knowledge, understanding Down's syndrome. 8.356 -8.359 Sibling as role model. Power imbalance in sibling relationship. 8.394 Faith is not a priority for the family.

	• Containment, impact on choices. • Realities of up's and downs of life. • Lack of knowledge, parents protecting sibling, sibling with ID, family narrative. • Agency, loss of agency, vulnerability, narrative of family about ID, sibling needs can be overlooked. [assumptive overshadowing?] • Sibling knowledge unique and undervalued • Siblings can contribute to resilience and support of other siblings • Empowerment of siblings would be valued, use knowledge chose how, where this is provided.	8.395 – 8.398 Sibling identifies with parents, shared interests. 8.435 – 8.438 Understanding sibling with ID needs/ capabilities, potential exclusion of sibling with ID? 8.586 Maturity, recognising need for credible sources of information. 8.232 Protecting self, sibling, family narrative. 8.261- 8.262 Family stressors, sibling with ID needs support at times to manage emotions/anxieties. 8.271 Recognising sibling with ID 'happiness', the narrative of positivity and happiness seems to be prioritised, [potential containment/avoidance of more rounded perspective of daily life]. 8.402 – 8.407 Protecting one another, containment, of frightening narratives [volcano as potential metaphor for ID?] 8.421 Choices restricted for sibling? Following parents' interests, [linked to ID narrative, choices restricted, sibling taking cues from parents?] 8.530 – 8.534 Powerful reflection for other siblings, insight of ID '*down and upsides'*. [Family narrative of positive projection '*everything is meant to happen for a reason'*, vulnerability, protecting from reality things do not always work out]. 8.537 – 8.541 idealised picture, positive narrative of being a sibling, though questions of uncertainty, reassurance it will be ok. 8.192 - Siblings do not always have things explained to them, [lack understanding parents protecting them, age/life stage impact] 8.550 - 8.553 - Valuing sibling knowledge and lived experience, this offers support for other siblings to share. 8.625 - Sibling age impacts understanding.

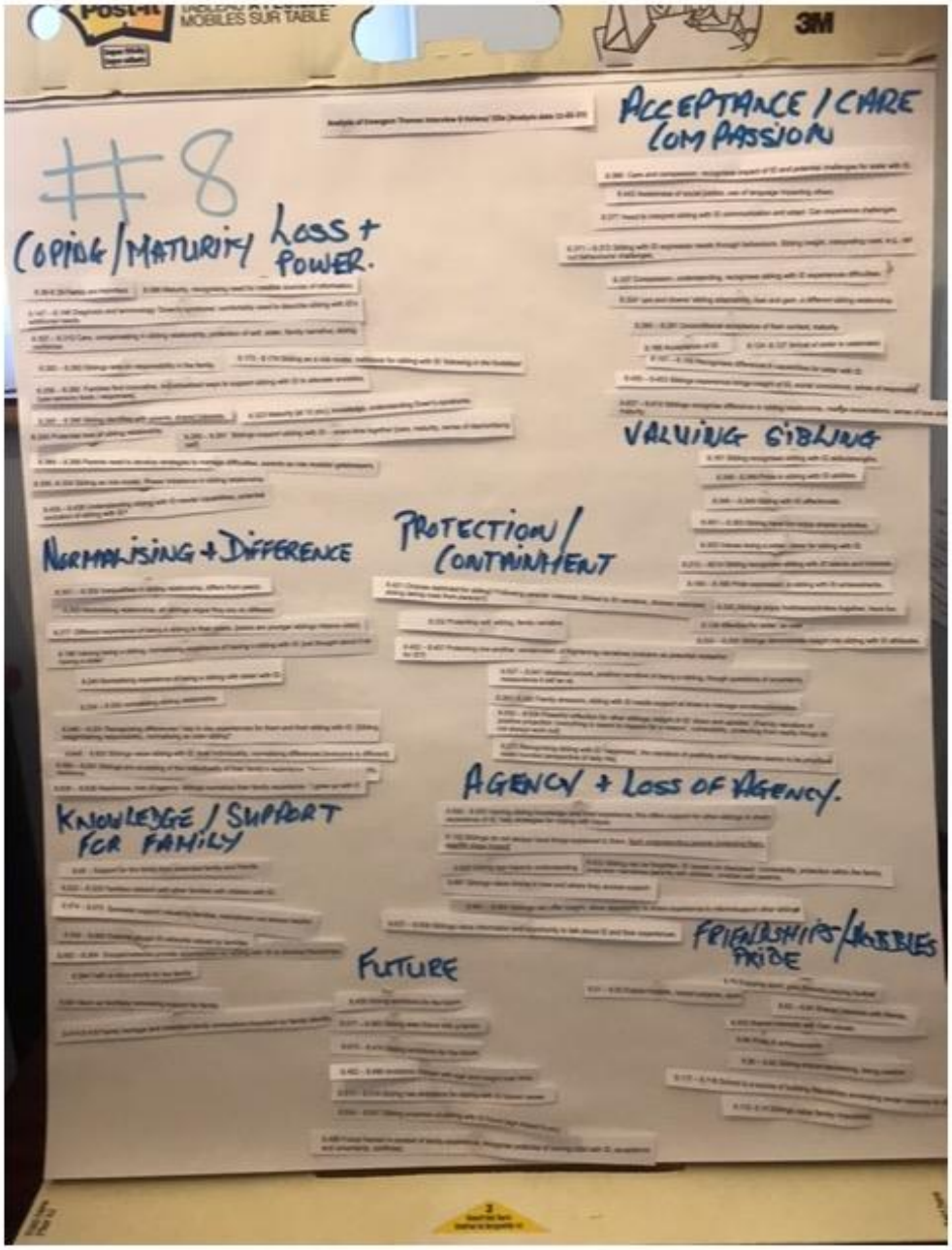
		8.632 - Sibling can be forgotten, ID issues not discussed. Vulnerability, protection within the family, unspoken narratives parents with children, children with parents. 8.637 – 8.638 - Siblings value information and opportunity to talk about ID and their experiences. 8.667 - Siblings value choice in how and where they access support. 8.667 - Siblings value choice in how and where they access support experience of ID, help strategies for coping with future. **[28 Refs]**
2. Normalising and difference, valuing sibling, acceptance, care and compassion	• Valuing being a sibling, valuing sibling with ID. • Care and compassion, maturity, resilience. • Normalising experience as sibling, same and different. • Power inequalities, sibling relationships. • Acceptance of sibling and family norms. • Loss of agency. • Age and sibling status, older/younger. • Acceptance of ID • Celebrating sister, individuality, uniqueness. • Loss of 'expected' sibling relationship.	8.188 Valuing being a sibling, normalising experience of having a sibling with ID '*just thought about it as having a sister*' 8.227 Different experience of being a sibling to their peers, [peers are younger siblings Helene older]. 8.240 Normalising experience of being a sibling with sister with ID. 8.249 – 8.251 Recognising differences in day to day experiences for them and their sibling with ID. [Sibling insight/taking responsibility, normalising as older sibling? 8.300 Normalising relationship, all siblings argue they are no different. 8.301 – 8.302 Inequalities in sibling relationship, differs from peers. 8.334 – 8.335 normalising sibling relationship. 8.590 – 8.591 Siblings are accepting of the individuality of their family's experience. Demonstrates maturity, resilience. 8.626 – 8.628 Resilience, loss of agency, siblings normalise their family experience. '*I grew up with it*'.

	• Sibling insight, understanding and compassion. • Resilience, adaptability. • Sibling with ID valued as individual • Siblings enjoy activities together • Pride, care and enjoyment as a sibling	8.648 – 8.650 Siblings value sibling with ID, their individuality, normalising differences [everyone is different] 8.124 - 8.127 Arrival of sister is celebrated. 8.157 – 8.159 Recognises difference in capabilities for sister with ID. 8.186 Acceptance of ID 8.290 – 8.291 Unconditional acceptance of their context, maturity. 8.324 '*ups and downs'* sibling adaptability, loss and gain, a different sibling relationship. 8.337 Compassion, understanding, recognises sibling with ID experiences difficulties. 8.371 – 8.372 Sibling with ID expresses needs through behaviours. Sibling insight, interpreting cues, e.g., opt out behaviours/ challenges. 8.377 Need to interpret sibling with ID communication and adapt. Can experience challenges. 8.380 Care and compassion, recognises impact of ID and potential challenges for sister with ID. 8.443 Awareness of social justice, use of language impacting others. 8.450 – 8.453 Siblings experience brings insight of ID, social conscience, sense of responsibility. 8.607 – 8.610 Siblings recognise difference in sibling relationship, manage expectations, sense of loss and maturity. 8.213 – 8214 Sibling recognises sibling with ID talents and interests. 8.129 Affection for sister '*so cute*' 8.161 Sibling recognises sibling with ID skills/strengths. 8.165 – 8.168 Pride expressed in sibling with ID achievements. 8.196 – 8.200 Siblings enjoy hobbies/activities together, have fun.

		8.252 – 8.255 Siblings demonstrate insight into sibling with ID attributes. 8.345 – 8.349 Sibling with ID affectionate. 8.348 - 8.349 Pride in sibling with ID abilities. 8.353 Values being a sister, cares for sibling with ID. 8.361 – 8.363 Sibling have fun enjoy shared activities. **[32 Refs]**
3. Knowledge/ support for families	• Family identity, heritage. • Family support networks • Specialist support • Different parental roles, Mum as facilitator of knowledge, information, accessing support for family.	8.95 Support for the family from extended family and friends. 8.223 – 8 225 Families network with other families with children with ID. 8.394 Faith is not a priority for the family. 8.414 - 8.418 Family heritage and extended family connections important for family identity. 8.558 – 8.560 External groups ID networks valued by families. 8.562 – 8.564 Groups/networks provide opportunities for sibling with ID to develop friendships. 8.574 – 8.575 Specialist support valued by families, mainstream not always helpful. 8.581 Mum as facilitator accessing support for family. **[8 Refs]**
4. Context outside the family, friendships, hobbies, pride.	• Pride in achievements of self. • Value external relationships, friends • School, clubs valued source of shared experiences, developing hobbies important.	8.51 - 8.52 Enjoys hobbies, varied subjects, sport. 8.63 - 8.64 Shared interests with friends. 8.66 - Pride in achievements. 8.75 - Enjoying sport, girls [friends] playing football. 8.80 – 8.82 Sibling enjoys socialising, being creative. 8.110 -8.14 - Siblings value family/ friendships. 8.117 – 8.118 - School is a source of building friendships accessing social networks for sibling. 8.400 - Shared interests with Dad valued. **[8 Refs]**

5. Future	• Siblings have ambition for the future, careers for self and sibling with ID. • Conflicted, positive family narratives, yet potential uncertainty of the unknown future [having child with Down's syndrome].	8.459 - Sibling ambitions for the future. 8.462 – 8.466 - Ambitions change with age and insight over time. 8.473 – 8.474 - Sibling ambitions for the future. 8.477 – 8.480 - Sibling sees future with a family. 8.488 - Future framed in context of family experience, recognise potential of having child with ID, acceptance and uncertainty, conflicted. 8.504 – 8.507 - Sibling uncertain of sibling with ID future [age impact 9 yrs.] 8.513 – 8.514 - Sibling has ambitions for sibling with ID future/ career. **[7 Refs]**

Appendix 14 (d): Transcript data analysis board image participant 8



APPENDIX 15: Excerpts from reflexive diary

Reflexive diary excerpts - J Kelly

Excerpts from my reflexive diary. Excerpts highlight early thoughts; reference group reflections; and reflexive dialogue as I engaged with the analysis of the interviews.

July 2014
Completed online UH induction and explored the studynet support.
Read the UH Doctoral College Handbook and Research Development Programme handbook.
Two weeks of reading and consideration of the data more confusion than understanding, but I find I am enjoying the reading that is a surprise but it feels great.
Realise I do not want to do a quantitative study, though have found good article O'Brien et al. 2009 lit review of papers that all undertook quantitative studies in relation to sibling experience. I found this very interesting and enlightening but realise it is not just my view that qualitative is a more relevant approach better for me, and the manner I wish to go about this. Seems to suit what I am looking to explore i.e., experience and a people engaged approach.

Thinking about whether or not I have a good research question have refined this several times current working question….

What is the relationship between the parents' reaction to having a child with a learning disability and the reaction of their other children, the siblings?

Fluctuating between being very daunted by the prospect of the length of time this will take and being really scared and feeling deskilled, I am all over the place. Learning that it is good to talk spoke to ****, she helped to start anchoring down the question limit the scope more than I might there is so much to think about. Spoke to ***** really helpful about the research approach, I have found myself very interested in hermeneutic approaches, in fact hermeneutic phenomenological approaches to research, but dilemmas prevail. To have a hypothesis or not, in the real sense and the systemic sense, that is a real dilemma now. But no hypothesis if phenomenological approach is the way I go. Grounded theory interesting and has possibilities but I somehow felt restricted by this, not clear how to articulate that restriction yet, more reading required! How can you not have a hypothesis if you are a human being, and yet much of the reading contradicts held views and thinking? Definitely feel phenomenological is the way to go but not sure this will be the right "fit" for what I want to achieve. Hence more reading and discussion required.

Very aware of the self-reflexive element throughout I find I read things in layers that of the curious new researcher, the nurse, the teacher, but most especially the mother. Why do we always look to find something that brings us up short? Onwards…..

Reading… Aveyard "Doing a Literature Review".
Very easy to read text, has developed my thinking in terms of my approach to a literature review. In particular adopting a systematic approach and due consideration of refining the research question. Thoughts around this are "What do siblings reflect of their experience of having a brother or sister with a learning disability". This is an interrogative rather than a declarative question, either are ok as defined

Diary entry Jan 2015
Terminology in the question needs to be explained in the introductory chapter, i.e. learning disability, sibling systemic etc. this can be referred to as "operational definitions".

To refine the question, I should utilise the PICO(T) or SPIDER acronym,
PICO formula (O'Connor et al., 2008) Population, Intervention/Issue, Comparison/Context, Outcome, Time; SPIDER Sample Phenomena of Interest, Design Evaluation, Research SPIDER used for Qualitative questions (Cook et al., 2012).

Need to set the literature review in a socio-politically informed context.

From my perspective both the study and the literature review are based within a theoretical framework of a systemic perspective. Need to clarify with supervisors Sally and Sandra if this interpretation is correct??

Considered the hierarchy of evidence and have proposed ideas for this and alongside the inclusion and exclusion criteria.
It all seems quite overwhelming just now, but I am working through this systematically to frame what I am doing.

Will discuss with Sally and Sandra a structured plan for the next 3 months/ 6 months/ 8 months to the progression point. Need a more structured plan? Will discuss this further with Sally and Sandra at the next supervision??
Aveyard book really useful.

Entry Feb 2015

Supervision:

Discussed the title of the study.
Originally I had proposed, "What are siblings' perceptions and responses to having a brother or sister with a learning disability"?

Discussed some consideration I had been giving in recent weeks from reading and my own reflections, to change this to, "What do siblings reflect of their experience of having a brother or sister with a learning disability."?

Following discussion with Sandra we explored what is it I really want to explore? We considered the "wooliness" of the term reflect/ reflections I need to be more specific.
The key issue for me is to ensure the voice of the sibling is heard and to minimise the influence I have as a researcher of predicting or prompting what their experiences and views are that they chose to share.

Followed on to consider a different slant to the research question.

"What are the views and experiences of siblings growing up with a brother or sister with a learning disability"?

Hence I now have a new working research question to consider.....Getting there..?

We explored the age range that I might consider and debated and reviewed the ethical challenges and issues to consider in working with children.

Discussed the previous MA and small empirical research that I had undertaken with adult siblings reflecting on their childhood experiences. Noted that Sally and I had already discussed this somewhat and I had concluded that it would be hugely valuable to have the experience of the child, as is their current lived experience rather than retrospective as an adult. I had been anxious about the ethical minefield this might expose me to, but the data would be rich.

My readings thus far show limited direct research where siblings are asked their views and share their experiences other than through their parents. I wanted to try to gain data directly from siblings valuing their independent view as children.

We considered that it might be an idea to set the target participants in the age range of children at secondary school so age 11-16. They still have the reflection of children but particularly at the upper range are also looking forward to the future but are still young enough to reflect on their past. This might give the opportunity to create much richer data for the study.

May 2016
Discussed the reference group, gained agreement from a local secondary school in ***** to meet with sixth form students to explore the children and young people information booklet and general ideas for the research and process. To gain their views and insight into accessibility for the age group and any others factors to consider. The meeting will take place on 10th June face to face with further virtual meetings possible as required. EC2 from was submitted to agree to the change re: reference group.

June 2016
Notes from Reference Group, a Secondary School
8 Students from Year 12
Feedback from young people on the research and the information sheet for children and young people.

Some of the questions from the students were, "am I working with people with different intellectual disabilities"? They felt it was ok to work with a broad range. I explained that I was not limiting this to one diagnosis of intellectual disability but that this would be something I would need to comment on in the discussion of any findings from the research.

They asked if this was all about the sibling and if the focus was on them and their experiences. I explained that was the purpose of the research and discussed some of the other studies where this had not been the case or had only been part of the study.

They advised me to break the paragraphs up into bullet points as this would make it appear there was less to read, be more engaging and easier to understand.

They advised that I did not need to use simple definitions such as what a sibling is. They felt most children between 11-16 would know what this term meant and that it might be quite patronising if it were included.

They advised using two separate booklets; one for 11-13 year olds with less information further simplified and with the pictures enlarged, with more use of colour differentiation to make it attractive. They felt the current booklet with the adjustments they had suggested added in, would be appropriate for 13-16 year olds. For 11-13 year olds they advised simplifying the language. For 13-16 year olds they felt the definition of intellectual disability could be left out or reduced to advise that learning disability and intellectual disability in this context were one and the same.

In considering the definition of intellectual disability they felt this started out as feeling quite negative. They suggested more appropriate terms would be that people with ID can or may have different thought processes, "they think differently" and "experience things differently". They did not feel it was always the case that they develop slower, but they felt it was fine to leave this in as an "or" statement, perhaps adjusting the language to use a term such as "at different rates".

They felt the term learning disability was more readily understood in the UK, but they appreciated why the term intellectual disability was being used and felt adding in a note to state that they were interchangeable terms for the purpose of the study, would suffice to explain this.

Under the question “Do I have to help”? they felt this was valuable and was appropriately placed in the booklet.

In terms of safety issues, we discussed this in quite a lot of detail. They felt that this was off putting. They understood the need for people to feel safe, but they suggested that this was made as more generic statements i.e. less personalised not using “I”. They felt children and young people would know what this meant and also felt that the booklet only needed to give an introduction, and any further explanation could be given when I meet with the young person.

Under “What will I have to do?’ they advised putting in an example of a type of question that might be asked. I explained that the semi-structured approach meant I was not aiming to be very prescriptive with questions. They felt that was helpful but still thought an example of an initial question would be useful and give the young person an idea of the type of things they might be asked.

In relation to keeping a diary or blog, they thought this was useful. However, there was some discussion about the format of the blog, and they felt it need to be in the young person’s chosen format. I.e. they could keep an audio, written or electronic record. They suggested using the term private blog, so this was clear it was not an open access blog. However, they felt the term blog would be meaningful to young people in this age range and suggested keeping the terms diary and blog.

They did feel there needed to be more of a frame or guidance as to the types of things they might be asked to keep in a diary/blog. Again, they suggested this could be explored in more detail when I meet with the young person, but they suggested giving an outline of the type of things that might be helpful, otherwise they considered this might produce a lot of data that was not relevant or useful to the study.

On the whole they suggested it was important to present this as something of value, they generally felt if young people came forward to do this that they would therefore be motivated and committed to keep the diary/blog. But they also suggested it should not be presented as burdensome.

They were concerned with the statements about hurting someone or someone hurting them, they felt the statements here were too strong, as if suggesting it was likely young people in these circumstances would have problems. They felt this could be perceived very negatively. They understood why it was important to mention this but suggested it was stated in a more generic way rather than using the first person. One young person used the term “this needs to be toned down”.

In relation to the question “what if I get upset”? again they felt this terminology and statement was too strong and could be negatively perceived, they all felt quite strongly about this one. They suggested adding this into the "what if I have questions" section as an additional bullet point and advised that the statement needed to be less “harsh and direct”. Again, as before they felt it would be useful to make this less personalised, They also stated they did not like the downturned non-smiling face image for this question and suggested using a bubble person similar to other images with a question mark to demonstrate this.

Generally, they liked the layout of the booklet and felt the pictures were particularly “cute” and helpful. They liked the use of the comic sans font and the background watermark image. They also felt the size of the booklet as A5 was appropriate and were not concerned with the number of pages. They felt all the information needed was contained within the booklet with the adjustment suggested, and that it explained what I had suggested I was aiming to do.

Overall, the young people felt this would be helpful and understood that the outcome could not be predicted but all considered it would informally support and provide information for siblings about ID for the future, which they felt, was valuable.

Reflexive diary entries meeting with families

March 2017

03-03-17
So excited to finally be starting data collection potentially.
Initial meeting with this family. Single mum son and daughter who had ID. Live with grandmother and aunt. mum works in the city. Family delightful. Discussed the project and ******* the son is happy to participate. Arranged to meet on 10th Mar.

Reviewed the semi structured interview sheet as a guide. Tested the Dictaphone.
Confess to feeling very nervous about this, as it is the first one. But excited too as I was beginning to despair that I would never get started.

10-03-17
Fantastic interview I was very nervous, but a delightful young man. Full of positivity. Very mature for his 15 years. I was struck by his maturity. Particularly when he talked about the future. He believed there was a future for both him and his sister. But he was clear that she would be his responsibility. I was again struck by how matter of fact this was stated. He took it for granted that this was just the way it was going to be. He seemed to have grown up with this view as it had always been that way. He was young age 5 his sister was 2 when his father died and therefore, he feels as a young man, they are a Muslim family, that he should take the male role and support the family in the future. He was conscientious about his studies. But he also talked about friends and how much he enjoyed time with them. He also talked about enjoying family time too and outing with his Mum Grandmother and Sister.

Came away and reflected a sense of feeling sense of responsibly to get this right, try to tap in to all the rich information he provided. Feel a bit overwhelmed.

Now to transcribe, frustrated as I type too slowly!

24-03-17
Supervision Sally K

Discussed undertaking my first interview and the learning from this already. I expressed to Sally how powerful the experience had been. I felt so humbled by the young man's conversation and answers to my questions. I am transcribing the interview but it is taking time.

In listening back to the tape recording, I noted my hesitations 'ums' and 'errs' as I become more familiar with interviewing as researcher and not engaging as a therapeutic intervention. Very conscious to keep this in check. Sally reassuring re: the approach and that in turn reassured me, helpful to chat about it all.

The semi structured interview guide was helpful and although I did not follow this rigidly, the flow of the questioning felt right and the conversation with the young man was not stilted as I had thought it might be. However, this was also due to the fact that he was very articulate, confident, open and honest. I was "blown away" by his maturity and positivity in sharing his reflections of his experience. I have kept in touch with him via email as agreed and he advises that the diary is going well.

31-05-17

Visit with participant 2

During the visit I was struck by the resilience of the family, mum talked about resilience and her tenacity to keep knocking on doors, writing letters until she was heard and got the services she needed for *** but she did say it can be exhausting. Resonated with me as mum I too know what this feels like as a mum.

Note to self, discuss with Sally and Sandra at next supervision, I didn't share information that I was a mum with a child with ID, I felt dishonest, but also protective of my son's narrative. Important to explore this though.

She talked about offering help to others through ******** ** ***** as she is 'good at paperwork' and it felt good to be able to use her intellect and skills to help others. I was struck by how much people can feel defined by one thing in their life, in this case a child with special needs and how important it is for all of us to see the holistic perspective of family and of each of the individual therein. Was I connecting, I felt torn again as a mum, nurse and systemic practitioner not to intervene therapeutically, this feels like a 'tug of war' for me, as I am new to being a researcher.

Participant and I tested out the tape recorder so he could see how it worked; we joked about me being a grown up and not so good at technology as he might be! I arranged to meet again on 17th June to conduct the interview. We discussed how he would like to keep his diary; he will chat about it with Mum and we can agree this when we next meet.

Mum took some flyers to share with others she knows who might be interested in participating in the research.

Subsequent positive discussion with Sally appropriate not to share my 'mum' story.
Reading Finlay (2011) & Smith et al. (2015), 'bracketing! Double hermeneutic.

Moved diary to handwritten…feels more connected….

***Handwritten diary transcribed to support accessible reading.**

Dec 2018
Shafeeq participant 1

I was struck by his sense of responsibility - his emphasis on the need for academic achievement (non-negotiable). Yet loves his sport - sacrifices this?
Does he feel constrained to be the perfect son.

On listening to the interview early questions from me or sometimes lengthy. I was conscious of 'not doing harm trying not to lead' but inevitably my influence is there.

As his father died what role is he playing, responsibility a big feature of this family. Must take responsibility, work together but 'don't rock the boat'. Is this a judgement here from me?

Line 1.377
Finding 'right' support is a struggle for all families, is there an influence of my own experience here as a nurse and a parent, knowing but finding the right services can be hard.

Novice researcher! At times too many components in the question making it difficult for Shafeeq to give focus in answer.

Line 1.428

Most powerful sentence all about Shafeeq sense of his responsibility. I felt in the interview, and as I listen and re-read this now such a powerful emotion.
I think of my role as a parent, what responsibility do I put on my children, important to be conscious of this (bracket), but also own this openly, part of reflexivity.

Sometimes the length of my questions could reflect my discomfort – i.e., not wanting to probe too deeply or cause any distress, upset to Shafeeq.

Only two siblings so he has no other comparison.

Line 1.478
I reflect that perhaps I could have followed up with a question on "what would have happened if you were not patient"? Was I too worried or being too protective and therefore didn't ask this question?

Line 1.504
lengthy questions at times jumping from one thing perhaps too quickly? As if I'm trying to get through my questions.
Line 1.560
I wondered if using the words "I don't mind" Suggested that he might actually mind at times? Where is his personal space to be a teenager?

Line 1.621
as I listen to the interview, I am referring to my questions as if I need to complete them all links to novice researcher and my concern I might miss something I'm not using all my prompts! – May Have missed something I relied too much on my prompts!
Line 1.616 – 618
Perhaps I did not pursue this as it resonated with me as a mother what my own children might feel or experience? Very conscious of this as I listened to and engage with this transcript.
Line 1.652
feels like a missed opportunity to explore more about their relationship it was quite emotional not a sense there was any more to say but this does feel like an area I could have questioned more.
Line 661-684
I believe I felt unsure about broadening the subject of culture and religious belief I struggle to focus the question, but I did acknowledge the struggle as I asked it.
Line 760 -768
VERY POWERFUL. Where is his choice and sense of self? Personal links here for me thinking about my own children, what choices do they interpret that they have, again resonates with the importance of reflexivity so I engage with this study.
Line 1.782 -1.784
I state how he comes across it's responsible I was overwhelmed at the time of the maturity of this young man, it yet the sense of 'no choice' that he presented. He was so mature and sincere in his statements.
Line 1.901
My naivety comes across, "sticking to the script" at times I'm missing some potential follow up questions. Asking similar questions so Shafeeq repeats answers. I reflect was he frustrated with this, did that restrict what he answered? Did he feel I was prejudging?
Line 1.995
I could have asked what he thought about keeping the diary? Why it might be useful?

Line 1.334 -1.336
in identifying emergent themes have again revisited the text and have a strong personal connection with the mum. I need to check my connections here, is she laying the foundations for his future responsibilities? My 'interpretation' here strongly influenced by my own context? Approach as a mum? Important to ensure this is grounded in what Shafeeq is saying. Yet conscious that I am inevitably connected and hearing things as I engage with the data, double hermeneutic.

Line 1.428-1.429
I felt a little overwhelmed have a sense as he spoke that he had a ‘weight’ on his shoulders. Did I? Identify as apparent here? I wanted to scoop him up tell him he wasn't alone and let him live a little, it felt ‘heavy’ in the room/air as we spoke, but he was calm matter of fact and accepting, I was ‘wowed’!
Line 439
I could have just asked the question I really have so much to learn and hope I can grow in confidence an undertaking this type of qualitative research
*Line 1.478
A huge sense of being patient, understanding the needs of his sister it was powerful. I have a sudden awareness of the data emerging on its own, IPA is exciting!

Line 1.659
I feel on reflection this was a missed opportunity to explore more. He describes this as a ‘first’ experience. This was a powerful exchange and realisation of how much his sister cares for him. She was almost giving back, he let the ‘keeping her happy’ go, and it was OK - she coped.

Excerpts from reflexive diary Participant 7
Feb 2020

Struck by the enormous sense of social justice from Iain, in the family, aware of helping others, as a sibling helping his parents. He was so mature at thirteen years old! His brother is older at 16 years.

Such a mature young man, he also expressed a sense of isolation at times for him and for his brother. He talked about needing to help his parents. Recognises that life can have difficulties for all for his sibling Christopher, for him but he emphasises but this is far more difficult for his parents. Emphasises a need for people to be aware siblings can be tired, can be anxious.

Iain was very supportive of his parents (his mum especially) he had a real sense of responsibilities that his parents faced wants to help them by being less of a burden (7.884)
also struck by his vulnerability, he used the term ‘take a backseat’, when describing how his parents might need to prioritise his brother's needs on the impact on him, but he was at pains to emphasise how he realised this was a consequence and not a fault of his parents, (7.359 -7.361).

Iain was very direct in his responses. I recall feeling like I was ‘probing’ and not wanting to push him too much he came across as a very thoughtful young man. However, he also seems to be containing a lot, not wanting to be difficult or cause any upset to his family. I wondered how much he was ‘holding in’. Something here about his needs feeling overshadowed, assumptions being made (assumptive overshadowing?), similar sentence comes to mind for some of the other siblings ‘holding in’. Are Iain’s needs masked or missed as he tries to “be less kind of needy” (Line 7.363), in order to support both his brother and his parents.
He takes responsibility to be more independent as the younger sibling, his care and support and level of understanding far exceed what might be expected from a young person at thirteen years old.

Excerpts from reflexivity diary – participant 8

Dec 2021
My introductory meeting with the family was delightful, recalled this sense as I reengaged with the transcript. When I next met Helene at the interview, she reflected the approach her mum had outlined of the family managing the needs of their daughter her sister Ellie who has Down’s syndrome. Family narrative was very positive.

I was struck by how positive Helene was about her sister, I felt concerned at times that I was pushing less positive narrative asking about when “things are more difficult”. The family appeared close knit, I did not meet dad. Helene was so caring towards her sister. Her responses were mature, a real sense of social justice emerging. I did wonder if under the surface there was less certainty and at times, she was perhaps answering what she thought I wanted to hear, or what/how she thought her mum might respond?

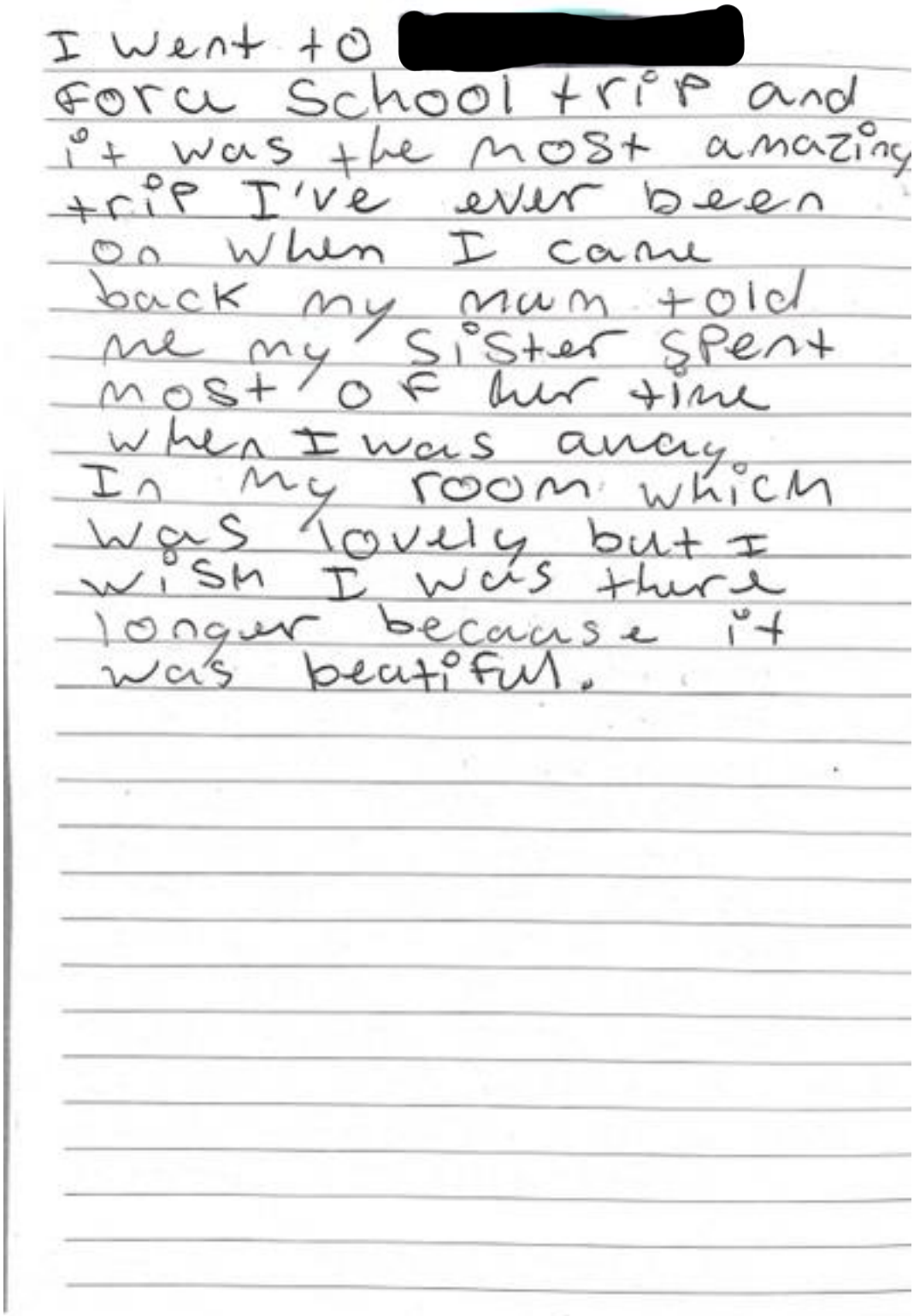
She expressed genuine love for her sister doesn't see any barriers as it were.

I asked how she came to realise her sister had Down’s syndrome she expressed this as their ‘normal’ stating she just had a sister Didn't understand any difference. The latter statement made me wonder if she felt there was more to understand (Line 8.186 – 8.190).

Unlike some of the other siblings, Helene spent time with her sister she expressed that they enjoyed similar things (art, movies, dance), And she seemed to take pleasure in being a big sister.

I'm mindful of birth order being the older sister and type of intellectual disability (Ellie is the only sibling of those interviewed with Down’s syndrome). I reflected on the behaviours presented by others and weather as older siblings grow, the challenges and differences become more stark.
I was left with the feeling of care but the sense of containment for this family.

APPENDIX 16: Excerpts from participants' diaries


I went to [redacted]
for a school trip and
it was the most amazing
trip I've ever been
on when I came
back my mum told
me my sister spent
most of her time
when I was away
in my room which
was lovely but I
wish I was there
longer because it
was beautiful.

Today ~~we~~ me and [redacted]
spent a day with are
dad, we went over to
[redacted] it was a lovely
~~stand~~ sunny day but
after we walk up the
Canal and back to get
lunch [redacted] started
to mone a lot. she
moned at not having
a toastie and there being
lettis on her ~~Plait~~ Plait
~~band~~, then when we went
home she started moning
because we had 1 ~~hour~~
hour on the xbox but
she started getting angry
so I turned it off any
way so she stomped off
to watch youtube. Then
we went back to are
mum's house and she
moned about her Pizza
and bit her arm and
stormed off. But other-
wise it was a good
day.

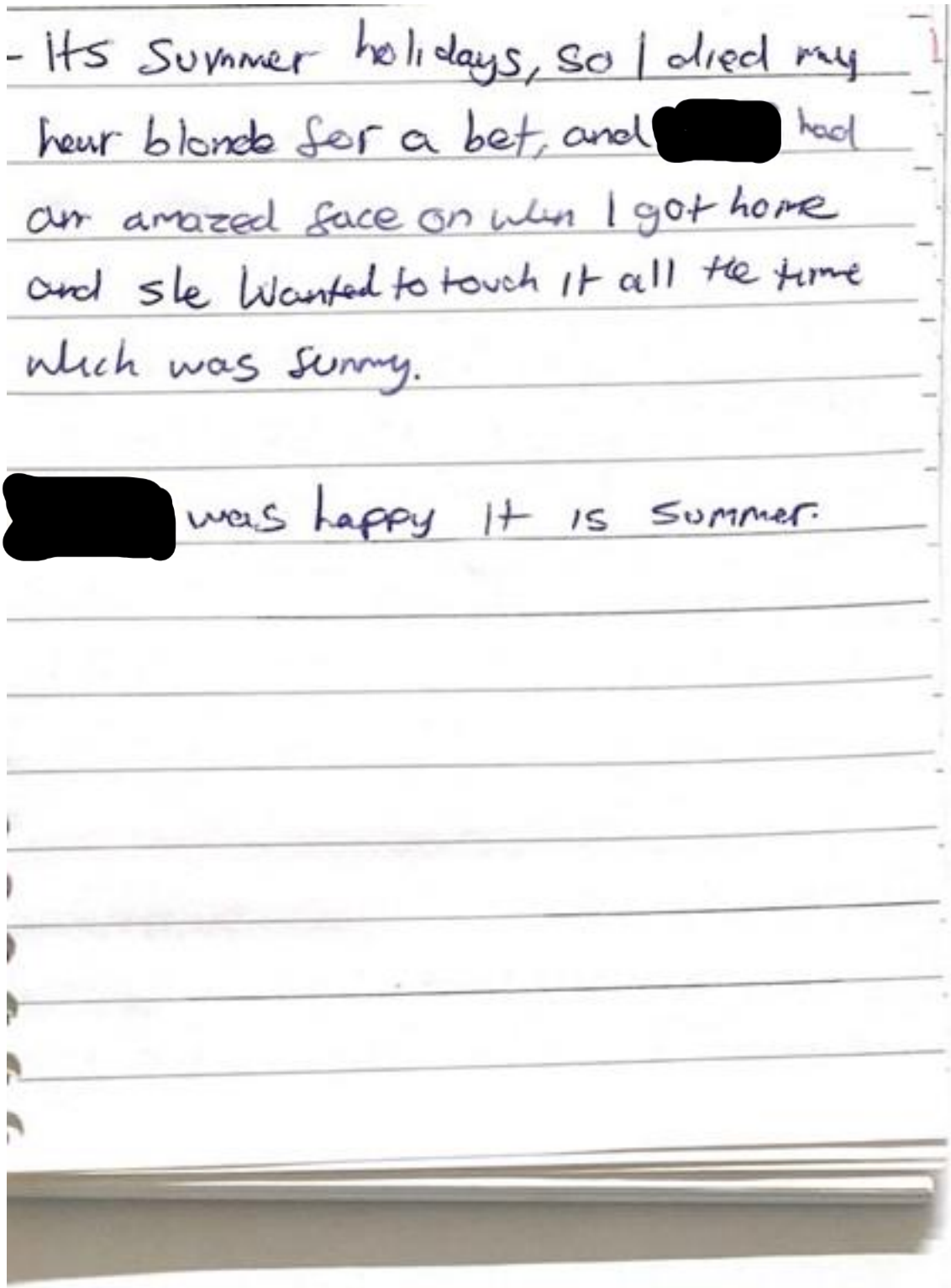
today me and mum
mum ~~had~~ talked about
how [redacted] has like a
little super power like
she can pick up a persons
Feelings like today i was
Feeling Sad and she
made me Feel better
by showing me her new
toy but befor that
we went to brancaster
beach and all I did
was swim in the Sea
because the tide was
coming in and I could
ride the waves then
we went shopping to get
People some holiday Gifts.
So That day was good.

[redacted] has her first sleep over in 2 days and she can't stop going on about it she has already packed about 5 bags, most of which she does not need but thats ok. And ofcourse it is with her best friend. Me and mum are predicting that she may need to come home just because her sleeping pattern has been a bit off at the moment.

So she did it. She stayed overnight and didn't even get up. We underestimate her but this has taught us not to. When we arrived to pick her up this morning, she didn't want to leave. She had a great time and we are definately going to give her this opportunity again.

14

Today was [redacted] sports day and because I had an Inset day. She did 100m and beanbag Shuffel. She came 4th out of Fith both times and it is really Sweet because all the kids and adults on the sideline all cheer for her and Its really nice as it shows the kindness and respect that people have for her.


- Its Summer holidays, so I died my hear blonde for a bet, and [redacted] had an amazed face on when I got home and she wanted to touch it all the time which was funny.

[redacted] was happy it is Summer.

[redacted] appears to be mostly happy in the sixth form of his school, but doesn't seem to be very happy at home. Today, he tried to take some hooks out of his bedroom wall and left some holes that he tried to colour in. He doesn't always realise that he should ask someone for help before trying to do something he doesn't know how to do. Perhaps he finds it hard to realise when he is not capable of something.

I notice that when [redacted] is angry, he becomes much more annoyed when people touch him than he usually is. He didn't used to be like this, in fact, he never used to even say anything when people touched him.