The social worlds of disabled young people and their experience of child protection enquiries and their aftermath

PhD Thesis

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Abstract

Disabled children are vulnerable to personal and social adversities, including an increased risk of maltreatment. By examining disabled young people's views of their social worlds and experiences within support and protection processes this thesis fills a significant gap in the research literature. It also offers unique insights into the lives of disabled young people, including their involvement with child protection processes, and adds to our knowledge and understanding of their specific support needs.

Sixteen disabled young people aged between 11-18 took part in this qualitative study. Undertaking individually tailored activity-based interviews enabled young people with diverse impairments to engage in the research. This approach allowed participants to raise issues that were meaningful to them, avoided stereotyping disabled children as lacking competence and agency and encouraged a more nuanced account of their lives to emerge.

Thematic analysis revealed these young people to be competent and adaptive in the face of their family's difficulties and the challenges posed by their impairments. Participants' spoke of the stressful nature of their experiences of child protection enquiries and their aftermath and the need for social workers and other professionals' to build relationships with them and help them to manage the emotional impact on themselves and on their family relationships. While wanting to be kept safe, participants' stressed their need to be kept informed and involved in decision-making, and for practitioners' to adopt an enabling approach to their impairments, respect their own view of their support needs, and appreciate their family's strengths and the significance of family relationships.

Based on the study's findings, a model for understanding the complexities of child protection practice with disabled young people is presented. Suggestions are made for social workers and other professionals' to apply the findings to their practice in order to better engage disabled young people within support and protection processes.

Acknowledgements

Firstly, I would like to thank the young people and their families who took part in this research, for their willingness and courage in sharing their experiences with me. Without them this thesis would not have proved possible and I am extremely grateful for the trust which they have placed in me to give voice to their accounts.

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I am also extremely grateful for the advice and support I have received from colleagues, other researchers, practitioners and fellow PhD students. In particular, for the many conversations that have inspired new ideas and fresh perspectives on my participants' accounts.

I owe a particular debt of gratitude to my family. To my parents for their unwavering support and belief in me, and especially my husband James, for the many hours spent assisting me in the final stages to ensure I made it across the finish line and to him and both our parents for caring for our family to enable me to study. To our girls, Niamh, Caitlyn and Erin, thank you for your patience and understanding and for simply being yourselves, I am immensely proud to call myself your Mum.

Finally, I want to dedicate this thesis to Joshua and his family, whose courage, humour and determination in the face of considerable adversity continue to inspire me.

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Introduction

This study aims to explore disabled young people's subjective views of their experiences of child protection enquiries and their aftermath and how they understood and made sense of these experiences in the context of the rest of their lives. An explanation of the key terms used to describe participants' experiences of child protection and other professional processes is included at Appendix 1.

Motivation for the study

The initial impetus for this study came from my years working as a children's social worker. Moving to specialise in social work with disabled children after five years supporting mainly non-disabled children who were the subject of child protection plans, receiving support as children in need and/or separated from their families in care, I was struck by the very different approaches taken to engaging with disabled children and their families. I was used to working in partnership with parents and carers. I was also aware that social work involvement with disabled children was usually based around their family's need for support to meet their impairment needs rather than safeguarding concerns. I did not, however, anticipate the difficulties and lack of emphasis given to working directly with disabled children themselves.

High eligibility thresholds to the Children with Disabilities Service meant most of the children I was social worker for had severe disabilities and often additional communication needs as well. The barriers to building a relationship with many of them included the additional time often required to get to know each other, my own lack of skills in communicating with them, and sometimes parents' presumption that my primary role was to work with them rather than with their child. This sharply contrasted with my previous experience of working with children living in out-of-home care where, despite similar pressures on my time, supporting their involvement in decision-making and undertaking life-story work had been an important part of my role. Whereas with disabled children, despite my own best efforts and the skilled and creative efforts of colleagues, I was aware that the child's perspective was not always included in assessments and decision-making, a trend that has also been reported by research studies (Morris, 1998) and practice surveys and inspections (Franklin and Sloper, 2009; Ofsted, 2012).

Although most of the children I supported nevertheless seemed happy and well cared for by their families, I found this discrepancy most unsettling during child protection enquiries involving disabled children and young people. One case involving a 14-year-old boy with severe learning disabilities, who also experienced difficulties with behaviour and communication, particularly troubled me. There were concerns that his parents were struggling to cope with meeting his complex needs but were reluctant to accept outside support. This reluctance might have been affected by his mother's nervousness about her son being looked after by strangers and having a learning disability herself and his father's own negative experiences of spending part of his childhood in care.

In addition, this young person made regular, serious but unsubstantiated allegations of abuse against various members of school support staff. I sought the support of his speech and language therapist to help me try and understand what might be happening for him as his speech was 'echolalic", meaning he often repeated what he had heard without necessarily comprehending it. I was shocked to learn from working with her that in twenty years acting as an appropriate adult for disabled children and adults at joint protocol interviews with the police following suspected abuse, none had, to her knowledge, ever led to the alleged perpetrator being successfully prosecuted. This is in keeping with conviction rates reported by research studies (Cooke and Standen, 2002; Taylor *et al*, 2016). Moreover, although I was eventually able to persuade the family to allow me to arrange short breaks for this young man, which he appeared to really enjoy, his own views about the circumstances surrounding his allegations of abuse, despite my efforts to engage him during the child protection enquiries that followed, remained unknown and unexplored.

I was well aware that the child protection system was far from perfect, and like other areas of social work practice, responses were often weighted towards the needs and concerns of adults and organisations rather than those of children (Gunn, 2008). Reflecting on my involvement in this and similar cases left me with the growing conviction that disabled children's voices whether in support or protection processes were shockingly lacking. My frustration at my own lack of skills further sparked my interest and curiosity as to how this situation was experienced from the child's point of view, as well as how social work with disabled children could be improved.

Rationale for the study

I was already aware from reading and attending training courses that disabled children are three to four times more likely to experience maltreatment than those without disabilities (Jones *et al*, 2012). A closer look at research reflected my own impressions of practice, that how concerns involving disabled children are responded to during child protection enquiries and subsequent decision-making, especially the weight given to the child's views, seemed to differ from that involving other children. For example, in 2011 disabled children made up 3.8% of children on child protection plans (Ofsted, 2012) despite between 7-8% of children having a disability (Office for National Statistics, 2017). Though I also recognised that increasing the numbers of disabled children within child protection processes is not good in and of itself and that disabled children and their family's additional support needs are often better met in other ways. For example, Ofsted's (2012) thematic inspection of child protection cases involving disabled children identified many cases where emerging concerns for disabled children being dealt with at an early stage through the co-ordination of multi-agency support had negated the need for further child protection involvement.

Notwithstanding that the underlying causes of maltreatment and what constitutes an appropriate response have been the source of considerable debate (Featherstone *et al*, 2018), studies have raised concern that maltreatment involving disabled children more often remains "hidden". Evidence suggests that practitioners' lack of knowledge and skills regarding disabled children's needs may prevent them from recognising and/or cause them to misattribute signs they are being abused (Taylor *et al*, 2016; Miller and Brown, 2014). Brandon *et al* (2011) found that some practitioners in cases resulting in a serious case review had missed signs of abuse as a result of "seeing the disability, not the child". They also identified a tendency for practitioners' to accept "a different, a lower standard of parenting than would be tolerated for a non-disabled child" (p.9), with other studies reporting similar findings (Taylor *et al*, 2016; Kelly and Dowling, 2015).

Despite the increasing emphasis on children's rights to support in expressing their views and having these taken seriously (United Nations Convention of the Rights of the Child, 1989; Children Act, 1989), research suggests that disabled children are less likely to be spoken to during child protection enquiries (Cooke and Standen, 2002). Notwithstanding some evidence of good practice, the extent to which disabled children's views are sought and included in social work assessments appears to be highly variable in practice (Ofsted, 2012). Practitioners also report struggling to adapt child protection processes to take account of disabled children's communication and learning needs (Taylor *et al*, 2016; Kelly and Dowling, 2015).

Stalker and McArthur's (2010) review concluded that the needs of disabled children are largely "invisible" within the child protection policies of the four UK countries. This, they argue, reflects a long-standing tendency for childhood disability to be regarded as a separate policy issue. For example, although the introduction of specific practice guidance "Safeguarding Disabled Children" (Murray and Osbourne, 2009) in England was largely welcomed, its accessibility and status as an addendum to the statutory child protection guidance Working Together (HM Government, 2018) has been potentially undermined following revisions aimed at slimming down this document. Moreover, no reference was made to disabled children's specific needs or increased risk of maltreatment within Munro's comprehensive review of the child protection system in England (Munro, 2011).

There has been some policy recognition of the links between childhood disability, maltreatment and other forms of disadvantage. This is reflected for example in the "Think Family" (Morris, 2012) and "Troubled Families" (National Audit Office, 2016) programmes. However, this association has rarely been made explicit and has not resulted in specific policy or practice initiatives specifically focusing on addressing the high rates of poverty and disadvantage among disabled children and their families (Blackburn, Read and Spencer, 2010). The "Every Disabled Child Matters Campaign" (Council for Disabled Children, 2007-15), for example, has criticised government policy initiatives for failing to take into account differing needs and outcomes among disabled children (Sloper, *et al*, 2009). Policies specifically aimed at addressing disabled children's social exclusion during the last two decades, such as the Aiming High Programme (HM, Treasury 2007), have also been criticised for perpetuating a focus on the needs and concerns of their parents' and carers', rather than those of children themselves (EDCM, 2011).

Despite the proliferation of research with children and disabled adults due to the emergence of childhood and disability studies as distinct fields of study, research focusing on disabled children's perspectives of their lives is relatively lacking (Watson, 2012). Stalker (2012) notes that disabled children's views are largely excluded from mainstream children's research. Researchers commonly report parents' and professionals' negative attitudes and assumptions regarding disabled children's competence and vulnerability as affecting their willingness to allow them to take part in research, including that focused on children's experiences of child protection (Cossar *et al*, 2011). Consequently, while there now exists a considerable literature regarding children's views of child protection enquiries and their aftermath (van Bijleveld *et al*, 2015), very few studies have so far focused on disabled children's experiences of these processes (Jones *et al*, 2017).

Why is this study important now?

During the last decade evidence has accumulated of the long-term adverse consequences of child maltreatment on children's welfare and development, including increased risk of mental health problems, drug and alcohol use, risky sexual behaviour, obesity and criminal behaviour (Gilbert *et al*, 2009a). Research has similarly highlighted the consistently poorer outcomes experienced by disabled children compared to their non-disabled peers, especially as they move towards adulthood (Hughes and Lackenby, 2015). This includes high rates of social exclusion, lack of access to employment, fewer opportunities for friendship and intimate relationships (Hart *et al*, 2014) as well as higher rates of mental ill health (Emerson and Hatton, 2007) and an enduring vulnerability to violence and maltreatment as adults (Hughes *et al*, 2012).

Since this study's inception evidence of disabled children and young people's disproportionate risk of "newer" forms of abuse has emerged, including: child sexual exploitation (Davies, 2013); sexual violence and exploitation perpetrated by groups and gangs (Berelowitz, *et al*, 2015) and on-line bullying and abuse (Smeaton, Franklin and Raws, 2015). Concern has also been expressed about the reduced availability of financial, social and other supports for disabled children and their families as a result of cuts to benefits and services since the 2007 global financial crash and the knock-on effect on caregivers' ability to cope with the demands placed on them (Stalker *et al*, 2015; Contact a Family, 2012; Mencap, 2013), and the impact on disabled children's already high levels of social exclusion.

Studies have also reiterated specific areas of concern in relation to child protection and other areas of social work practice with disabled children (Taylor *et al*, 2016; Kelly *et al*, 2016). The majority of studies to date have, however, maintained an almost exclusive focus on the perspectives of practitioners, parents and other caregivers. Of the four studies I identified that have sought disabled children's views: two focused on disabled adults' retrospective accounts of childhood maltreatment (Jones *et al*, 2017; Shah *et al*, 2016); one on child sexual exploitation as experienced by young people with learning disabilities (Franklin, Raws and Smeaton, 2015) and the other on disabled children's experiences of out-of-home care (Kelly *et al*, 2016).

I located no study which explored disabled children's specific experiences of their interactions with professionals within child protection processes while they were still children. This is vitally important in order to understand where disabled children are situated emotionally, psychologically, socially and politically within child protection processes, and how these experiences intersect with other aspects of their lives. Only then will we be able to effectively attend to the needs of disabled children and their families within support and protection processes and assist them towards achieving their potential, both for their own benefit and that of society. Hence the need for the current study.

Study aims

Drawing on theoretical perspectives from disability and childhood studies, this study aims to contribute to the gap in knowledge regarding disabled children's own views of their experiences during child protection enquiries and their aftermath by seeking to address the following research questions:

- How do disabled young people see themselves within their families and wider social worlds?
- What are disabled young people's experiences of child protection enquiries and taking part in decision-making?
- What are disabled young people's experiences of receiving help and support following initial child protection enquiries?

Activity-based interviews were undertaken with 16 disabled young people, aged 11-17 years who were, or who had been the subject of a child protection conference or plan as a result of initial child protection enquiries. A range of participatory research techniques was used to engage young people, which were tailored to meet their individual learning and communication needs, based on an understanding of disabled children as competent social actors able to express their views regardless of their impairments. Their caregivers were also interviewed in order to gain a deeper understanding of these disabled young people's lives and experiences.

Use of terminology

In this study the terms child or children are used to refer to and include any person aged between 0 and 18 years. Study participants are primarily referred to as a young person singular, or collectively as young people. This was considered more appropriate to their ages, since all were aged between 11 and 17 years at the time, as well as reflecting a desire to stay as close as possible to how participants would refer to themselves.

The term caregiver is generally used to refer to young people's primary carer, which could either be a birth parent, another relative or foster-carer, though the terms mother, father, parent and carer are also specified where relevant.

This study adopts a broad and inclusive definition of the term "disabled". Based on the Equality Act (2010), a "disabled child or young person" is defined as someone aged 0-18 years with "a physical or mental impairment, which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities" Based on this definition an estimated 8% of all children and 10% of young people aged 10-19 in the UK were disabled in 2016/7, according to the Family Resources Survey (Office for National Statistics, 2017). There were also slightly more disabled boys aged 10-19 (11.5%) than disabled girls (9.5%).

This study also adopts and applies the social model of disability. This is based on the understanding that children and young people are disabled by the way society is structured and organised which takes "little or no account of people with … impairments and that this excludes them from the mainstream of social activities" (Union of Physically Disabled Against Segregation, 1976, p.14). This study also acknowledges that definitions of disability are fluid and open to interpretation by individuals with impairments themselves as well as by others and organisations. Finally, this study recognises disabled children and young people are a heterogeneous group and that their views and experiences are likely to be as varied and individual as those described by children in similar studies.

This study adopts the definition of "child maltreatment" set out by Gilbert *et al* (2009a)**.** This is taken as referring to: "any acts of commission or omission by a parent or another caregiver that results in harm, potential for harm, or threat of harm to a child (usually interpreted as up to 18 years of age), even if the harm is not the intended result. Four forms of maltreatment are widely recognised: physical abuse; sexual abuse; psychological abuse, sometimes referred to as emotional abuse; and neglect … witnessing intimate partner violence is also increasingly considered a form of maltreatment" (p.69).

The term child protection is used in this study as defined by UNICEF (2012), as "a broad term to describe philosophies, policies, standards, guidelines and procedures to protect children from both *intentional* and *unintentional* harm. For a detailed explanation of the key terms used in this dissertation to refer to participants' experiences of child protection and other professional processes please see Appendix 1.

The structure of the thesis

This thesis is set out in four parts: Part 1 is a wide ranging review of the existing literature and comprises three chapters; Part 2 outlines the methodological considerations that informed how the study was designed and conducted; Part 3 explores the study's findings, arranged across three chapters, each addressing one of the study's research questions; Part 4 discusses the contribution to knowledge made by the study's findings and the implications for child protection policy and practice with disabled children and young people.

Part 1: The Literature Review

This part of the thesis explores issues from the existing body of literature of relevance to this study's aims. It is arranged across three chapters. The first chapter seeks to understand and explore theory, research, policy and practice relating to disabled children and childhood disability. The second chapter explores what is known about recognising and responding to maltreatment involving disabled children. The third chapter explores how disabled children's right to contribute to decision-making is upheld within child protection processes and other areas of social work practice.

Part 2: Methodological issues and considerations

This part of the thesis explains the study's epistemological underpinnings, drawing on the theoretical perspectives that informed the approach taken to the research design. It then discusses how ethical issues were addressed and the needs of study participants attended to, given the sensitive nature of the topic, as well as how I sought to resolve the challenges that arose during the research process. How participants' accounts were analysed is then described, before concluding with my own reflections on my experiences of undertaking this research.

Part 3: Findings

Participant interview data yielded rich and often complex accounts of their lives and experiences of child protection. Each of the three chapters relates to one of the study's research questions, as well as broadly reflecting how the literature review chapters are arranged. The first findings chapter provides an overview of participants' lives and relationships in order to enrich our understanding of them as individuals, not just as subjects of child protection processes. The second chapter explores participants' understanding and experiences of child protection enquiries and the extent to which they felt informed and included in decision-making processes by their social worker and other professionals. The third chapter presents participants' overall impressions of the help and support received as a result of child protection enquiries and subsequent decision-making, including their thoughts and feelings about its impact on their lives and families.

Part 4: Discussion and conclusions

In the final part of the thesis the study's findings relating to each of the study's research questions are discussed in relation to issues raised within the literature reviewed in Part 1. Cross cutting themes identified from participants' accounts are then integrated to demonstrate the contribution to knowledge made by the study's findings. The wider implications for policy and practice are then discussed and suggestions made regarding how social workers can better respond to the needs of disabled children during child protection enquiries and decision-making processes and when providing on-going help and support.

Part 1

Literature Review

Introduction

Over the past two decades a growing body of research exploring disabled children's own perspectives of their lives has emerged (Stalker, 2012). Despite this important and encouraging development, to date there have been virtually no studies specifically concerning disabled children's experiences within child protection processes. This literature review is therefore used to locate the study which is the subject of this dissertation within what is known about maltreatment involving disabled children and policy and practice responses to this issue. Existing literature relating to other topics considered relevant to addressing the study's research questions is also reviewed. This includes research concerning disabled children's own views of their lives and social worlds in relation to issues such as identity, family, friends, school and communities; their participation in formal and informal decision-making processes and of receiving support from social workers and other professionals. Research concerning parents' and professionals' perspectives on these topics is additionally reviewed where relevant. A table providing a summary of the methods and findings of the key empirical studies drawn upon in this dissertation is included at Appendix 2.

Approach to literature search

In view of the breadth of topics covered and the dearth of specific research on this topic a narrative rather than purely systematic approach was taken to the searching and reviewing the literature (Aveyard, 2014). The flexibility offered by this approach, one that does not necessarily follow predetermined steps or exact procedures, allowed me to capture and comment on the broad theoretical trends in how childhood disability has been researched and responded to in social work practice (Carey, 2012). A narrative approach also reflects the need to include research reports, law, policy and practice documents given their relevance to social work with disabled children (Stalker and McArthur, 2012). The findings of practice inspections (Ofsted, 2012), policy reviews (Stalker *et al* 2010) and reports of empirical studies (Brandon *et al*, 2011; Taylor *et al* 2014) are therefore discussed alongside research published in peer-reviewed academic journals.

Nevertheless, a narrative approach, although common in social work research has been criticised for lacking coherence and rigour (Carey, 2012). Therefore, in order to ensure a systematic and comprehensive approach, the stages set out by Arksey and

O'Malley (2005) for scoping studies were used to select and 'map' the literature relevant to understanding disabled children's lives and their experiences within child protection processes. This was achieved by:

Stage 1: Identifying the research question

The choice of topics included in each chapter was driven by one of the study's three research questions set out in the introduction. Accordingly:

Chapter one reviews existing theory and research concerning childhood disability in order to contextualise disabled young people's own understanding of themselves, their families and wider social worlds.

Chapter two examines what is known about disabled young people's increased vulnerability to maltreatment and reviews existing research evidence as to how this issue is recognised and responded to in practice.

Chapter three examines the factors resulting in an increasing policy focus children's rights and participation and reviews existing research concerning disabled children and young people's participation during child protection enquiries and within other social work decision-making processes.

Stage 2: Identifying relevant studies

Specific search terms relating to each research question were also identified to scope the relevant literature concerning that topic (Aveyard, 2014).

For chapter 1, the search terms used were: disab*, child*, experiences, identity, well-being

For chapter 2, the search terms used were: disab*, child welfare, protect*, maltreatment, abuse

For chapter 3, the search terms used were: disab*, child* rights, partic*

The literature mainly focused on the UK, due to the specific social and political context and because the study findings will relate directly to social work with disabled children in the UK. However, due to the general lack of specific research on disabled children international studies published in English were included. Journal articles were retrieved by entering key search terms, into Applied Social Sciences Index (ASSIA), PsycINFO and SCOPUS databases to search for articles in English published after 2000. Research reports, policy and practice documents were retrieved by entering search terms into Google Scholar and Social Care Online.

In addition to systematic searches of electronic databases, consistent with Arksey and O'Malley's (2005) framework, a range of other strategies were also used to search for relevant literature. These included searching the reference lists of studies found through database searches to search for relevant articles that I had missed. I also undertook hand searching of key journals including: The British Journal of Social Work, Children and Society, Disability and Society, Child and Youth Services Review and Disability Studies Quarterly. Finally, I regularly attended conferences to keep abreast of relevant developments and sought additional literature through new and existing professional networks and contact with researchers in my field.

Stage 3: Study selection

Balancing the paucity of research with the pragmatic need to place some limits on the amount of literature included (as outlined by Aveyard, 2014), the database searches excluded literature published prior to 2000. However, since this meant certain seminal papers would be excluded, a decision was made to include earlier work by key authors such as Morris' (1995, 1998) important work concerning disabled children's experiences in residential schools, and Schofield and Thoburn's (1996) key discussion of children's participation in child protection decision-making processes.

Stage 4: Charting the data

The majority of studies examined employ qualitative methods with findings based on interviews and focus groups with parents and carers of disabled children, practitioners and disabled children themselves. The quality of evidence varies, for example many studies rely on recall and self-report. Qualitative studies also lack generalisability due to their small sample sizes, although they help our understanding of disabled children's lives and experiences.

Stage 5: Collating, summarising and reporting the results

Despite these limitations, the studies reviewed highlighted a number of consistent themes concerning disabled children's experiences in relation to each topic. The relevant findings discussed in each of the chapters that follow were then arranged thematically under subheadings for each topic. The structure used in each chapter being partly informed by relevant existing theory and the findings of previous research reviews. The strengths and weaknesses of research evidence for each topic are also critically analysed and the implications for this study's research questions discussed.

Chapter 1 – Understanding disabled young people's lives

Introduction

This chapter appraises how theory and research have helped inform our understanding of disabled young people's lives and experiences. The first part explores how differing theoretical perspectives and the broader social and policy context have each influenced the development of research on childhood disability. It touches on the evolving context of social work and child protection practice with disabled children, as well as helping to explain why research on disabled young people's perspectives only began to appear in the mid-1990s (Stalker, 2012). This literature on disabled children's perspectives is then reviewed in the second half of the chapter, providing important insights into this study's first research question concerning how disabled young people see themselves within their families and wider social worlds. The strengths and weaknesses of this literature are evaluated, and gaps in knowledge highlighted.

Overview of relevant theoretical perspectives

Much disabled children's research has been criticised for insufficiently focusing on theory, contributing to a lack of theoretical integration in this field (Carpenter and McConkey, 2012). There is broad consensus, however, that developmental psychology, disability studies, childhood studies and human's rights perspectives, as well as policy and practice developments have each influenced the development of disabled children's research (Watson, 2012; Ytterhus *et al*, 2015). The contribution of each of these different theoretical perspectives to disabled children's research is set out in Figure 1. The connections, tensions and contradictions between these perspectives are then described and discussed, before going on to explain the theoretical framework underpinning this dissertation's study.

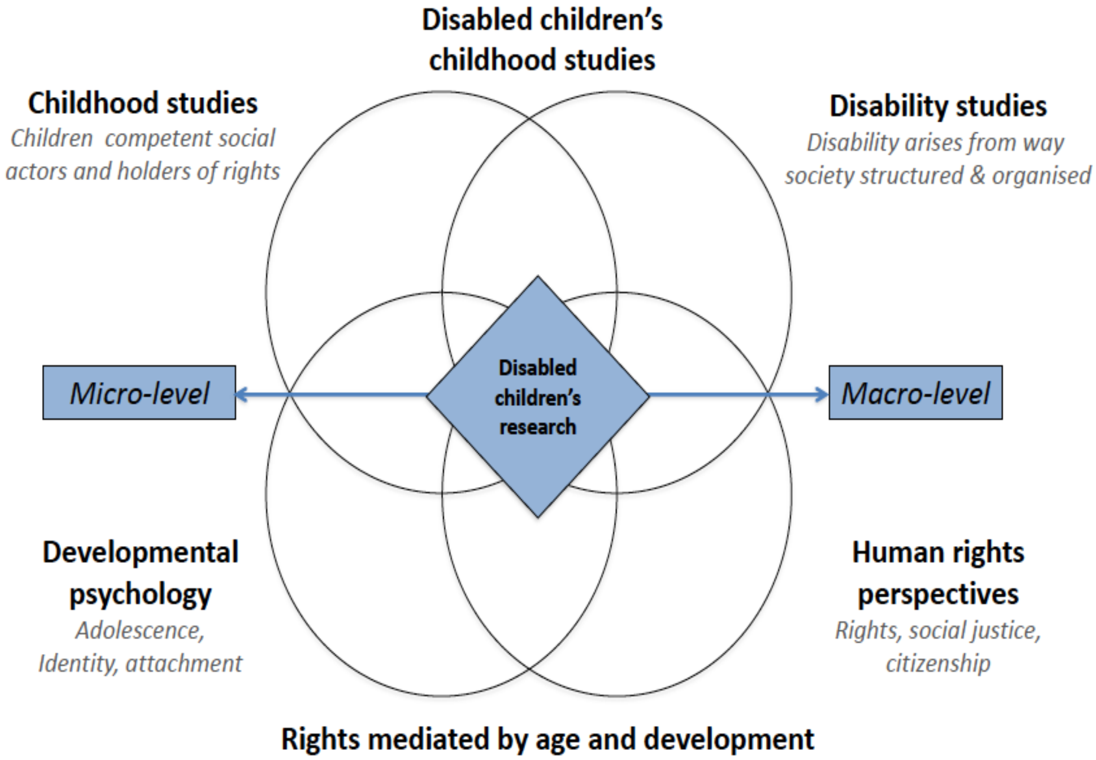

Figure 1: Theoretical perspectives informing the development of disabled children's research, policy and practice

Developmental Psychology

Early research on childhood disability drew on theories of child development to understand and interpret how children's impairments affected them (Baldwin and Carlisle, 1994). Such theories, growing out of the "scientific"' discipline of psychology, seek to categorise and define childhood as occurring according to a series of measurable and 'normative' stages. The 'successful' completion of these stages is seen as resulting in the child developing rational competence, marking the transition to adulthood (Ytterhus, *et al*, 2015). Psychological theories of child development have also been seen as reinforcing the idea of childhood as a distinct life-stage, separate from adulthood (Clarke, 2010).

Apart from a tendency to focus on micro-level understanding of children's identities and interactions with their environment, as indicated in Figure 1, "new" childhood studies almost entirely challenges and contradicts developmental psychology's notion of the standard "child" and its somewhat narrow deterministic view of individual children's capabilities, (Jenks, 1996). Instead normative child development is viewed as an arbitrary construct (Burman, 2007), which fails to see children as having multiple, fluid and complex identities due to differences in gender, class and ethnic background as well as biological age. Within childhood studies children are instead viewed as competent social "beings", actively negotiating their own lives in the present moment, rather than being seen as still developing, and by implication irrational or immature "becomings" in comparison with adults (Qvortrup, 1994). "New" childhood studies emphasise childhood as a sociological rather than psychological construct and celebrate children's diverse childhood experiences. This approach does not fit well with developmental psychology's standardised, Eurocentric view of childhood and child development (James and Prout, 1997).

By creating a set of 'norms' governing child development, developmental psychology is critiqued by disability studies scholars as creating the 'problem' of the disabled child (Davis *et al*, 1995). This stems largely from the promotion of a deficit approach to impairment, which constructs childhood disability as a tragedy due to its deviation from the 'norm' (Davis *et al*, 2003). In addition, children's needs are individualised in such a micro-level manner that the social, macro-level contexts that produced them are obscured, (Curran and Runswick-Cole, 2014), as indicated by its' alignment with the micro-level in Figure 1. Ongoing debates still remain about whether some human rights are conferred on children in accordance with their age and maturity (e.g. involvement in decision-making), and children's perceived level of (in)competence continues to create inconsistencies in the weight given to their views in practice (Tisdall and Morrison, 2012). This is particularly the case for disabled children (Taylor *et al*, 2014).

Despite its conflicts with other theoretical perspectives, developmental psychology does have significance for understanding how children's impairments interact with their growth and development and this is acknowledged by some within disability studies, (Carpenter, 2010; Watson, 2012). It also helpful in understanding the influence of impairment and maltreatment on children's attachment relationships (Howe, 2006). Other theorists within developmental psychology also incorporate a more relational or psycho-social approach in their work, acknowledging the impact of interactions between the child and their environment on children's development (Bronfenbrenner, 1979; Vygotsky, 1986;).

Childhood studies

"New" childhood studies, a field also known as the sociology of childhood, emerged out of a strong critique of psychological theories' tendency to cast children as inferior to adults based on their biological immaturity (Prout and James, 1990). As outlined above, childhood studies has been important for disabled children in broadening out the discussion to include the impact of sociological factors on children's development and their experiences of childhood (Ytterhus *et al, 2015*). By celebrating children's diversity, and encouraging their active participation and "voice" within research, childhood studies has also helped promote the inclusion of disabled children, whose development and/or experiences deviate from a mythologised "normative" standard. As a result, the developments associated with childhood studies have been largely welcomed within disability studies (Watson, 2012). Both disability and childhood studies share the common aim of challenging the oppression of an historically and culturally marginalised group and highlighting the capabilities, rights and agendas of children and disabled people respectively. This is indicated by the overlap between these two perspectives with each other and human rights perspectives in Figure 1.

Nevertheless, certain tensions and contradictions persist between disability and childhood studies. For example, research focusing on personal experience and agency is largely accepted, even promoted within childhood studies, but is contested within disability studies because it is at odds with an understanding of people as disabled by attitudes and barriers within society rather than their impairments (Connors and Stalker, 2007). Childhood studies' emphasis on children's agency and including their "voices" in research has likewise received criticism from within disability studies for tending to privilege the views of those considered most competent and articulate (Tisdall, 2012). This continues to reproduce, albeit perhaps unconsciously, dominant 'normative' standards of child development and an individualising deficit approach to childhood disability more associated with developmental psychology (as indicated by the overlap with childhood studies in Figure 1) (Curran and Runswick-Cole, 2014).

By prioritising verbal utterances and written text, childhood studies' also serves to reinforce disabled children's marginalisation and exclusion, since the views of those with learning or communication impairments will be harder to include (Komulainen, 2007). Relatedly, though childhood studies' emphasis on treating all children as "children first" appears inclusive and likely beneficial for disabled children, it can be associated with a homogenising ‘one size fits all’ approach to practice, with insufficient attention being paid to disabled children’s differing needs related to their impairments (Stalker, 2012).

This may partly explain why, despite childhood studies supposed focus on diversity, it has been unable to further the development of children’s human rights. It has failed to get to grips with the meaning of children’s differing needs and experiences in practice and also with the lack of engagement with macro-level structural causes of young age discrimination (Tisdall, 2012). There is, though, some acknowledgement that while childhood is a permanent category in society, for individuals it inevitably represents a transient phase, which along with children’s subordinate status, makes it harder to claim as a collective identity around which to organise the political activism required to achieve change (Qvortrup, 1994).

Disability studies

In contrast with childhood studies, disability studies is credited with driving forward anti-discriminatory legislation and policy changes towards disabled people (Shakespeare, 2014). This has been achieved via disability studies’ strong links to the disability rights movement, both wedded, at least initially, to the idea of a social model of disability, indicated by the overlap between disability studies and human rights perspectives in Figure 1.

Within a social model approach, people are disabled not by their impairments, but by the ways society is structured and organised to discriminate against disabled people (Watson, 2012). Disability studies research has been important in highlighting structural oppression faced by disabled children, such as their disproportionate risk of poverty (Blackburn, Read and Spencer, 2010) and the effects of segregationist policies in education (Davis and Watson 2001). These developments have, in turn, helped to achieve greater recognition of disabled children’s specific rights and needs.

By claiming society rather than individuals’ impairments are responsible for their disability, the social model has been personally liberating for disabled people (Crow, 1996). Disability studies’ focus on emancipatory research, challenging the barriers to disabled people’s inclusion, has been important in promoting disabled children’s involvement in research alongside the participatory methodologies pioneered within childhood studies (Ytterhus, *et al* 2015). This is indicated by the overlap between disability and childhood studies in Figure 1.

The social model's exclusive focus on structural, macro-level factors has been critiqued as denying the limitations disabled children and adults' experience caused by their impairments, and their agency in resisting discrimination and social barriers to their inclusion. By focusing on structural oppression, Shakespeare (2013) argues the social model "assumes what it needs to prove, that disabled people are oppressed" (p.218). Disability studies' failure to explore how disability intersects with other characteristics, including age, gender, class and ethnicity is also at odds with childhood studies' emphasis on diversity (Curran and Runswick-Cole, 2014).

Developments within disability studies have attempted to address the social model's limitations and tensions with childhood studies' focus on diversity and personal experience. These are briefly outlined here and discussed in more detail later in the chapter. Thomas (1999), for example, introduced the concept of "impairment effects" to account for the limitations disabled people experience due to their individual impairments rather than societal barriers. Critical or "cultural" disability studies, on the other hand, sought to address tensions between socio-structural and individual-biological accounts of disability by challenging the binary categories of disabled vs able-bodied and disability vs impairment which underpin the social model (Meekosha and Shuttleworth, 2009). These, they argue, create an arbitrary and unnecessary divide between disabled and non-disabled people, especially given most people will develop disability-causing impairments in their lifetime (Davis, 2002). They further question much of the discourse surrounding disability and biological labels applied to disabled people by pointing to larger areas of similarity than difference between disabled and non-disabled people (Goodley, 2010). Instead they argue for a stronger focus within disability studies on the impact of negative cultural representations of disability on the discrimination and disadvantage disabled people experience (Meekosha and Shuttleworth, 2009).

Human rights perspectives

During the past 25 years human rights perspectives have become an increasingly important means of conveying disabled children's needs and experiences and furthering their interests at a national and international level (Children Act, 1989; UNCRC, 1989; UNCRPD, 2006). Within this approach, whenever disabled children's lives fail to meet universal human rights standards this is viewed as discrimination and a violation of their rights, which is to be challenged, and not as a consequence of their impairment or developmental status (Ytterhus *et al*, 0215).

Thus, human rights perspectives share with childhood studies and social model approaches to disability an understanding of disabled children as experts on their own lives and holders of rights and citizenship. Human rights, social approaches to disability and childhood are consequently often seen as “mutually reinforcing” (Bickenbach, 2001) as demonstrated by the overlap between these perspectives in Figure 1. Albeit that some human rights, such as the right to vote and to self-determination, are denied or attenuated by the continued influence of developmental psychology (Quennerstedt, 2010) as noted by the annotation accompanying the overlap between these perspectives in Figure 1.

Therefore, it is perhaps not surprising that in practice human rights agendas have continued to place a greater emphasis on children’s rights to protection than to their participation, due to their perceived vulnerability related to their immaturity (Hammarberg, 1990). Although applicable to individual children, due to the emphasis on achieving policy change, children’s rights-based perspectives are more explicitly focused at a macro level, as indicated in Figure 1. This may also help account for research demonstrating the continued tension between the rhetoric of children’s rights (UNCRC, 1989; UNCRPD, 2006) and their realisation in reality, including in disabled children’s lives both individually and as a group (e.g. Blackburn, Read and Spencer, 2010; Larkins *et al*, 2013).

However, despite large areas of congruence between human rights perspectives and childhood and disability studies, areas of tension remain. As already noted, childhood studies emphasis on children’s diverse individual experiences and agency is viewed as diluting its capacity to support political change (Tisdall, 2012). Moreover, by refuting the existence of the basic categories of disabled and non-disabled, critical disabilities studies has been critiqued as denying disabled people the opportunity to challenge the discrimination and inequalities they face based on their shared experience of disability and impairment (Watson, 2012; Shakespeare, 2014).

Disabled children's childhood studies

In addition to the theoretical perspectives already discussed, a network of academics, activists, disabled children, their families and allies have sought to establish Disabled Children's Childhood studies as a distinct field of study (Curran and Runswick-Cole, 2013; Runswick-Cole, Curran and Liddiard, 2017). This approach attempts to build on the insights and strengths of childhood and disability studies, as indicated by its positioning between these two perspectives in Figure 1. Accordingly, within this approach disabled children are seen as active participants and experts on their own lives, whose voices and experiences are included at the heart of the enquiry, rather than marginalised, as is often the case in childhood studies research (Tisdall, 2012).

The focus on disabled children's perspectives is also seen as necessary to shift discussion away from developmental psychology's talk "about" disabled children's deviation from normative child development and disabilities studies' pre-occupation with the concerns of disabled adults (Watson, 2012). The aim of research instead being to listen to and learn "with" disabled children about their priorities and aspirations, beyond their experiences of service provision (Stalker, 2012). This approach also aims to embrace critical disability studies challenging of binary categories of disabled/able-bodied in order to promote an agenda for change which seeks to trouble the hegemony and cultural practices of the 'norm' (Curran and Runswick-Cole, 2014, p. 1618).

Theoretical framework underpinning this dissertation's study

Of the theoretical perspectives outlined, the approach proposed by Disabled Children's childhood studies chimes most closely with the aims of this dissertation's study. In particular the desire, reflected by the initial research question, to understand participants' view of themselves within their families and wider social worlds (Carpenter and McConkey, 2012. This approach also sits well with this dissertations' study's aim to include young people with diverse impairments, while offering sufficient flexibility to allow neither impairment or disability to define participants' accounts of their lives (Curran and Runswick-Cole, 2014) or experiences of child protection processes.

However, though disabled children's childhood studies represents an exciting and important development, it remains an under-theorised and still emerging field of study

(Carpenter and McConkey, 2012; Byrne and Kelly, 2015). The capacity of this approach alone to offer a coherent theoretical framework for this dissertation's study is also potentially undermined by its use of ideas from critical disability studies. Critical disability studies commitment to deconstructing the binary distinction between disabled and able-bodied people, as already noted, is particularly problematic, since it risks reducing disability to relative cultural understandings (Watson, 2012). This also makes it hard to then see how these same categories can be legitimately operationalised in empirical research capturing 'disabled' participants' real life experiences. This arguably remains an important priority in social sciences research, given the need to continue to highlight the inequality disabled people experience and the ways their rights are not actioned in order to make a difference to their everyday lives (Shakespeare, 2014).

Ultimately, neither disabled children's childhood studies, the social model of disability nor perspectives focusing on individual experience can adequately capture the complexity of childhood disability (Ytterhus, *et al*, 2015). Since each of these perspectives provides only a relatively small window through which to explore disabled children's lives and identities (Watson, 2012). A multi-factorial interactionist approach to studying childhood disability was therefore chosen as the theoretical framework for this study (Shakespeare and Watson, 2010), drawing on ideas from critical realism (Bhaskar and Danermark, 2006) and the Nordic relational model of disability (Gustavsson *et al*, 2005).

Within a critical realist relational approach, disability is viewed as arising from complex interactions between the individual child living with an impairment, and their physical, human-built, social, attitudinal and cultural environment (Shakespeare and Watson, 2010; Ytterhus *et al*, 2015). This approach allows the experience of disability to be explored at multiple levels, including the physical; biological; psychological; psycho-social and emotional; socio-economic; cultural and normative (Bhaskar and Danermark, 2006). This permits the complex interactions between the different levels to be observed, but without privileging one over the other in understanding the experience of disability (Watson, 2012).

This relational, person-in-environment approach to disability also overlaps with Bronfenbrenner's (1979) ecological systems theory of child development (Ytterhus, *et al* 2015). Ecological systems theory has been widely applied to social work practice with children and their families (Department of Health, 2000), and has also previously been used in the study of childhood disability (Ytterhus *et al*, 2015). It therefore seems entirely appropriate to utilise eco-logical systems theory as the theoretical framework underpinning this dissertation's study. This includes employing a person-in-environment approach to structure discussion of research concerning disabled children's perspectives in the second half of this chapter. This follows the discussion in the next section regarding how theory, research, policy and practice concerning disabled child and adults have evolved.

The development of theory, research, policy and practice and concerning disabled adults and children

Origins of ideas concerning disability and disabled people

Understanding how ideas about disability and impairment have developed is essential for making sense of disabled young people's lives in the present, and how research concerning them has evolved. I say this not because I view this as the most important aspect of study participant's lives, but rather because evidence suggests that growing up disabled significantly shapes young people's relationships, opportunities and experiences (Connors and Stalker, 2007; Raghavendra *et al*, 2012; Kelly, 2013).

Ideas about disability and impairment are complex and not fixed in time or space (Oliver and Barnes, 2012). Across almost all historical periods both societal and individual responses towards disability and disabled children and adults have oscillated between hostility, and sometimes extreme cruelty on the one hand and tolerance, compassion and beneficence on the other, with evidence of both responses co-existing during any given period (Oswin, 1998; Borsay, 2005). This is illustrated by the fact that during the lifetime of the young people taking part in this study comprehensive equal rights legislation for disabled people has been introduced (UNCRPD, 2006; Equality Act 2010), but there has also been an alarming rise in disability related violence and hate crime in the UK (Emerson and Roulstone, 2014).

It therefore seems reasonable to conclude that disabled people have always tended to be somewhat socially and economically marginalised (Oswin, 1998). However, commentators within disability studies contend that negative attitudes towards disabled people closely relate to the extent to which impairment is viewed as a problem for society (Oliver and Barnes, 2012). Pointing to evidence of greater tolerance and integration of disabled people within agrarian societies (Borsay, 2005; Miles, 2006) these authors argue that the societal oppression of disabled people is the result of industrialisation and the cumulative influence of medicine and scientific thinking from the late 19th Century onwards (Barnes and Mercer, 2010; Oliver and Barnes, 2012).

Industrialisation, it is argued, rendered many disabled people ineligible for paid employment due to being unable to operate factory machinery or learn to read and write (Oliver and Barnes, 2012). Industrialisation also simultaneously reduced disabled people's family's ability to care for them, due to the need for their non-disabled family members to work long hours outside the home (Ryan and Thomas, 1987). The needs of those unable to work and/or without family support had previously been met by the provisions of the Poor Law. However, the growing numbers excluded from emerging wage labour markets due to impairment created a pressing need to accurately categorise the numbers and needs of disabled people in the population to assist with the allocation of finite resources (Barnes and Mercer, 2010). This process led to the gradual conceptualisation of disability as a personal tragedy and "burdensome problem" both for the individual, their family and society (Oliver and Barnes, 2012). This attitude is reflected in UK reform of welfare benefits for disabled people during 2013-14, including the introduction of strict eligibility criteria for Incapacity Benefit (UN Committee on the Rights of Persons with Disabilities, 2016).

Though arguments about paid employment apply less directly to disabled children, the parallel growth of science and medicine reinforced disability's construction as an individualised 'problem' for people of all ages (Barnes and Mercer, 2010). Medicine and allied professions' emphasis on 'curing' or 'correcting' impairment and science's hypothesised relationship between genetic 'inferiority' and impairment, in turn helped legitimise disabled people's segregation from mainstream society, frequently through institutionalisation (Oliver and Barnes, 2012). This situation has significantly impacted the lives of both disabled adults and children throughout the 20th century, reflected, for example, in disabled children's segregation in special education, residential schooling and short breaks provision (Shah and Priestley, 2011).

Hidden from view

Aside from medicine and allied disciplines, of these developments the emergence of developmental psychology has had perhaps the most influence on disabled children's lives (Ytterhus *et al*, 2015). Theories conceptualising child development in measurable stages (e.g. Piaget, 1953; Erikson, 1969) contributed to an increasingly precise definition of what it means to be a 'normal' child. Whilst simultaneously delineating and defining deviation from this constructed norm resulted in the negative connotations of 'abnormal' development becoming closely associated with childhood disability (Ytterhus, *et al* 2015).

This pathologising approach has significantly influenced the focus and tone of much, particularly early, research on childhood disability, which Baldwin and Carlisle (1994) describe as pre-occupied with categorising, assessing and treating children's specific conditions and impairments. This approach to theorising and researching childhood disability both reflected and serviced a system which resulted in many disabled children being hidden away in long-stay hospitals (Oswin, 1998) or within their families (Shah and Priestley, 2011).

Consequently, for much of the 20th century mainstream child care policies largely excluded disabled children or reinforced their segregation (Connors and Stalker, 2003). The Children Act (1948), for example, set up under the auspices of the post-war welfare state to improve conditions for children living away from home, specifically excluded the 10,000 or so severely disabled children then living in long-stay hospitals (Oswin, 1998). While the Education Act (1944) reinforced the segregation of disabled children through the setting up of special schools, with those deemed 'ineducable' being sent to occupational centres or mental handicap hospitals (Shah and Priestley 2011). As a result of these policies and prevailing social attitudes disabled children's lives "were often so segregated from mainstream society that their concerns and needs rarely impinged on public consciousness," and were of little interest to researchers and policy-makers (Carpenter and McConkey 2012, page 251).

Political activism, the social model and disability studies

This situation gradually began to change from 1960s and 1970s onwards. This was partly as a result of increased public awareness of childhood disability through high profile cases of children disabled through exposure to thalidomide in utero, and campaigns for better, publicly funded support for disabled children by parent-led organisations such as SCOPE and MENCAP (Oswin, 1998). These developments were supported by emerging research on childhood disability from within the newly established social sciences (Baldwin and Carlisle, 1994). This included studies exposing the deprivation experienced by disabled children in long-stay hospitals (Oswin, 1971; Oswin, 1978), and emphasising the benefits of children being brought up within a family environment rather than in institutions (King, *et al* 1971).

Research highlighting the social and economic disadvantage faced by disabled people in general, despite rising living standards, also contributed to political activism by disabled people. Disabled activists mobilised around the idea that they were disabled not by their impairments but by the way society is structured and organised to take "little or no account of people with … impairments and this excludes them from the mainstream of social activities" (Union of Physically Disabled Against Segregation, 1976, p.14).

This central premise, a reaction to the medicalised labelling, enforced social segregation and institutionalisation of disabled people, became known as the social model of disability (Oliver, 1981). The social model gradually gained authority through the work of disabled academics in the emerging field of disability studies (Oliver, 1986; Finkelstein, 1980; Barnes, 1991). This, along with continued political campaigning by disabled people's organisations, and growing concern about the ill-treatment of disabled people in institutions (Jay Report, 1979) led to the development of more enlightened social policy towards disabled people.

Significant achievements associated with the social model in the UK include: community care legislation leading to the closure of long-stay hospitals; introduction of direct payments and later personal budgets giving disabled people greater choice and control over the support they receive; and the passing first of anti-disability discrimination legislation and subsequently equal rights legislation (Shakespeare, 2013). These developments resulted in a substantial social work role administering social support for disabled people (Oliver, 2004), and also impacted disabled children's lives, albeit in a more limited way (Watson, 2012). This is given that, for example most disabled children were living with their families rather than institutionalised, neither are they able to have control over a direct payment or personal budget due to their continued dependence on their parents or carers.

Criticisms of the social model and 'relational' approaches to disability

Despite the social model's undoubted impact on policy and practice, empirical research has contributed to critical debate within disability studies about its validity (Shakespeare, 2013). Its focus on defining disability as a collective form of oppression caused by structural barriers in the environment or social organization was felt by many to deny the individual's experience of limitations directly caused by their impairments, such chronic pain and fatigue (Crow, 1996).

Disabled feminists were among the first to challenge resistance from within disability studies that studying individual's experiences of impairment would inevitably mean a return to pathologizing disability as a tragedy or personal failing. Thomas (1999) instead termed the limitations caused by living with impairment "impairment effects" (p.43), further asserting that since "the micro is constitutive of the macro experiential narratives offer a route to understanding the socio-structural" (p. 78).

Based on researching disabled women's lived experiences Thomas (1999, 2004) subsequently developed a relational approach to disability. She argued that disablist, in the same way as racism and sexism, arises not only from "barriers to doing", i.e. economic or material barriers enacted on disabled people by non-disabled people that restrict their participation, but also from "barriers to being", namely insensitive and/or inappropriate behaviour detrimental to the disabled person's sense of who they are or can become. Thomas (1999, 2004) coined the term "psycho-emotional disablism" to describe the process by which these "barriers to being" are experienced by disabled people at a micro-level in their everyday lives as a result of the actions and reactions of family members and professionals. She saw this type of disablism as distinct from disablism within society at large and argued for the term "psycho-emotional disablism to be incorporated into the social model's more functional macro-level definition of disability and disablism.

Thomas' (1999, 2001) work developing definitions of disability that can be applied to individuals lived experience is important for research with both disabled children and adults (Connors and Stalker, 2007). However, other commentators felt that Thomas' changes insufficiently addressed the social model's other weaknesses. Shakespeare and Watson (2001) point out that disability does not represent a cohesive collective identity in the same way as gender or race, since the term 'disabled' includes people with heterogeneous impairments. This is reflected by research showing that many people with impairments do not consider themselves 'disabled' (Watson, 2002) and revealing wide variations in lived experience even between individuals with the same impairment (Thompson *et al*, 2008). Edwards (2005) similarly asserts that categorising people as discriminated against on the basis of impairment is simplistic, when in practice this is not easily distinguished from discrimination based on individual's other characteristics, such as race, gender or class.

Shakespeare and Watson (2010) are likewise critical of Thomas' attempt to separate "impairment effects" from discrimination caused by "barriers to being" or "barriers to doing". Since, in reality it is difficult to differentiate the impact of each on disabled people's lives. For example, a disabled person may experience depression: as an impairment itself; a consequence of the effects of another impairment; a result of their own or other's negative responses to their impairments; or because of social exclusion due to their impairments (p.69).

Consequently, Shakespeare and Watson (2010) argue that disability should not only be viewed relationally as Thomas (1999) suggests, but also as arising from a complex interaction between the individual and their wider physical, social and cultural environment. Drawing on the approach developed by Nordic critical realists (Bhaskar and Danermark, 2006) they contend that in order to capture the oppression disabled people's face, and accurately portray their lived experience, disability needs to be seen as operating at multiple inter-connected levels, ranging from the physical, biological, psychological, psycho-social and emotional, socio-economic and cultural, as set out in Figure 2.

Intrinsic *(individual)* factors	**Extrinsic *(environmental)* factors**
Type of impairment	Physical environments
Severity of impairment	Social arrangements
Motivation, attitude to impairment	Expectations and roles
Self-esteem, confidence	Cultural meaning, representations

Figure 2: Disability as an inter-action (Shakespeare and Watson 2010)

Debates regarding the definition and experience of disability are ongoing within disability studies. Other developments include the field of critical or cultural disability studies. As outlined earlier, this approach uses post-structuralist concepts and ideas to analyse how cultural representations and discourse surrounding disability helps reinforce unequal power relations and the false dichotomy between disabled and able-bodied people in society (Meekosha and Shuttleworth, 2009; Goodley, 2010). However, this approach also risks reducing disability and impairment to discourse, and by seeking to de-construct the dualism between disabled and non-disabled people potentially detracts from the structural disadvantage and discrimination that disabled people face (Shakespeare, 2014).

Thomas' (1999, 2001) and Shakespeare and Watson's (2010) relational ideas concerning disability are also each reflected in the current international definition of functioning, disability and health (ICF) (WHO, 2001) shown in Figure 3.

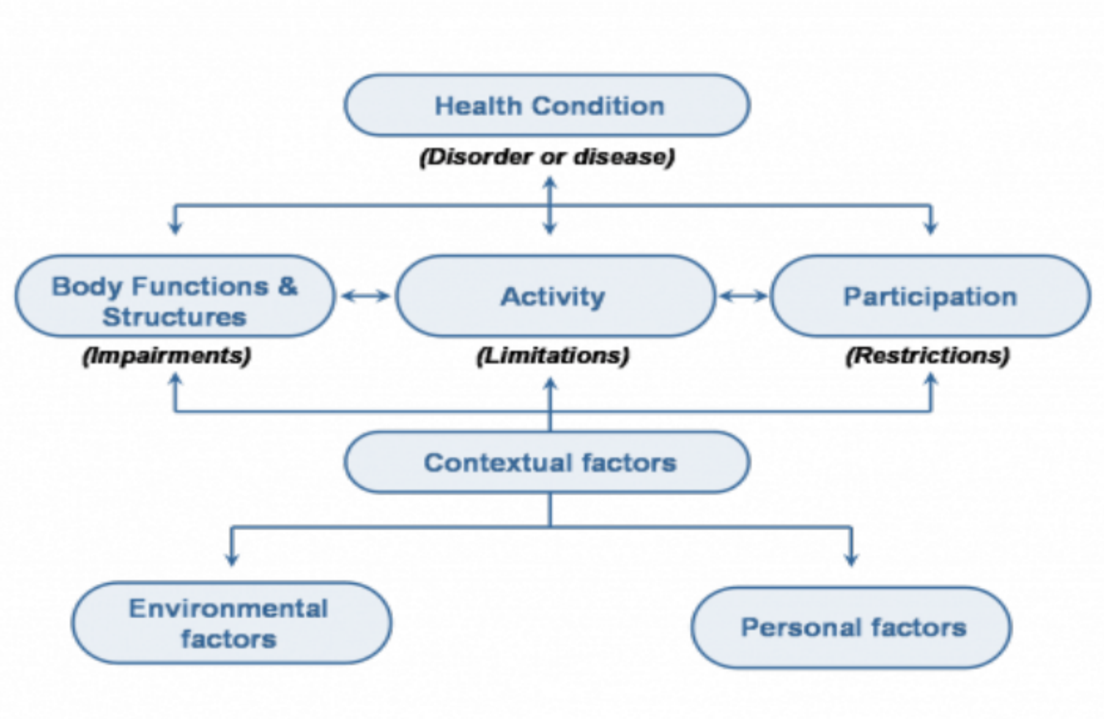

Figure 3: International Classification of Functioning, Disability and Health (WHO, 2001)

The ICF also takes a universal approach, concurring with theorists in critical disability studies that all members of the population are potentially at risk of developing impairment and its potentially disabling consequences (Bickenbach *et al*, 1999). However, the ICF has been critiqued for taking the reality of health conditions for granted (Shakespeare, 2014). The ICF also, it is argued, sees the biological dimension of people's impairments as ultimately determining their experience of disability in other areas of their lives. whereas a critical realist relational approach sees disability as arising from the complex interplay between multiple different levels, without prioritizing one over another (Söder, 2009).

Theory, research, policy and practice concerning disabled children

Disabled children, disabled families

A further criticism of the social model is that its ideas and achievements have mainly been applied to disabled adults, rather than disabled children (Watson, 2012). Some policy changes, notably the Chronically Sick and Disabled People's Act (1970) and Disability Discrimination Act (1995) have been applied to disabled children. However, much specific policy and practice to date has retained at least some focus on the segregation of disabled children and/or meeting their carer's needs (Shah and Priestley, 2011), a trend reflected, for example, in the Breaks for Carers of Disabled Children Regulations (Children Act, 1989, Schedule 2, paragraph 6.2) introduced in 2011.

Much, particularly early, research on disabled children's lives has likewise tended to focus, on the 'burden of care' their parents' experience, often infantilising their needs and experiences (Philp and Duckworth, 1982). Glendinning (1983) for example, describes the 'daily grind' of caring for a severely disabled child as "prolonging of the dependencies of early childhood…. giving rise to a an essentially repetitive set of servicing functions which can be physically taxing, mentally exhausting and dispiritingly monotonous" (p. 41).

Early studies similarly emphasised the restrictions imposed on parents' social opportunities by their children's mobility difficulties (Gough *et al*, 1993) or anti-social behaviour (Meltzer *et al*, 1989). Other studies reported a higher incidence of stress-related health problems among parents of disabled children (Parker, 1990; Beresford, 1993). This evidence was not conclusive, since many studies drew on small sample sizes, focused on the experiences of parents of children with particular conditions, and failed to seek disabled children's views about their lives (Baldwin and Carlisle, 1994).

Quantitative surveys also drew attention to disabled children's increased risk of poverty, the additional expenditure associated with their impairments, their parent's reduced employment opportunities and the inadequacy of disability benefits to compensate (Meltzer *et al,* 1989). This research importantly contributed to the gradual establishment of a publicly funded system of social care and welfare provision for disabled children (Baldwin and Carlisle, 1994). By the late 1980s, schemes to provide short-term breaks for carers of disabled children, often in family-based settings were being developed across the UK (Stalker, 1990).

By locating the problem of disability within the individual, however, such research continued to construct caring for a disabled child as an inevitably negative and burdensome task (Connors and Stalker, 2003). This approach was exemplified by McCormack's (1978) assertion that "a handicapped child makes a handicapped family". Accordingly, parents' positive reports of caring for their disabled child, were sometimes interpreted by researchers as evidence of guilt, denial or a need to 'normalise' their experience (Stainton and Besser, 1998).

Beresford's (1994) study "Positively Parents" exploring how parents actively manage and cope, by contrast, began to challenge deterministic stereotypes of caring for a severely disabled child. She found that rather than being related to the complexity of their child's additional needs, parents' stress levels and well-being depended on a range of personal coping strategies and the availability of social resources. These ideas have been further researched and applied to understand the factors associated with resilience among families with disabled or sick children (Woolfson, 2004; Patterson, 2005).

Disab(ling) childhoods

Research exploring the impact of disability on children and young people's lives initially adopted a similarly pathological approach (Connors and Stalker, 2003). Baldwin and Carlisle (1994), echoing Philp and Duckworth's (1982) earlier review, described this research as fixated on the negative psychological and social consequences of impairment rather than exploring factors that enable some children to adjust and cope. Mattson (1972), for example, presents a three-fold typology of poor adjustment among children with a chronic condition, "over-dependency; over-independency and isolation". This implies that disabled children inevitably experience emotional problems as they grow up due to parental difficulties bonding during infancy, and a lack of confidence subsequently in parenting such children (Baldwin and Carlisle, 1994).

Baldwin and Carlisle's review (1994) also questioned the validity of the measures used to ascertain children's social and emotional adjustment in some studies and identified other methodological difficulties in others, such as lacking a control group from the general population or restricting their scope to children with specific impairments (Baldwin and Carlisle 1994). They nevertheless concluded that the available research evidence pointed to disabled children being at increased risk of social and emotional problems, particularly during adolescence. However, they further criticised this body of research for relying on parent and professional proxy views and reported finding "no studies focusing in detail on the disabled child's daily life and the way disability affects her" (p. 33). This led them to conclude that the research available at the time of their review was able to shed little light on the reasons for the variation in outcomes across the population of disabled children or how disabled children themselves felt about the way professionals and other children treat them (Baldwin and Carlisle, 1994, p.33).

Ascertaining the wishes and feelings of the (disabled) child

Research exploring disabled children's own views and experiences did begin to emerge as the 1990s progressed, largely due to the coming to fruition of changing ideas concerning children and childhood. The "discovery" of battered child syndrome (Kempe, 1962) and reporting of high-profile child deaths in the UK, starting with Maria Colwell in 1973, contributed to children's welfare no longer being considered an entirely private matter, resulting in a growing understanding of children as separate entities with rights distinct from those of their parents' (Fox-Harding, 1991).

These developments in many ways mirrored changing policy and attitudes to disabled people (Tisdall, 2012). Nevertheless, it took far longer to move beyond children being thought of only in terms of their dependence on adults for protection. This was partly because unlike other marginalised groups, children were unable to directly engage in political activism, with any pressure for change being applied by adults on their behalf, as earlier outlined in relation to disabled children's support needs (Oswin, 1998). Stage theories of child development also reinforced the idea of children as lacking competence and somehow "less than fully human, unfinished or incomplete" (Jenks, 1996, p.10), until reaching the rational competence and maturity associated with adulthood.

These ideas, essentially portrayed children as “human becomings” rather than “human beings” (Qvortrup, 1994), were critiqued with the emergence of the sociology of childhood or childhood studies from the 1990s onwards. From this theoretical standpoint, notwithstanding children’s biological immaturity, how childhood “is understood and made meaningful” is socially and culturally constructed (James and Prout, 1990, p.7). Through research giving voice to children’s views and demonstrating their ability to influence their lives and relationships at their current stage of development this approach sought to challenge children’s marginalised position in research, policy and practice (Tisdall, 2012). This research highlighted, for example, the capacity of children as young as eight to contribute to decision-making about undergoing surgery (Alderson, 1995).

Similar thinking also began to be reflected in policy and practice during the same period. These developments were encapsulated by Dame Butler-Schloss’ now famous assertation in her report to the Cleveland Enquiry (HMSO,1988) into practitioners’ handling of child sexual abuse allegations that: “the child is a person and not an object of concern” (p. 425). The Gillick ruling also importantly recognised children’s competence to make decisions based on their capacity for understanding rather than their age (*Gillick vs West Norfolk and Wisbech Health Authority,* [1986] AC112). Both these developments contributed to the Children Act (1989) requiring social workers and other professionals’ to seek and take account of children’s wishes and feelings in decision-making. This echoed the emphasis on children’s rights to participation and support alongside protection in the United Nations Convention on the Rights of the Child (1989).

The Children Act (1989) was also the first piece of mainstream child welfare legislation to acknowledge disabled children’s support needs by specifying them as a vulnerable group in need of services to safeguard and promote their welfare under Section 17 (c) (Connor and Stalker, 2003). Child in need services, provided under Part III of the Act, also marked an important policy turn towards preventing child maltreatment and family breakdown within social work and child protection practice (Parton, 2005).

This move, which was consistent with a public health approach to supporting vulnerable children and their families (McMillan, 2009), was later reinforced by the introduction of statutory practice guidance based on an ecological systems theory approach to assessing children's support needs (Department of Health, 2000). Although, assessments of need have been criticised for the proceduralised approach taken in practice (Horwath, 2007), and those involving disabled children for focusing on children's deficits rather than their capabilities (Beresford, *et al*, 2007).

Projects undertaken within disability studies (Morris 1995; Morris, 1998; Middleton, 1999) also began to apply the social model of disability to understanding disabled children's lives and experiences (Connors and Stalker, 2007). These studies helped provide an alternative discourse to previous research focused on children's limitations arising from their impairments (Davis *et al*, 2003), as well as highlighting policy and practice issues for disabled young people. Research exploring how the Children Act 1989 was being applied to disabled children, for example, found they were not being consulted regarding their views and that social workers commonly assumed they were too impaired to express an opinion (Morris 1998; Ward 1999). The "Still missing?" studies (Morris, 1995, Morris 1998) also importantly raised awareness of the distress and isolation disabled young people attending residential special schools experience at being separated from their families and lacking adequate support from professionals.

These studies also provided evidence that disabled children, even those with significant communication needs had opinions, which they were able to convey given the right approach (Watson, 2012). This prompted a number of authors to publish accounts of methods enabling disabled children to take part in research (Beresford, 1997, Ward, 1997 and Morris, 1998). Simultaneously placing an onus on researchers and practitioners to establish ways of communicating with children with a wide range of needs (Alderson and Goodley, 1996; Morris, 1999).

Criticisms of child 'voice' and childhood studies

In spite of these achievements, research with disabled children has not been as prolific as that with non-disabled children or disabled adults (Stalker 2012). Disabled children's "voices" are likewise often excluded from mainstream children's research (Lewis, 2010). Both findings reflect a core criticism of childhood studies' and children's rights approaches' tendency to privilege the voices of the most confident and articulate, rather than the views of younger, less articulate, children (Komulainen, 2007), particularly disabled children, who rely on or prefer non-verbal means of communication (Franklin and Sloper, 2006), choose not to answer researcher's questions, or whose views are considered less reliable due to concern about suggestibility or acquiescence (Lewis, 2010). Others likewise point out that childhood studies focus on agency risks excluding contexts where children's agency is constrained or limited (White and Choudhury, 2010), such as by their impairments.

A further criticism of childhood studies is that the "child's voice" is itself a social construct, based on the simplistic assumption that "children have message-like thoughts … that match the situations defined by adults" (Komulainen, 2007, p.25), rather than acknowledging their understanding of themselves as complex and variable. This is an issue that raises further questions about the authenticity of children's voices, when these are represented by quotes chosen by adult researchers (Tisdall, 2012). Researchers may also sub-consciously choose to exclude children whose views do not easily 'fit' their agenda (Fielding, 2004) or who prompt uncomfortable self-examination (McIntyre *et al*, 2005) a finding that seems especially relevant for disabled children given dominant social attitudes towards impairment.

Beresford *et al* (2007) further contend, based on their own experience, that the research funder's not allowing adequate time and resources for disabled children to properly express their views often results in their views being left out or not included in a meaningful way in research projects. This, in itself, may been seen as evidence that the current focus on child voice owes as much to neo-liberal intention to re-cast them as consumers of services as to a desire to promote their human rights, a paradigm, within which disabled children may be seen as having less potential 'buying' power and influence (Lewis, 2010). Certainly, early research studies tended to focus on disabled children's experiences as service users rather than on their everyday lives and identities (Connors and Stalker, 2003). While this approach may be empowering for individuals and help improve services, others argue it continues to reinforce stereotypes of disabled children as passive and dependent recipients of services (Watson, 2012). Thus providing the motivation for the wider focus on disabled young people's social worlds adopted in this study.

Disabled children's rights and perspectives

Studies with a broader interest in disabled children's everyday lives and relationships were slower to emerge (Connors and Stalker 2003). Robinson and Stalker (1998), for example, had to commission specific studies for their book "Growing up with disability" because at the time so few studies had been carried out (p. 7). The resulting collection, despite mostly consisting of very small-scale qualitative studies, identified a number of recurring themes regarding disabled children's experiences, many of which have been corroborated by later research (e.g. Connors and Stalker, 2003: Kelly, 2005). These include disabled children's extremely common experience of being bullied and the crucial significance to them of their relationships with their parents and siblings. Perhaps the most significant theme for the research undertaken for this dissertation is the importance to disabled children of being asked their views and of services and practitioners' taking account of their wider needs within their families and social environment.

The post-millennial period saw a steady rise in research presenting disabled children's perspectives in the UK and more widely (Stalker, 2012). This topic was the also subject of an ESRC Seminar Series during 2010-11, reporting further development of creative participatory methodologies and the inclusion of children with wide-ranging impairments in research (Beresford *et al,* 2007; Wickenden, 2011). Disabled young people also started to become more involved in research planning and design (Lewis *et al* 2008), including as co-researchers in some projects (VIPER, Council for Disabled Children 2013; Larkins *et al*, Office of the Children's Commissioner 2013).

Increased funding of research with disabled children partly reflected further policy development of social justice and rights-based discourses during the same period. New Labour's policy initiative, Every Child Matters (DCSF, 2003), following Lord Laming's report into Victoria Climbe's death, reflected a further shift towards a preventive community-based approach to child welfare and reducing child poverty (Parton, 2014). These changes also resulted in an unprecedented policy commitment to disabled children (Read *et al*, 2012), including the Aiming High for Disabled Children Programme (HM Treasury, 2007) investing £340m in developing services to promote disabled children and their family's participation and inclusion. This came about partly due to persistent evidence of a complex relationship between childhood disability and poverty (Pantazis and Gordon, 2000) and the increased barriers and costs associated with raising a disabled child (Dobson and Middleton, 1998). It also resulted from growing concern that inadequate and poorly co-ordinated services were exacerbating disabled children and their family's social exclusion (Audit Commission, 2003; Parliamentary Hearings: Services for disabled children and their families, 2006).

How these policy changes were applied to disabled children attracted criticism, however. The "Every Child Matters" outcomes to be healthy; achieve economic well-being; enjoy and achieve etc, were based on ableist notions of a "good childhood", and risked marginalising disabled children's unique views, experiences and capabilities (Sloper *et al*, 2009; Runswick-Cole and Goodley, 2011). Aiming High was also criticised for insufficiently focusing on disabled children's own wants and needs (Council for Disabled Children, 2011), as reflected in the duty subsequently placed on local authorities to provide a range of short breaks services to their carers under Section 104 (3A), Children Act (1989) (HM Government, 2011).

The policy shift towards characterising disabled children as citizens with distinctive rights was nevertheless welcomed (Lenehan, 2010). These changes were partly driven by international recognition of disabled people's rights (United Nations Convention on the Rights of Persons with Disabilities, 2006), and within the UK by a desire to extend policy developments relating to disabled adults to disabled children and their carers' (Children and Families Act, 2014). Rights-based perspectives also became more common place within disabled children's research (Tisdall, 2012) and efforts made to develop a distinct approach to theorising disabled childhood through the establishment of Disabled Children's Childhood studies (Curran and Runswick-Cole, 2014).

Scope and limitations

Commenting on research on disabled children's perspectives, Stalker (2012) concluded that most studies tended to be small scale, qualitative studies of cross-sectional design with large-scale, quantitative, longitudinal or ethnographic studies being comparatively rare. The majority of studies identified for the review undertaken for this dissertation similarly involved between 10 and 40 participants.

However, there are some important exceptions to this overall trend. Of the larger qualitative studies, the Life as a Disabled Child Project, involving participant observation of over 300 disabled children aged 11-16 of whom 165 took part in in-depth qualitative interviews, is perhaps the most significant (Watson *et al*, 2000). This was also one of the first studies to evidence disabled young people's ability to influence their everyday lives (Davis *et al*, 2003) as well as how social, cultural, and environmental practices restrict their opportunities for participation (Davis and Watson, 2001). Larkins *et al*'s (2013) study likewise broke new ground by shedding light on 78 disabled young people's experiences of living on a low income, complementing successive quantitative surveys documenting disabled children's increased risk of poverty and social exclusion (Blackburn *et al*, 2010). It also showed how timely and appropriate service provision can help alleviate these young people's difficulties.

A few quantitative, ethnographic and narrative studies have also been carried out. Though these have commonly focused on the experiences of children with specific impairments. Two of the largest longitudinal quantitative studies, for example, respectively commented on the self-reported quality of life of children with cerebral palsy (Dickinson *et al*, 2007; Colver *et al*, 2015) and children with spina bifida (Holmbeck *et al*, 2003; Holmbeck *et al,* 2010) which they found to be broadly similar to their non-disabled peers. By contrast two of the smallest studies, Wickenden (2011) and Boggis (2011) ethnographic works focused on giving voice to young people dependent on technological communication, a group of disabled children whose views had hitherto been largely excluded from research. These studies have value for young people with specific impairments and have also allowed the scope of research regarding disabled children's perspectives to be extended. This approach limits the generalizability of these studies' findings to other groups of disabled children (Watson, 2012), potentially betraying the social model's emphasis on a shared experience of oppression. Though, as Carpenter and McConkey (2012, p.257) assert there is arguably room for both approaches to make their contribution to research.

Moreover, even studies including children with wide-ranging impairments have tended to rely on convenience sampling, meaning their findings' validity may be challenged by policy-makers as unrepresentative of disabled children in the population (Tisdall and Davis 2004). Franklin and Sloper (2006) likewise observed that disabled children involved in service planning are those who are "easiest to reach, most able to communicate, most articulate and confident" (p. 736). Many studies have focused on the experiences of older disabled children, although a few have included the views of disabled children aged 7 and under (Kelly, 2005; Boggis, 2011). Finally, while disabled adults' retrospective narrative accounts of their childhoods have also added to our understanding of disabled children's lives (Thomas, 1999; Middleton, 1999: Shah and Priestley 2011; Shah *et al*, 2016), methodological concerns have been raised about the reliability of findings based on participants' memories of past events. Moreover, the historical nature of these studies affects the generalisability of their findings to subsequent generations of disabled children.

These concerns about representativeness highlight an important tension relating to the heterogeneous characteristics and experiences of children classified as "disabled". This means there can be no one-size-fits all approach to research or policy concerning disabled children and their families (Davis *et al* 2003). A reasonable way forward, as Carpenter and McConkey (2012) suggest, is for researchers to ensure that "a range of voices under the rubric "disabled children" are represented….as their opinions, needs and experiences may differ substantially." (p. 254). This sentiment has been echoed by other commentators (Davis, *et al* 2003; Stalker, 2012), providing a clear rationale for including the views of young people with a range of disabilities in the research conducted for this dissertation, whose experiences have received little prior attention (Stalker and McArthur, 2012).

How disabled children view themselves and their experiences within their families and wider social worlds

In this section themes from research findings regarding disabled children and young people's perspectives are presented in relation to this study's first research question, regarding participants' perceptions of themselves within their families and wider social worlds. This discussion is structured thematically within a broadly ecological framework (Bronfenbrenner, 1979), beginning with an analysis of what disabled young people have to say about themselves and their lives, including the impact of their impairments on their sense of self (*individual*). Then moving onto consider disabled children's perspectives regarding family life and relationships, of friendship and life at school (*micro-system*) and finally their experiences within their communities (*exo-system*) and wider society (*macro-system*).

Disabled children's view of themselves and their lives

Sense of self and quality of life

Most studies indicate that the majority of disabled children, almost regardless of age and impairment have a positive view of themselves and their lives. Colver *et al* (2015), for example, found self-reported quality of life among adolescents (n=431, 13-17 years) with cerebral palsy was broadly comparable to that of their non-disabled peers and consistent with that reported in middle childhood (n=818, 8-12 years, Dickinson *et al*, 2007). Similar findings have been reported among children with spina bifida (n=68, Holmbeck *et al,* 2003; Holmbeck *et al,* 2010). Children with a range of impairments including learning disabilities and autism (n=20, 8-16 years) described feeling valued (Foley *et al*, 2012), while Wickenden (2011) reports that the self-descriptions of physically disabled teenagers in her study (n=9, 10=17 years) suggested they had a positive sense of self.

Several studies have also found that disabled children tend to be more positive about themselves and the impact of their impairment than do their parents (Creemens *et al*, 2006; Dickinson *et al,* 2007). Disabled children and young people likewise commonly emphasise their similarities to their peers rather than their differences (Stalker, 2012). Most of the 14 children with mobility impairments (11-16 years) in Singh and Ghai's (2009) study, for example were "confident they could do whatever they decided to do" and half said they saw themselves as "no different from "normal" children" (p. 133). In interpreting these findings, Beresford (2012), reflecting on her work on subjective well-being with 10 disabled adolescents, sounds a note of caution that disabled children's impairments may themselves affect their awareness of their abilities and social and material disadvantages relative to others.

Disability and identity

Disabled children also tend not to identify themselves as disabled and/or see their disability as only one part of themselves. All but one of the disabled children Connors and Stalker (2003) interviewed, for example, did not view their impairment as a big deal, and only three of the young people with learning disabilities in Kelly's (2005) study (n=32, 2-16 years) referred to their impairment as something they would like to change about themselves.

Physically disabled young people in Wickenden's (2011) study reported feeling puzzled and sometimes irritated when their disabled identity was prioritised by others. They viewed their gender identity and emerging identity as teenagers as more important to their sense of themselves and their aims for the future than being disabled, a finding echoed by Smith and Traustadottir's (2015) similar study with physically disabled young people in Iceland (12-16 years). Studies with LBGTQ disabled young people (Toft *et al*, 2018) and disabled young people from black and minority ethnic backgrounds (Watson *et al*, 2005) similarly emphasise these aspects of themselves as equally important to their developing sense of self, demonstrating the complex and inter-sectional nature of identity (McCall, 2005), particularly during adolescence (Erikson, 1968). This represents an important consideration for young people in this study.

Studies also suggest, however, that the changes and increased awareness associated with adolescence can themselves have a negative effect on disabled young people's perception of themselves and their impairments. Teenage girls (14-15 years) with spina bifida in Holmbeck *et al*'s(2010) study were more likely to have a negative self-perception of their physical appearance than their non-disabled peers. McLaughlin and Coleman-Fountain (2014) also found that as the physically disabled young people in their study got older, they grew more concerned about how their impairments and associated disablism limited their independence and desire to form intimate and sexual relationships. Similar findings were also reflected in the accounts of young men with muscular dystrophy (n=40, aged 15-33) (Abbott and Carpenter, 2010).

Disability and "difference"

Despite down-playing the significance of their impairments with regard to their identities, disabled young people in most studies described an awareness of themselves as different from others. Sometimes this difference was directly attributed to the functional limitations of their impairments. Children with mobility impairments study felt "disabled" when they could not undertake certain tasks or activities (Singh and Ghai, 2009 p.133). However, disabled children in most studies placed greater emphasis on other's negative reactions to them and the stigma associated with having an impairment. Connors and Stalker (2007), applying Thomas' (1999) ideas concerning psycho-emotional disablism, found that disabled children in their study described "barriers to being", such as being excluded or made to feel inferior as hurting the most. They further suggest that such experiences occurring during the important identity forming stage of adolescence may have damaging consequences for disabled children's self-confidence as adults. This seems particularly relevant to disabled young people in this study, given their additional experiences of suspected maltreatment.

Most disabled children also describe experiencing being made to feel different within their families as well as in other contexts. Young people in Kelly's (2005) and Singh and Ghai's (2009) studies, for example both described being restricted from activities their (often younger) siblings were allowed to do, such as baking and visiting friends' houses. Disabled children and young people in these and other studies also commonly report experiencing high levels of adult surveillance as a result of their impairments at school and in the wider community (Watson *et al*, 2000; Smith and Traustadottir, 2015). Children with autistic spectrum disorder in Preece and Jordan's (2009) study (n=13, 7-18 years), however, sharply contrasted their family members' positive attitudes towards them with their experiences of disablism at school.

Disabled children in several studies also described feeling less aware of the differences caused by their disability in segregated settings, such as special schools where all pupils have impairments (Kelly, 2005; Smith and Traustradottir, 2015). Many of the physically disabled adults in Shah and Priestley's (2011) study who had attended special schools described being largely unaware of themselves as disabled during their childhoods, and only experienced this in terms of the limited opportunities and negative attitudes they later experienced on transferring to mainstream settings on reaching adulthood.

Though disabled children in some studies also report positive benefits from mixing with other disabled youngsters in segregated settings. One young woman in Watson *et al* (2000) study, for example, felt relieved that her disability 'disappeared' in the context of playing wheelchair basketball.

Other studies report finding that disabled children and young people's experience of feeling different varied according to the nature of their impairments. Generally, children and young people with more visible impairments are more likely to report experiencing disablist bullying (Wickenden, 2011; McLaughlin, 2014). By contrast those with less visible impairments, such as non-complex epilepsy, are less likely to identify problems with peers or to describe themselves as disabled (Laybourn and Hill, 1994). These differences perhaps reflecting the pressure on children, particularly during adolescence, to "pass as normal". Davis *et al* (2000) also observed that some disabled children rejected disability as an identity for themselves but used it to label others, with reference to an imagined "hierarchy of impairments". Wickenden (2011) similarly found that young people using alternative forms of communication disliked being misattributed as having learning difficulties as they felt this undermined their value as people.

Davis *et al* (2000) highlight a further finding that whether individual young people claimed disability as an identity varied across different contexts. For example, identifying themselves as disabled was used by some young people to claim certain privileges, for instance young people asking their teacher "can we go early, Miss, cos' we're disabled" (p.18). This was interpreted as evidence of individual agency, young people using their disability status to influence the direction of their everyday lives (Davis *et al* 2005). By contrast, but equally assertively, other disabled young people rejected the notion of a binary distinction between disabled and non-disabled people (Goodley, 2010), by putting forward the view that everyone is impaired to a greater or less extent.

Disabled young people's experiences of family relationships

A dominant theme in the studies examined was the significance of family relationships with regard to how disabled children make sense of their lives and identities. This is perhaps hardly surprising. However, it remains important given that psychological research suggests that how disabled young people adapt, and cope is strongly mediated by the strength and resilience of family relationships, parental attitudes and adaptation, as well as the nature of their impairments (Baldwin and Carlisle 1994). It is also particularly relevant to this study since disabled young people who have been subject to child protection processes are highly likely to be living in family environments with fewer resources and more relationship difficulties than other groups of disabled children.

Family relationships as a source of support and resilience

Having supportive family relationships was mentioned as important by disabled children in most studies. However, it emerges as a particularly strong theme in studies with children and young people with complex and communication disabilities.

Belonging to a family was identified as being of primary significance to their sense of themselves by young people with visible physical disabilities (Smith and Traustadottir, 2015). It was also one of five core themes in Wickenden's (2011) research with young people who use augmented and alternative communication, because they viewed close family as being more likely to see them for who they are rather than what they can or cannot do.

Young men with Duchenne's Muscular Dystrophy in Abbott and Carpenter's (2010) study similarly described extremely strong bonds with their parents, especially their mothers. These relationships were often characterised by high levels of dependence as a result of these young people's complex physical impairments and health needs. However, some felt the intensity of familial relationships restricted their opportunities for independence and developing other social relationships.

Disabled young people with a range of impairments similarly identify family relationships as important to their well-being and in helping them cope with the effects of their impairments. One young person with Asperger's syndrome in Foley *et al* (2012) study said, for example, "I think you have to have a family to have a happy life yourself" (p.382). Young people with epilepsy (n=15, 13-16 years) in Chew *et al* (2018) identified shared beliefs and connectedness in family relationships as helping them cope with the stressful effects of their impairments. Young adults with learning disabilities similarly described family members' enabling attitudes as helping mitigate disabling experiences and promote healthy self-esteem (Kelly, 2013).

Many other studies similarly report that parental support of disabled children can help them overcome the barriers they face because of their impairments. Disabled adults in Shah and Priestley's (2011) study felt that their parent's resisting or challenging professional decisions, such as whether they should attend mainstream or segregated schooling as children, had significantly improved the opportunities subsequently available to them as adults. Young men in Abbott and Carpenter's (2010)'s study similarly appreciated their parents' support managing and mediating their relationships with professionals. Young people in Wickenden's (2011) study reported their parents as collaborating with them to resist the disablist attitudes they frequently encountered from strangers.

Disabled children in several studies also identify their siblings as important people in their lives. Children in Foley *et al* (2012) study described their siblings with respect, while most participants in Connor and Stalker's (2003) study valued sibling relationships as a source of friendship, especially where other relationship opportunities were lacking. Though a few children in both studies also reported being bullied by their non-disabled siblings, these relationships were generally characterised by "fun and conflict in equal measure" (Connors and Stalker, 2003, p. 43). Non-disabled siblings in Connors and Stalker's study (2003) presented a similarly positive account of their relationship with their disabled sibling, challenging the view, portrayed by earlier research, that having a disabled sibling was an inevitably negative and stressful experience (Baldwin and Carlisle 1994).

Other experiences of family life

Disabled children's experiences of family life are inevitably varied, however, and research also outlines less helpful aspects of these relationships. Disabled women in Thomas' (1999) study identified their parent's negative attitudes and responses to their impairment as having adversely affected their developing sense of self during childhood as well as well their confidence negotiating their lives as adults. Some children felt their parents' blamed them for their impairments (Singh and Ghai, 2009), though the findings of this Indian study may partly be influenced by cultural factors or beliefs. However, disabled adults in a UK study perceived parental rejection or lack of acceptance of their impairments as significantly contributing to their decision to send them to residential schooling (Shah and Priestley, 2011). Negative parental attitudes concerning disability may also help account for disabled children's over-representation in out-of-home care (Baker 2007; Kelly *et al*, 2016).

Many studies involving disabled children and their parents report finding that children's impairments tend not be discussed within families (Connors and Stalker, 2003; Shah and Priestley, 2011). Kelly (2005), for example found only five out of 32 parents had talked with their child about their learning difficulties because they felt the child would not understand or they did not want to upset them. Young men and their parents in Abbott and Carpenter (2010) similarly reported that their muscular dystrophy was rarely mentioned at home, even though the effects of their condition dominated their daily lives.

Disabled children and young people in several studies report their awareness of their parents being over-protective of them and/or underestimating their capabilities in other ways (Kelly, 2005; Singh and Ghai, 2009). Disabled children and young people also commonly report spending more of their free time with family members than their peers (Davis *et al*, 2000; Connors and Stalker, 2003), perhaps partly as a result of parental over-protection, as well as barriers to socialising associated with their impairments. There is also some evidence that disabled children are at risk of internalising negative beliefs about disabled people as inevitably vulnerable and dependent that these over-protective attitudes represent (Thomas, 1999; Singh and Ghai, 2009).

Other studies, however, report finding that the limitations and restrictions parents imposed on their children's independence are often resisted by disabled children themselves, supporting an alternative view of them as competent social actors (Kelly, 2005; Watson *et al*, 2005). Some children in Kelly's (2005) study, for example, despite lacking information from their parents, had idiosyncratic understandings of their impairments which had helped them develop a positive sense of self and successfully negotiate family life.

Overall the research evidence suggests however disabled children's views and experiences of family relationships are complex and variable (Carpenter, 2010). Many disabled children report their family relationships as providing a safe haven from, and/or an alternative discourse to the disabling barriers and attitudes they encounter outside the home (Wickenden, 2011), while in other disabled children's families it would appear that these negative experiences are reflected and reinforced. Most importantly for participants in this study, given the likelihood of difficult family relationships, is evidence of disabled children's own capacity to influence family and other relationships (Davis *et al*, 2003).

Disabled young people's experiences of friendship and life at school

In studies exploring disabled children's desired outcomes, having good friends ranks at least as highly as having supportive family relationships. It was noted as the favourite topic of conversation among children with complex health needs in Raibee *et al* (2005) and described by children with a range of impairments as their number one priority in Foley *et al* (2012) study on well-being. Perhaps not surprisingly this finding closely reflects the priorities identified in similar studies with non-disabled children (Amplify *et al*, 2013). Friendliness is also a key aspect of themselves where disabled children themselves are keen to emphasise their similarity to other children. Young people with cerebral palsy in Wickenden's (2011) study, for example, viewed themselves as friendly and sociable people and wanted friends who saw them for who they are.

A consistent finding across studies, however, is that friendship is an area where disabled children commonly encounter difficulties (Stalker, 2012). Although the majority of disabled children, regardless of impairment, usually describe having at least one close friend (Connors and Stalker, 2003; Wickenden, 2011), and some say they have many friends (Davis *et al*, 2000)**,** most report having restricted social lives. Children and adolescents with Spina Bifida in Holman *et al* 's longitudinal study (2003; 2010), for example, had fewer social contacts than their non-disabled peers in both middle childhood and adolescence.

Like other children, disabled children describe their peers at school as their main source of friends (Ytterhus, 2012). However, several studies report finding that for disabled children the type of schooling they attend due to their impairments strongly mediates their opportunities for friendship both within school and outside (Connors and Stalker, 2003; Shah and Priestley, 2011). Disabled children attending special schools, generally report feeling more accepted by their peers who inevitably also have impairments, and having fewer difficulties making friends than those in mainstream settings (Davis *et al*, 2000).

In special schools disabled children's pool of potential friends is often described as being limited by smaller class sizes (Connors and Stalker, 2003). Disabled girls in Davis *et al* (2000) study also reported having fewer female friends than those attending mainstream schools, probably due to boys being over-represented in special education due to the higher incidence of disability among males. Disabled children attending special schools, often long distances from their homes, often have few opportunities for meeting with their friends outside school. They also commonly report having fewer friends in their local community and consequently often feel socially isolated (Connors and Stalker 2003; Kelly, 2005).

Disabled children report experiencing a different set of challenges to forming positive relationships in mainstream settings. They particularly identify being taught in segregated classes in the presence of learning support assistants for much of the school day as limiting their opportunities to make friends with their non-disabled peers (Davis *et al*, 2000; Ytterhus, 2012). The friendships that do develop between disabled and non-disabled children are also often characterised in disabled children's accounts as unequal (Davis *et al*, 2000) and strongly mediated by parental influence (Connors and Stalker 2003). Raghavendra *et al* (2012) also suggest that high levels of adult contact further inhibit physically disabled children (n=25, 10-15) from developing good social skills and can foster dependency. Though, Davis *et al* (2000) and Kelly (2005) both also found evidence of disabled children challenging these restrictions, for example, by using play areas that were out of bounds in order to play with non-disabled peers.

As well as often having greater difficulties making friends, disabled children commonly report being bullied at school as a result of their impairments (McLaughlin *et al*, 2012). Although affecting children with a range of impairments, rates of bullying tend to be higher in mainstream settings and among children with more visible impairments (Watson *et al*, 2000). Children who are wheelchair-users (Yude *et al*, 1998), or have impairments that affect social interaction, such as speech difficulties (Hunt, *et al*, 2006), ADHD or autism (Twyman *et al*, 2010), for example, generally report higher rates of bullying than those with chronic health conditions, such as cystic fibrosis (Twyman *et al*, 2010). Moreover, studies have found that negative or disablist attitudes among teachers, including "turning a blind eye" can implicitly or explicitly reinforce bullying behaviour towards disabled children, further increasing their sense of social isolation and cultural exclusion (Davis and Watson, 2001; Lindsay and McPherson, 2012)

Despite generally reporting less bullying, disabled children frequently describe attending special schools as negatively affecting their development in other ways. Disabled adults in Shah and Priestley's (2011) study felt that the culture of low expectations regarding their educational attainment they experienced within special education had failed to prepare them for adult life and employment. Importantly for this study, young people with learning disabilities in Franklin and Smeaton's (2018) study (n=27, 12-23 years) who had been sexually exploited similarly identified the protective environment and lack of sex and relationships education in special schools as inhibiting their understanding of risk and healthy boundaries in relationships.

Wider opportunities and social worlds

As these examples suggest the difficulties disabled children and young people describe experiencing at school tend to be mirrored or exacerbated in their wider social worlds. The majority of disabled children report having very restricted social lives, commonly describe being involved in more family than peer-based leisure activities (Connors and Stalker, 2003; Abbott and Carpenter, 2010) and more often have close friends who are adults, such as personal assistants or family friends, than a network of peers their own age (Wickenden, 2011; Hultman *et al*, 2015).

Disabled children and young people consistently report difficulties accessing social and leisure opportunities in their local communities. Many of the disabled children (n=105) in Turner's (2003) study, for example, felt they were missing out on a social life because there were few things to do in their area. Only 12% disabled children in Finch *et al* (2001) survey reported that they were members of a sports club outside school compared to 46% of non-disabled children.

Disabled children and their parents identify a range of barriers to their participation and inclusion in community leisure and recreation activities. These include inaccessible buildings and a lack of inclusive facilities such as parking, toilets or suitable changing facilities (Petrie *et al,* 2007; Mencap, 2008), poor disability awareness among staff and negative attitudes towards disabled children from members of the public (Ludvigsen *et al,* 2005; Every Disabled Child Matters, 2008). Although work to address these material barriers has been prioritised under the provisions of the Equality Act (2010) and Aiming High Programme (2008-11), disabled children commonly report being bullied within "inclusive" settings (Mencap, 2007) and the cost of activities is often a further barrier, especially among those on low incomes (Larkins *et al,* 2013).

Evidence suggests that some groups of disabled children are particularly likely to be affected by social exclusion. A review by Beresford and Clarke (2009), found that young people with learning difficulties, autism and multiple impairments are least likely to report taking part in regular social activities. Petrie (2000) also observed that children who attend special schools particularly struggle to integrate in inclusive activities due to being uninitiated in the rules and norms of mainstream youth culture.

Disabled children also report experiencing more social exclusion as they get older. Adolescents with cerebral palsy (13-17 years) in Colver *et al*'s (2015) longitudinal study, for example, reported a significantly lower quality of life in the area of social support and peer relationships than their non-disabled peers, a difference not reported by children who took part in the same study during middle childhood (8-12 years) (Dickinson *et al*, 2007). This age-related difference in perceived social support possibly partly relates to young people's increased desire for greater peer contact and independence during adolescence (Carpenter, 2010). They may also arise as a result of disabled young people's own developing awareness of the stigma and limitations associated with their impairments, as noted by participants in McLaughlin and Coleman-Fountain's (2014) study.

However, studies highlight that disabled young people's experiences of social exclusion are also exacerbated by reduced support and services during and following the transition from children to adult services (Kaehne and Beyer, 2011; Broadhurst *et al,* 2012). Young men in Abbott and Carpenter's study (2010), for example, reported more difficulties making friends on entering mainstream college and had much more restricted social lives on finishing education.

For some disabled children, not taking part in social activities may represent an active choice. In some cases, this may relate to children's impairments, while in others it may simply reflect the heterogenous nature of children's preferences. Lewis *et al* (2007) for example, found that some disabled children did not wish to take part in organised activities, were naturally shy or preferred home-based pursuits. Young people with autism in Preece and Jordan's (2009) study reported preferring solitary activities and described new and noisy environments as affecting their enjoyment of both school and short breaks.

Not surprisingly the majority of disabled children say they want more opportunities to socialise and a greater choice of things to do in their free time (Petrie *et al*, 2007; EDCM, 2008). Disabled children also report benefits to their well-being and development as a result of taking part in social activities, whether segregated or inclusive. These include experiencing a greater sense of belonging and acceptance (Goodwin *et al*, 2004) and improved confidence in themselves and their abilities (Lewis *et al,* 2007). However, Welch *et al* (2014), evaluating the impact of short breaks activities provided under Aiming High, found disabled children (n=73, 5-19 years) tended to emphasise immediate benefits such as trying out activities, having fun and making new friends rather than the improvements to their confidence or skills prioritised by their parents.

Other disabled children, whilst positive about receiving support to access social activities, nevertheless remain acutely aware of barriers to their inclusion. Physically disabled young people (n=16, 16-21 years) in Hultman *et al* (2015) grounded theory study positively valued receiving personal assistance because it allowed them to achieve “assisted normality”, which they defined as a measure of independence and social interaction on a par with their peers. Young people also emphasised the importance of assistants having an enabling attitude, but nevertheless felt this support did not always compensate for the lack of acceptance they frequently encountered in the wider community.

Negative attitudes from non-disabled children and members of the public may also help explain why disabled children commonly express a preference for socialising with other disabled children (Keil *et al,* 2001; Petrie *et al,* 2007). Disabled children in Murray's (2002) study for example, identified spending time with children with similar impairments as affirming of their identity, and often viewed these relationships an important source of emotional support. However, some reported that the strength of these relationships was partly based around a shared experience of bullying and social isolation in mainstream school.

Disabled children’s individual experiences both in education and within their communities point to a wider need to challenge the deeply embedded cultural exclusion of disabled children in society (Curran and Runswick-Cole, 2014). Policy initiatives such as Aiming High (HM Treasury, 2007), and the Children and Families Act (2014) referencing the social model of disability and seeking to increase disabled children’s participation and inclusion represent a promising start (Read *et al,* 2012; Byrne and Kelly, 2015). Since the barriers to disabled children’s social inclusion are multi-faceted, a sustained and holistic rights-based policy commitment, backed up with financial and other resources is arguably required to effectively overcome them (McNeilly *et al*, 2015). However, at the time of writing, several studies have raised renewed concerns about rising levels of social and economic exclusion among disabled children and their families in the UK due to significant cuts to short breaks and other services as part of austerity measures (Stalker, 2015; EDCM, 2015) coupled with the impact of disability welfare benefit reform (Larkins *et al,* 2013; Contact a Family, 2014).

Conclusion

This chapter has reviewed the contribution of theory, policy and existing research to understanding of disabled children's lives. Since 2000 there has been a significant increase in research on disabled children's perspectives. By the time of writing there exists a growing literature exploring disabled children's identities and experiences within their families and wider social worlds, based on an understanding of them as social actors and experts on their own lives (Byrne and Kelly, 2015). The research reviewed also has important implications for this dissertation's study, given disabled young people's commonly reported difficulties within their families and at school, and experiences of social exclusion. Research with maltreated children highlights similar themes (Cossar *et al,* 2011), suggesting that such issues may be especially pertinent for participants in this dissertation's study.

Research with disabled children is also an area where further application and integration of theoretical perspectives would enhance understanding of their lives (Carpenter and McConkey, 2012). Attempts to achieve this by developing insights from disability and childhood studies represent a promising development, which would benefit from more collaboration across health, education, sociology and psychology disciplines (Curran and Runswick-Cole, 2014). Critical realist relational approaches to disability, such as that used as the theoretical framework for this dissertation's study, would also allow a more nuanced understanding and analysis of disabled children's childhood experiences to emerge (Watson, 2012). Both these approaches would also help further understanding of disabled children's experiences of professional responses to maltreatment, given the inherently multi-dimensional and multidisciplinary nature of both childhood disability and child protection practice.

This review has also highlighted areas where further research would improve our understanding of disabled children's lives. The inter-sections between disability and other aspects of children's identity, such as age, gender, race and their experiences as looked after children are little explored (Davis *et al,* 2003; Jones and Liddiard, 2017). Research regarding disabled children's perspectives on sensitive or risky topics is also limited, despite evidence that their right to experience positive family, intimate and other relationships is often violated or denied (Jones *et al,* 2012; Franklin *et al,* 2015). As well as providing a clear rationale for this study, this also points to the need for social workers and other professionals' to develop a better understanding of risk and resilience among disabled children in order to help them achieve their potential (Hart *et al,* 2014), the existing evidence base for which is explored in the next chapter.

Chapter 2 – Disabled children, maltreatment and child protection

Introduction

The previous chapter highlighted how disabled children's identities and aspirations are largely similar to those of non-disabled children (Stalker, 2012), It also reviewed research findings regarding some of the challenges associated with growing up with a disability. These include pressure on family relationships and restricted access to friendship and other opportunities, often at least as much related to negative attitudes concerning disability and a lack of appropriate support as to children's impairments themselves (Davis, *et al*, 2003). Although, despite these stresses, the vast majority of disabled children report feeling happy and well supported by their families (Connors and Stalker, 2003; Wickenden, 2011; Foley *et al*, 2012).

As well as other forms of adversity there is clear evidence that disabled children's overall risk of violence and maltreatment is significantly higher than that of non-disabled children (Jones *et al*, 2012). Moreover, research suggests that maltreatment involving disabled children is particularly likely to go un-recognised and be under-reported (Miller and Brown, 2014). Disabled children are also less likely than other children to be receiving support via a child protection plan (Ofsted, 2012), but more likely to be placed in out-of-home care (Baker, 2007; Kelly *et al*, 2016). This concerning situation therefore justifies this study's focus on the experiences of the minority of disabled children receiving support via child protection processes.

This chapter reviews what is known about how maltreatment involving disabled children is recognised and responded to within child protection systems in the UK and elsewhere. This is in order to contextualise this study's research question concerning disabled children's views and experiences of receiving help and support during and following child protection enquiries. It starts by briefly outlining how child maltreatment is defined and the circumstances under which it is seen as justifying professional intervention into family life. Research specifically linking disability with maltreatment is then reviewed and potential explanations for this association evaluated.

In the second part of the chapter the iCAN framework (ican.uea.ac.uk), for understanding the processes of recognition, telling and help from the child's perspective (Cossar *et al*, 2013), is used to analyse evidence regarding practice responses towards maltreated disabled children. A similar approach was used to review the literature about maltreatment and childhood disability in an earlier article by Hernon *et al* (2015) (Appendix 3). However, the material used here has been updated to reflect changes in Cossar *et al*'s (2013) framework, as well as research published since that time.

Child maltreatment and child protection

As outlined in the preceding chapter, child maltreatment has received increasing attention in the UK and other high-income countries from the 1960s onwards. This has come about partly as a result of growing evidence regarding both the prevalence and adverse consequences of maltreatment for children's long-term health and development (Gilbert *et al*, 2009a). This evidence, and an understanding of children as inherently vulnerable, has been seen as justifying and driving state-legislated intervention into family life through the setting up of child protection systems to protect children from such harm (Daniel, 2010). Social workers in the UK and other countries have a central role in administering and delivering these services in practice. This includes applying thresholds and helping to make decisions, alongside other professionals, as to what constitutes child maltreatment for individual children.

Understanding of what constitutes child maltreatment has developed over time, and continues to be subject to some variation, in a similar way to how debates regarding how disability is defined have evolved. From Kempe's (1962) 'discovery" of battered child syndrome, which focused on parental physical abuse, child maltreatment has generally come to be seen as including "any acts of commission or omission by a parent or another caregiver that result in harm, potential for harm, or threat of harm to a child (usually interpreted as up to 18 years of age), even if the harm is not the intended result" (Gilbert, 2009a).

Maltreatment is widely recognised as encompassing four types of abuse: physical abuse; sexual abuse; emotional or psychological abuse and neglect. Although, children witnessing intimate partner violence is increasingly also considered a form of maltreatment. The Adoption and Children Act (2002), for example, broadened the Children Act (1989) definition of "harm", used to guide child protection enquiries and assessments in England under Section 47 of the Children Act (1989), to:

"Harm means ill-treatment or impairment of health or development, *including for example, impairment suffered from seeing or hearing the ill-treatment of another*" Section 31 (9) Children Act (1989)

Moreover, most policy definitions place an onus on all caregivers to safeguard children from maltreatment, including teachers and childminders (e.g. Working Together, HM Government 2018). In practice, however, parents are responsible for over 80% of child maltreatment, except for sexual abuse, which is mostly perpetrated by non-relatives or extended family members (Gilbert *et al*, 2009a).

There is much less consensus, however, regarding at what level of severity parent or caregivers acts of commission or omission are recognised as maltreatment and as requiring a child protection response. Gilbert *et al* (2009b) found high income countries with a "child-safety" approach (US, most of Canada and Australia), where the child protection services' focus is on investigating/responding to reported maltreatment, had higher referral and substantiated maltreatment rates and lower levels of ongoing service provision than those with a "child and family welfare" approach (UK, Japan, New Zealand, and most European Countries), where child protection enquiries and decision-making processes form part of wider service provision for vulnerable children and their families.

In countries with a child and family welfare approach referrals involving neglect, emotional abuse and exposure to intimate partner violence were also more likely to be viewed as in need of support rather than protection (Gilbert *et al*, 2009b). As well as indicating a higher threshold for child protection intervention, such trends are also suggestive of a different interpretation of the causes of child maltreatment as at least partly related to family stress and/or an accumulation of other difficulties (Thoburn, 2013). A thematic inspection of child protection referrals involving disabled children in England, for example, found evidence of emerging concerns being dealt with effectively at an early stage through multi-agency co-ordination of support as children in need helped negate the need for formal child protection enquiries and intervention (Ofsted, 2012). This was offered as one possible explanation for the relatively low numbers of disabled children identified by this inspection as being the subject of a child protection plan (Ofsted, 2012).

Conversely, other evidence shows higher levels of child protection enquiries and intervention among children exposed to other forms of adversity. Despite more child and family support-oriented policies since the introduction of the Children Act (1989) and as a result of Every Child Matters (2003), Bywaters (2015) found that over 50% of the variation between English Local Authorities in rates of children who have a child protection plan or who are placed in out of home care is explained by comparative deprivation scores. A child living in a city with high rates of poverty, such as Blackpool, for example, is six to eight times more likely to have a child protection plan or to be placed in out-of-home care than one living in an affluent area, such as Richmond Upon Thames (Department of Education, 2013a; 2013b cited in Bywaters *et al*, 2016. Higher rates of poverty among disabled children may therefore partly help explain their greater likelihood of being placed in out-of-home care (Baker, 2007; Kelly *et al*, 2016), despite their apparently lower rates of other types of child protection intervention (Ofsted, 2012).

Evidence linking child maltreatment with other forms of disadvantage, including poverty is persistent, but remains under-researched (Bywaters *et al*, 2016). It has also received less policy attention in high-income countries, including the UK, since the global financial crisis of 2007, resulting in reduced investment in early help services (Gilbert *et al*, 2011), including services for disabled children and their families (Stalker, 2015). This has led some to argue for a social model of "child protection" to be applied to understanding and responding to macro-level structural causes of child maltreatment in a similar way to that developed in relation to disability and disabled people (Lonne *et al*, 2016; Featherstone *et al*, 2018).

Although, reaffirming the need for child protection systems to encompass both protective and supportive responses, the Munro Review of the child protection system in England also called for a rebalancing away from an individually pathologising over-focus on risk towards more preventive child and family-based approaches to child maltreatment (Munro, 2011). Children's internationally legislated rights (UNCRC, 1989) to protection from maltreatment (Article 19), to express their views (Article 12) and to achieve a good quality of life (Article 27), including receiving support to aid their recovery from abuse (Article 39) are likewise seen as crucially interconnected within a children's rights approach to maltreatment (UN Committee on the Rights of the Child, 2003).

All of the issues outlined above have important implications for this study's exploration of social work and child protection practice with disabled children. This is especially given evidence outlined in the previous chapter that they are at higher risk of experiencing poverty (Blackburn *et al*, 2010) and other forms of social exclusion (McLaughlin *et al*, 2012; Beresford and Clarke, 2009), as well as at increased risk of exposure to violence and maltreatment (Jones *et al*, 2012). The research evidence specifically linking disability with maltreatment is discussed in the next section, along with a more detailed exploration of the possible causes for this association.

Disabled children and maltreatment

Disabled children have long been considered at greater risk of violence and maltreatment (Kelly, 1992; Sobsey, 1994; Westcott and Jones, 1999). A substantial body of evidence exists to support this assertion. While estimates vary, Jones *et al* (2012) meta-analysis confirmed Sullivan and Knutson's (2000) earlier work, finding violence and maltreatment to be 3 to 4 times more common among disabled children, with emotional abuse and neglect most prevalent. Several studies indicate that disabled children's risk of maltreatment also varies according to impairment type, with having a mental or intellectual disability, communication impairment or behavioural difficulty being more strongly associated with maltreatment (Sullivan and Knutson, 2000; Spencer *et al*, 2005; Jones *et al*, 2012).

Despite persistent evidence linking disability with maltreatment, the underlying causes for this association are poorly understood. Robust, well-designed studies on this topic are scarce. There are very few population-based studies, with Jones *et al*'s (2012) systematic review and meta-analysis finding only four out of the 17 studies reviewed had adequately controlling for possible confounding factors, such as birth-weight and socio-economic status (Jones *et al*, 2012). Wide variation in how disability and maltreatment are defined also makes comparison across different studies difficult, further contributing to a lack of clarity regarding prevalence rates (Jones *et al*, 2012). Studies also shed little light on the important question of the extent to which disability can be a consequence of, rather than a risk factor for maltreatment (Jones *et al*, 2012). Moreover, scant consideration is given to theoretical perspectives (Leeb *et al*, 2012).

Regardless of the lack of methodologically sound studies, a number of possible explanations for disabled children's increased risk of maltreatment have been proposed. Early theories suggested that disabled children's additional difficulties and support needs potentially triggered maltreatment due to increased parental stress (Ammerman, 1991). Empirical evidence has provided little support for this explanation, however, since severity of disability does not necessary correlate with increased parental stress or risk of maltreatment (Benedict *et al*, 1992; Verdugo *et al* 1995). Nevertheless, Spencer *et al's* (2005), population-based study of 15,8229 children in West Sussex found children with learning difficulties or conduct disorders were 5 and 7 times respectively more likely to have a child protection plan than those without these conditions, which these authors suggested was partly due to a shared etiologic pathway between these conditions and child abuse and neglect.

Later accounts, drawing on transactional-ecological understandings of child development and maltreatment (Cicchetti *et al*, 2000), explain the association between disability and maltreatment as arising from complex interactions between vulnerability factors in the child, their caregivers and the wider environment. At an individual level, the quality of the attachment relationship between a child and his or her carers is seen as promoting or impeding the potential for both development and maltreatment. Howe (2006) argues it is this factor, rather than the presence of disability *per se,* that accounts for increased maltreatment rates among disabled children. This assertion is supported by a meta-analysis of 34 studies on attachment classifications within clinical samples finding lower levels of secure attachments and slightly more disorganised attachments among disabled children (van IJzendoorn *et al*, 1992).

Transactional-ecological perspectives may also help explain evidence of inter-relationships between disability, maltreatment and other forms of disadvantage. For example, numerous studies have identified increased incidence of both disability and maltreatment among children from lower socio-economic backgrounds (Sidebotham *et al*, 2002; Blackburn *et al*, 2010). As discussed, earlier caregivers of disabled children are also more likely to experience social isolation and financial problems, due to higher costs and reduced employment opportunities (Leeb *et al*, 2012). Similar factors have been shown to cumulatively affect maltreatment risk in population-based studies (Stith *et al*, 2009; MacKenzie *et al*, 2011). Moreover, a shift towards a relational, ecological interpretation of child maltreatment reflects similar developments in how disability is understood as affecting children and their family's quality of life, as outlined in the previous chapter (Thomas, 1999; Shakespeare and Watson, 2010).

Interactions between disability and other socio-demographic variables may also help account for the different maltreatment patterns noted among disabled children (Stalker and McArthur, 2012). For example, most evidence puts disabled boys at even higher risk of maltreatment than non-disabled boys (Kvam, 2000), in one study making up 70.3% of maltreated disabled children (Sullivan and Knutson, 2000). Herschkowitz *et al* (2007) also found disabled boys were significantly more likely than disabled girls to experience physical abuse, but less likely to be sexually abused. However, Briggs (2006) found disabled boys were equally likely to experience sexual abuse, but less likely to report it.

Evidence regarding how other factors may influence disabled children's risk of maltreatment is less clear. For example, while Sullivan and Knutson (2000) found maltreatment of disabled children began at earlier ages, Herschkowitz *et al*'s (2007) study found no such variation in maltreatment involving disabled and non-disabled according to age. Similarly, although cultural and religious attitudes towards disability have been shown to affect disabled children's' experiences and life chances (Danseco, 1997; United Nations, 2006), most research indicates no differences in maltreatment and disability rates between different races (Gourdine, 2013), though there is a noticeable lack of majority world studies. However, one American study found maltreatment rates among disabled children were significantly higher among white children than Hispanic children and those from other ethnic minority backgrounds (Jaudes and Mackey-Bilaver, 2008).

Westcott and Jones (1999) argue that growing up disabled in a society which places value on being able-bodied and discriminates against disabled people, as highlighted by social models of disability, may contribute to disabled children's increased risk of maltreatment. Since, partly as a result of these attitudes, disabled children are more likely to experience physical and social isolation (including institutional care) and have less control over their lives and bodies than those without disabilities. Negative societal attitudes towards disabled children may also help to explain evidence indicating that maltreatment involving disabled children tends to be more severe (Sullivan and Knuston, 2000; Kvam, 2004), is often more violent (Akbas *et al*, 2009), and is more likely to involve multiple forms and recurrent episodes of abuse than that involving non-disabled children (Sullivan and Knutson, 2000). This explanation is also further supported by research finding that disabled adults are also at elevated risk of experiencing violence and maltreatment compared to adults without disabilities (Jones *et al*, 2012).

It therefore seems reasonable to conclude from the evidence reviewed above, that disability represents an important risk factor for maltreatment. However, reliable evidence regarding the precise nature of this association is lacking, and its underlying causes are understood to be both complex and variable (Stalker and McArthur, 2012; Leeb *et al*, 2012). Nevertheless, maltreatment of disabled children represents a significant public health concern. This is especially given the devastating consequences of maltreatment for children's health and development. These include child mortality and morbidity, enduring effects on mental health, and increased risk of substance mis-use, risky sexual behaviour, obesity and criminal behaviour continuing into adulthood (Gilbert *et al*, 2009a). Moreover, research indicates that the risks to children's health and development are greatest where maltreatment involves multiple types and repeated exposure (Glaser, 2000; Lee and Hoaken, 2007), as is more often the case among disabled children (Sullivan and Knutson, 2000).

Recognising and Responding to the Maltreatment of Disabled Children

Given that disabled children are at greater risk of maltreatment, recognising and responding to maltreatment involving disabled children should be a priority. Disabled children have the same rights to protection and to receive support as other children under the United Nations Convention on the Rights of the Child (UNCRC, 1989) as well as under Section 47 of the Children Act (1989) in England and similar legislation in other parts of the UK. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) reinforces states' responsibilities to provide for disabled children's additional needs in sustaining their equal rights, including the right to express their views (Article 7) and that of protection (Article 16). Disabled children are specifically identified as a group of children in additional need of support and services under Section 17 (c) of the Children Act (1989). However, despite this legislative rhetoric the overlap between disability and maltreatment has received relatively little attention in policy and research (Mikton *et al*, 2014).

Successive reviews have identified areas of concern in relation to child protection practice with disabled children in the UK (Morris, 1998; Cooke and Standen, 2002; Stalker, *et al*, 2010; Ofsted, 2012; Taylor *et al*, 2016). Stalker *et al* (2010) concluded that disabled children were 'almost invisible' within mainstream child protection policies in the 4 UK countries and that recording practices regarding cases of maltreatment involving disabled children were poor. Although the issuing of specific practice guidance "Safeguarding disabled children" (Murray and Osbourne, 2009) in England was generally welcomed (Miller and Brown, 2014), it illustrates a continued tendency for childhood disability to be regarded as a separate policy issue (Stalker, 2012). Munro's comprehensive review of the child protection system in England and Wales (Munro, 2011), following Peter Conolly's death, likewise made no reference to disabled children's increased risk of maltreatment.

Taylor *et al* (2016) concluded that "there has been very little research conducted on child protection and disabled children in Britain over the last decade" (p. 62). Similar statements were also made by Morris in 1998, Cooke and Standen in 2002 and Stalker and McArthur in 2012, reflecting the long-standing dearth of research on this topic. Stalker and McArthur's (2012) review highlighted a particular lack of knowledge regarding disabled children and young people's own perspectives of their experiences during child protection enquiries and their aftermath.

There have been some studies published since 2012 whose findings are discussed in detail later in this review. The majority of these have been small-scale qualitative studies, involving case file analysis and interviews or focus groups with practitioners and other adult stakeholders (Ofsted, 2012; Taylor *et al*, 2014; Kelly and Dowling, 2015). The notable exception being Kelly *et al's* (2016) mixed methods study of the characteristics and experiences of disabled children in out-of-home care in Northern Ireland. This study involved quantitative analysis of the characteristics and circumstances of all disabled children placed in out-of-home care compared with their non-disabled peers (n=323). It also included 15 qualitative case studies involving case file analysis and interviews with disabled children, their caregivers and social workers.

Studies focusing on disabled children's perspectives of maltreatment have also been conducted by Shah *et al* (2016) (n=15, 18-65 years), Jones *et al*, (2017) (n=10, 12-51 years), and Franklin *et al* (2015; 2018), (n=27, 12-23 years). These study's findings are limited by their small sample size and self-selection being used to recruit participants, who consequently may be more likely to have pre-existing interest in the study's aims. Moreover, two of the studies draw primarily on disabled adults' retrospective accounts of maltreatment experienced during their childhoods, and the third focuses on learning disabled children and young adult's experiences of a particular form of maltreatment (child sexual exploitation). Despite the valuable addition that these studies represent, research relating to how disabled children's fare within child protection processes is generally scarce, underlining the important contribution to knowledge made by this study's findings.

The remainder of this chapter applies the iCAN (Child Abuse and Neglect) framework for understanding recognition, telling and help from children's perspectives about maltreatment, to the literature concerning disabled children and their experiences of maltreatment and receiving help during child protection processes. Particular attention is paid to research indicating specific barriers as well as possible enablers to maltreatment involving disabled children being identified and reported and their equal right to protection and support being upheld. It is important to acknowledge, however, in interpreting the findings of this review that disabled children's heterogeneity (Watson, 2012) means that their experiences of maltreatment and receiving help are likely to be as complex and varied as those described by non-disabled children. Areas where further research is indicated are also identified.

Recognising and responding to maltreatment: The child's perspective

From a children's rights perspective, understanding what children say helps them is essential for improving their access to support and protection, and for remaining focused on outcomes for the child (Munro, 2011). The iCAN framework is based on Cossar *et al*'s (2013) research for the Office of the Children's Commission in England, exploring how the processes of recognising and telling about maltreatment and receiving help are experienced from the child's point of view. Their study consisted of a structured literature review, content analysis of an online peer support website, in-depth qualitative interviews with thirty young people aged 11-20 at risk of maltreatment, and six focus groups with young people, parents, and practitioners.

The findings were used to develop a conceptual framework, to help practitioners understand both the barriers children face in recognising maltreatment and talking about it, but also how the responses children receive can promote or hinder their capacity to tell someone about maltreatment and access help (Cossar, *et al* 2013). This framework, which has since been developed into the iCAN framework, is represented in Figure 4.

Figure 4: iCAN Framework (http://www.uea.ac.uk/ican/the-framework)

The iCAN framework seems particularly relevant for disabled children given they are at greater risk of maltreatment (Jones *et al*, 2012) and that maltreatment involving disabled children is particularly likely to be under-recognised and under-reported (Cooke and Standen, 2002; Ofsted, 2012). Contributing to this under-reporting is evidence that disabled children themselves are less likely to report maltreatment (Herschkowitz *et al*, 2007). Practitioners' also tend to disregard disabled children's accounts (Kvam, 2004) or wrongly attribute signs of maltreatment to children's impairments (Brandon *et al*, 2011), contributing to maltreatment involving disabled children remaining undetected.

Recognition

The iCAN framework, based on Cossar *et al's* (2013) research, identifies recognition of maltreatment along a spectrum, from 'no recognition' to 'clear recognition', with many children describing their understanding as beginning with an emotional awareness that things were not right ('partial recognition'). Recognition was often gradual, and it was not the case that children first recognised their maltreatment, then told about it, and then received help. Sometimes children recognised maltreatment only after receiving help. Barriers to recognising maltreatment included children feeling they deserved it; difficulty acknowledging adults, particularly parents, as abusive (especially where relationships were sometimes good); confusion about boundaries between discipline and physical abuse and differences between appropriate and inappropriate touching in relation to sexual abuse (Cossar *et al*, 2013). Children found recognising emotional abuse or neglect especially difficult (Cossar *et al*, 2013).

No recognition

Research suggests that these barriers may be especially challenging for some disabled children. For example, many disabled young people in Connors and Stalker's (2007) research had experienced others making them feel different or of lesser value because of their impairments. In the context of maltreatment, the negative messages some disabled children may have internalised about their impairments could make it more likely that they would see themselves as to blame for the abuse. Moore's (2009) finding that disabled children commonly internalised their feelings or had low self-esteem as a result of being bullied at school, further supports this idea.

Disabled children's impairments mean that their relationships with parents and caregivers are often more complex. Disabled children are more likely to have insecure attachment relationships with their caregivers (Howe, 2006). For example, van IJzendoorn *et al's* (1992) meta-analysis of eight studies, including studies with children with a wide range of impairments, found rates of secure attachment were generally lower among disabled children (less than 50%) than those without disabilities (around 65%). They also found slightly higher rates of disorganized attachments among disabled children than those without disabilities. Disabled children's increased risk of insecure attachments may, in itself, make it more difficult for them to recognise abuse due to a reduced awareness of healthy relationship boundaries and poorly developed sense of self (Howe, 2005). Many disabled children on the other hand report particularly strong bonds with their caregivers due to their increased dependence on them (Abbott and Carpenter, 2010; Mitchell and Sloper, 2011). Feeling guilty about the additional demands their impairment needs place on their caregivers, may nevertheless also make it harder for them to recognise or acknowledge abuse.

Research suggests these difficulties recognising maltreatment may also apply to disabled children's other relationships with adults, such as personal assistants and professionals. One disabled young woman in Shah *et al* 's study (2016), for example, spoke about being in a coercive and sexually abusive relationship with her support worker from the age of 13 but being unable to recognise this at the time:

"I was in a relationship with someone who I believed at the time was trying to be protective of me … now I realise it was just someone trying to control what I was doing" (Shah *et al*, 2016, p.530).

Other participants in Shah *et al* study (2016) likewise felt their young age and relatively powerless position in relation to authority figures such as teachers or assistants had prevented them from understanding what they were experiencing as abuse.

Disabled children's impairments, and how these affect their care or development, may also contribute to their feeling confused about what constitutes maltreatment. For example, differentiating between appropriate and inappropriate touch may be more challenging for disabled children who have always relied on others for intimate care; who may have become accustomed to allowing others' unrestricted access to their bodies; or they may be physically less able to stop abuse from happening (Murray and Osborne, 2009). Cognitive impairments or autism can also affect children's emotional development and ability to understand appropriate boundaries. Smeaton *et al* (2015) found that young people's ability to recognise others' behaviour as sexually exploitative was affected by their learning disabilities as well as a lack of understanding about sex.

Disabled children's reduced access to social networks and friendships may likewise affect their ability to recognise maltreatment. For example, as a result of attending special schools a considerable distance from their homes (Watson *et al*, 2000); being placed in segregated classes within mainstream education (Ytterhus, 2012); having mobility difficulties or parents' and professionals' over-protective attitudes towards them because of their impairments (Kelly, 2005; Franklin *et al*, 2015). Reduced opportunities to visit or spend time with friends, limits disabled children's possibilities for comparing their situations and families with those of others', which Cossar *et al* (2013) identified as central to children's ability to recognise maltreatment.

Studies have identified disabled children's lack of access to information as an important barrier to their ability to recognise maltreatment. Deaf children and children with communication difficulties may lack access to information and vocabulary about sex and healthy relationships, which may consequently limit their understanding of and ability to communicate about maltreatment (Jones *et al*, 2017). Disabled young people in several studies also report a general lack of attention to sex and relationships education, especially within special schools, as inhibiting their understanding of sex, what represents abuse and how to recognise exploitation within relationships (Smeaton, *et al*, 2015; Shah, 2016; Jones, *et al*, 2017).

All these factors contribute to disabled children being less able to recognise maltreatment and can lead to them being targeted by perpetrators (Westcott and Jones, 1999). Disabled young people in studies by Jones *et al* (2017) and Shah (2016) reported that having few friends increased their vulnerability to forming inappropriate relationships with adults but also reduced their ability to recognise these relationships as abusive. Moreover, they reported that these relationships tended not to be questioned by peers or family members. Smeaton *et al* (2015) similarly found that the lack of exposure to social relationships and environments of young people with learning disabilities increased their susceptibility to online grooming and sexual exploitation.

Partial or clear recognition

Despite these barriers Shah *et al* (2016) and Jones *et al* (2017) found many examples where disabled children had been able to partially or clearly recognise their experiences as maltreatment. Although, as in Cossar *et al*, 2013 study, several participants described their awareness of abuse as having developed gradually over a long period of time. Disabled children in Jones *et al* study (2017) also identified adults' ability to detect and talk to them about abuse as having been important in enabling their own understanding of maltreatment to develop.

Disabled children in Shah *et al*'s (2016) and Jones *et al*'s (2017) studies also described recognising and resisting abusive behaviours or situations without adult assistance. Four participants in Jones *et al's* (2017) study, for example, reported leaving home in late adolescence in order to stop the abuse from happening. Though representing important evidence of disabled children's agency, as these authors point out, these examples also raise moral questions about the onus placed on disabled children to recognise maltreatment and act to protect themselves due to inadequate adult support and surveillance (Jones *et al*, 2017).

Telling

Cossar *et al* (2013) identified a similar spectrum related to telling, ranging from: maltreatment remaining 'hidden'; being indicated by 'signs and symptoms' in children's behaviour or presentation; through to children's 'prompted telling' (through another person persisting in enquiring about their welfare); and 'purposeful telling' about maltreatment (the child sought someone out to tell about the abuse). The first two categories, 'hidden', where the child may be actively denying maltreatment or is showing 'signs and symptoms' of maltreatment, do not require that the child him or herself recognises the maltreatment. Even where children recognised what was happening was wrong, they experienced many barriers to telling. These included: fear of consequences or of not being believed; struggling to find or express the right words; feeling ashamed or embarrassed; worrying about the impact on family relationships; or being threatened by their abuser (Cossar *et al*, 2013).

Hidden

Evidence suggests that maltreatment involving disabled children is more likely to remain hidden than that involving non-disabled children. Jones *et al* (2017), for example, report that shame or confusion about what constitutes maltreatment inhibited parents from reporting extra-familial abuse involving their disabled child to professionals. As a result of these factors seven of the ten participants in this study reported that their abuse had remained hidden during their childhoods, despite being severe and long-standing. Smeaton *et al* (2015) similarly found that adults, including professionals, were not proactive in identifying potential signs of child sexual exploitation among children with learning disabilities and autism.

Moreover, studies have found higher thresholds for child protection enquiries and intervention are sometimes applied to disabled children by professionals (Ofsted, 2012). Practitioners in Taylor *et al's* (2014) study reported that "a wee bit of neglect" was more likely to be tolerated in cases involving disabled children, due to over-empathising with parents due to the additional stress of caring for a disabled child. Brandon *et al's* (2011) analysis of serious case reviews identified similar instances of agencies accepting a different or lower standard of care for disabled children than their non-disabled peers.

Signs and symptoms

Disabled children's particular difficulties recognising maltreatment also increases the need for practitioners to be alert to possible signs that they are being abused. However, practitioners' lack of confidence and skills working with disabled children may contribute to them mis-attributing signs and symptoms of maltreatment to children's impairments (Taylor *et al*, 2014; Prynault-Jones *et al*, 2017). Analysis of practice in a sample of serious case reviews identified instances of bruising being implausibly accepted as related to children's impairments and practitioners failing to adequately scrutinise alternative explanations. This tendency to "see the disability, not the child" resulted in maltreatment involving disabled children being missed (Brandon *et al*, 2011). While there are occasionally instances where maltreatment is wrongly suspected when the issue is the impairment, for example fractures in osteogenesis imperfecta (Hibbard and Desch, 2007), it is worrying that fear of getting it wrong can deter practitioners from acting on concerns for disabled children (Taylor *et al*, 2014).

Given the barriers disabled children often face verbalising their experiences due to their impairments, behaviour seems likely to be a particularly important way of communicating about maltreatment among this group of children (Murray and Osbourne, 2009). However, practitioners report particular difficulties interpreting changes in disabled children's behaviour that might indicate maltreatment (Orelove *et al*, 2000; Cooke and Standen, 2002). Smeaton *et al* (2015) identified practitioners' lack of understanding of child sexual exploitation, learning disabilities and autism as contributing to disabled children's behaviour being viewed as "difficult to manage" rather than as a strategy for masking their vulnerability or a sign they were being exploited. Participants in Jones *et al's* (2017) study similarly described their frustration that their challenging or distressed behaviour, including one young person attempting suicide aged 9, was not interpreted by professionals as a possible sign of abuse.

Prompted telling

Disabled children have the same rights as all children to express their concerns, whether directly or through their behaviour, and for those concerns to be taken seriously (Article 12, UNCRC, 1989). Jones *et al* (2017) and Franklin and Smeaton (2018) found that adult's capacity to provide supportive opportunities to listen was crucial to prompting disabled children to open up about abuse. They also stress the importance of adults being approachable and willing to listen as encouraging them to share worries and concerns (Jones *et al*, 2017).

Moreover, as in Cossar *et al's* (2013) study, where disabled children in these studies shared concern about maltreatment this was usually in the context of supportive relationships built over a long period of time. However, practitioners report generally feeling ill-equipped to facilitate disclosures of maltreatment by disabled children, particularly those with communication and learning impairments (Cooke and Standen, 2002; Taylor *et al*, 2014). Disabled children themselves also report that adults, including professionals, often do not ask them about their experiences of risk or of relationships (Franklin and Smeaton, 2018).

Purposeful telling

Many of the factors contributing to disabled children's difficulties in recognising maltreatment may also affect their capacity to tell someone about their experiences. For example, disabled children's opportunities to spend time with their peers may be limited by their impairment needs, meaning that they may be less likely to have a trusted friend or adult to talk to about their problems. Studies in Australia and Norway highlight how this is particularly true of children with complex communication impairments (Raghavendra *et al*, 2013), and learning difficulties (Ytterus, 2012). Moreover, assistive tools for children who communicate non-verbally not including vocabulary relating to intimate and inappropriate acts may reduce these children's ability to talk about possible abuse (Murray and Osbourne, 2009). Conversely, Deaf participants in Jones *et al* (2017) study identified having consistent access to registered interpreters as an important enabler to their disclosing abuse.

Disclosing maltreatment may also involve greater risks for children who are physically or emotionally dependent on their abuser (NSPCC, 2003). Participants in studies conducted by Shah *et al* (2016) and Smeaton *et al* (2015) described being threatened not to tell by their abuser and feared getting into trouble. One young woman described delaying disclosing abuse for several years because she feared being left without support to meet her complex impairment-related needs. Participants in Jones *et al's* study (2017) similarly reported not being believed by professionals' or being blamed by family members when they did disclose abuse. Consequently, of 13 disclosures made by these participants in childhood only two reportedly resulted in the abuse being stopped.

Other studies have highlighted similar concerns that disablist attitudes may prevent disabled children's disclosures of abuse from being taken seriously. These include myths, such as, "these children won't understand what's happened, therefore won't be damaged by it" (Kennedy, 1992, p.186). Kvam's (2004) retrospective study of 302 deaf adults in Norway found 10% of those who reported being sexually abused as children were not believed. Disabled children in Herschowitz *et al's* (2007) study likewise reported delaying disclosing abuse for fear that they would not be believed.

Inspection and research reports nevertheless report finding that a wide range of professionals do identify and appropriately refer concerns for disabled children (Ofsted, 2012; Taylor *et al*, 2014). Numerous studies have likewise evidenced disabled children's capacity for agency (Watson *et al*, 2000; Connors and Stalker, 2003), including research with young people with cognitive and communication impairments (Kelly, 2005; Wickenden, 2011) and concerning their experiences of abuse (Shah *et al* 2016; Jones *et al*, 2017). Direct disclosure by disabled children themselves triggered most of the child protection enquiries in the Scottish cases examined by Taylor *et al* (2014), for example, leading these authors to conclude that the numbers of disabled children who lack the capacity to recognise and communicate about maltreatment may be overstated by practitioners. All of which underlines the onus on practitioners to develop the communication skills and child protection knowledge required to listen and act on disabled children's concerns about abuse, rather than relying on children's capacity to report it themselves (Brandon *et al*, 2011; Jones *et al*, 2017).

Help

Children's accounts of receiving help in relation to maltreatment in Cossar *et al's* (2013) study ranged from no help; help provided to address symptoms of maltreatment as indicated by children's behaviour or distress (often without the maltreatment underlying these problems being recognised or addressed); to help being received to address the causes of maltreatment (for example via child protection enquiries and decision-making processes, including the young person being placed in out-of-home care). Practitioners' availability and reliability was considered important in determining the quality of help received by children in Cossar *et al* (2013) study. Children who had experienced child protection enquiries valued access to clear information and being listened to and involved in decision-making but disliked having too many professionals involved, or being interrogated as a source of evidence (Cossar *et al*, 2011).

No help

Disabled children have the same rights to access these helping processes as non-disabled children. Yet, evidence suggests that, in practice disabled children's access to these services and relationships with helping professionals may not be the same as those without disabilities. Learning disabled children and young adults in Smeaton *et al's* study (2015), who had been sexually exploited, commonly said they lacked information about who they could turn to for help with concerns about their safety. Participants in Jones *et al's* (2017) study reported routinely coming into contact with numerous professionals, including social workers, teachers and health professionals. However, in only a small minority of cases were concerns for their welfare detected by these professionals, or help sought from those working with them by the disabled child or young person themselves.

Other evidence suggests maltreatment involving disabled children is far less likely to result in child protection enquiries and intervention than that involving non-disabled children. Although data is not routinely reported regarding the disability status of children subject to child protection plans, according to the Child in Need Census only 3.8% of children receiving support via child protection plans in England and Wales in

2011 were reported as having a disability (Department for Education, 2011), despite making up between 7-8% of children in the general population (Office for National Statistics 2017). Moreover, an earlier study by Cooke and Standen (2002) found that disabled children were significantly less likely to have a child protection plan following child protection conferences than were non-disabled children (54% vs 82%).

Disabled children's experiences within child protection processes also appear to differ from that of non-disabled children in other ways. Successive reviews have found that disabled children are less likely to be spoken to during child protection enquiries (Cooke and Standen, 2002; NSPCC, 2003; Ofsted, 2012). Studies by Taylor *et al* (2014) and Prynault-Jones *et al* (2017) found that practitioners often struggle to adapt child protection procedures and decision-making processes to meet disabled children's needs. Frontline practitioners often lack necessary skills for communicating with disabled children, however arrangements to involve professionals with appropriate expertise are *ad hoc*. Practitioners' difficulties related to engaging with disabled children can lead to an over-reliance on parents' views, meaning children's own views regarding their need for help and support are frequently overlooked (Brandon *et al*, 2011; Prynault-Jones *et al* 2017).

Help related to symptoms

As previously discussed, disabled children's physical, emotional or behavioural needs are much more likely to be attributed to their impairments than viewed as symptomatic of maltreatment (Brandon *et al*, 2011). This increases the likelihood that the underlying causes of maltreatment will remain hidden. Ofsted's (2012) inspection of child protection practice with disabled children in England, for example, identified "too many" cases where social workers had failed to detect child protection concerns among children already receiving support from children in need services. Disabled children in studies by Jones *et al* (2017) and Shah *et al* (2016) similarly reported a tendency for their emotional distress to be viewed by professionals as a mental health issue or related to their impairments rather than linked to maltreatment. One young woman in Shah *et al*'s (2016) study commented that her G.P. "spent all the time blaming it on my meds, implying I was a bit paranoid. I wasn't really. But you know they were saying "these are all the symptoms of this" ... trying to find a medical reason for it" (p. 531).

Even where maltreatment involving disabled children is recognised, similar concerns have been raised that a medical or impairment-centred approach continues to influence how professionals respond. Cooke and Standen (2002) found disabled children were more likely to undergo medical examination and/or treatment during child protection enquiries than were non-disabled children in the cases they examined. Manders and Stoneman's (2009) study similarly found that child protection workers in the US were more likely to view disabled children in case vignettes as having characteristics that had contributed to the maltreatment.

Other studies have highlighted the additional complexity often involved in differentiating between signs and symptoms of family stress related to the child's impairment needs and that indicating maltreatment. Caregivers of disabled children commonly report struggling to cope with meeting their child's impairment needs due to a lack of family and other support (Mencap, 2016). Moreover, this is often viewed as core contributory factor in cases where neglect or emotional abuse is suspected. Kelly *et al*'s (2016) quantitative analysis of disabled children in out-of-home care in Northern Ireland (n=323), found that although neglect was cited as the main reason for disabled children coming into care in 70% of cases, parents not coping was also a factor in over half of cases (53%), and in a further 19% of cases the child was considered to be beyond parental control. Consequently, practitioners' report having to make finely balanced decisions between providing intensive family support to enable disabled children to remain in their family's care and intervening to protect them (Kelly and Dowling, 2015; Taylor *et al*, 2016).

Help related to causes

The complex relationships between children's impairment needs, family stress and maltreatment mean that it is not always possible to clearly distinguish whether help is being provided to alleviate the "symptoms" or the "causes" of maltreatment. The policy emphasis on providing early help via short break services potentially blinds practitioners to possible maltreatment involving disabled children (Ofsted, 2012). Equally, a lack of sufficient support to meet disabled children's impairment needs, especially in financially straightened times (Stalker *et al*, 2015), itself appears to increase the risk of maltreatment as a result of the family reaching crisis point (Kelly and Dowling, 2015).

Both these factors appear to affect professional responses to the underlying causes of maltreatment involving disabled children. Analysis of serious case reviews identified a number of specific risk factors relating to disabled children (Sidebotham, *et al*, 2016). These include parental stress related to children's impairment needs and professionals' over-estimating parents' ability to cope, as well as parents' deflecting attention away from safeguarding concerns, professionals' misattributing signs of maltreatment to children's impairments and being less skilled in directly communicating with disabled children, and children themselves being less able to report abuse (Sidebotham, *et al*, 2016).

Taylor *et al* (2016) and Kelly and Dowling (2015) each suggest that the particular challenges practitioners face balancing family support with the protection of disabled children underlines the importance of maintaining a focus on understanding children's needs and experiences. It is therefore encouraging that Ofsted's (2012) inspection of child protection cases involving disabled children identified several examples where disabled children's views had been successfully included in assessments. Practitioners in Taylor *et al* (2014) study similarly identified examples of child protection processes being successfully adapted to obtain disabled children's accounts.

However, even where maltreatment involving disabled children is recognised and more serious cases referred to the criminal justice system, disabled children's evidence tended to be regarded as unreliable by police or prosecutors. For example, none of the 21 practitioners who took part in Taylor *et al*'s (2014) study was able to recall child protection enquiries involving the abuse of a disabled child that had resulted in a successful criminal prosecution of the alleged perpetrator. While these practitioners reported that adequate steps had been taken to protect these disabled children from abuse, a lack of access to criminal justice is disempowering, and may affect children's willingness to report future concerns and access help (Cossar *et al*, 2013).

Likewise, although Ofsted (2012) found that most disabled children with child protection plans made good progress, these plans lacked a focus on outcomes for the child, and advocacy services were rarely used to help understand disabled children's own perspectives of their support needs. Mikton *et al*'s (2014) systematic review identified a lack of research regarding the effectiveness of interventions to prevent and respond to violence and maltreatment involving disabled people. None of the interventions evaluated by the ten studies they identified was judged to be effective once risk of bias was taken into account, and the majority of studies (8 out of ten) focused on preventing violence and maltreatment against disabled adults rather than children. Evidence is also lacking regarding the factors associated with the development of resilience among disabled children (Hart, *et al*, 2014). This is especially concerning given evidence that disabled children generally experience poorer long-term outcomes relating to health, educational attainment and social and economic inclusion than their non-disabled peers (Hart *et al*, 2014).

Taylor *et al* (2014) highlighted a shortage of suitably trained foster-carers as adversely affecting child protection practice with disabled children. In one of the cases they examined, this had delayed a disabled child being removed from a risky family situation. Similar concerns were noted in Kelly and Dowling's (2015) scoping exercise of child protection services for disabled children in Northern Ireland. Moreover, although some (n=6) of the disabled children in out-of-home care in Kelly *et al's* (2016) study had good relationships with their foster-carers and were in long term placements, the majority (9 out of 15) reported experiencing multiple changes of placement, which was understandably a significant source of distress for these children.

This, and previous studies have highlighted that disabled children are more likely to experience multiple changes of placements and to be placed in residential care (Baker, 2007; Kelly, *et al*, 2016). This is especially concerning given research indicating that instability experienced within the care system may compound children's trauma following maltreatment and separation from birth parents and increase their vulnerability to developing mental health difficulties (McNicholls *et al*, 2011), particularly among those who are older on entering care, and are placed in residential placements and/or have intellectual disabilities (Tarren-Sweeney, 2008). [repeated content cut]. This situation highlights the need for greater attention to and monitoring of placement type, stability and outcomes experienced by disabled children entering care, whether as a result of maltreatment or the cumulative effects of family stress (Baker, 2007; Kelly *et al*, 2016).

Relatedly, disabled children have an equal right to help to recover from maltreatment and to achieve their potential (UNCRPD, 2006) and yet, evidence suggests that maltreated disabled children's access to services to meet these needs is also unequal. Cooke and Standen (2002), for example found that disabled children were less likely to be referred for therapeutic support following substantiated maltreatment. Kelly *et al* (2016) similarly found that despite high levels of mental health need among disabled children in out-of-home care, very few children in their study were receiving counselling or therapeutic support. Practitioners report that strict eligibility criteria for mental health and specialist disability services meant this support was often unavailable, and that they themselves lacked specialist skills and knowledge to help aid disabled children's recovery from abuse (Kelly *et al*, 2016).

Conclusion

Disabled children have the same rights as all children to be protected from maltreatment, to express themselves and to have their concerns listened to and appropriately acted upon during child protection enquiries and decision-making processes (UNCRC, 1989; UNCRPD, 2006). However, evidence suggests that disabled children's access to support and help at all stages of the child protection process in the UK is at best inconsistent (Cooke and Standen, 2002; Ofsted, 2012; Taylor *et al*, 2016). Research has highlighted that recognising and responding to maltreatment involving disabled children is often more complex, time consuming and frequently involves more finely balanced decisions between protection and family support and long-term commitment of resources than that concerning non-disabled children (Kelly and Dowling, 2015; Taylor *et al*, 2016).

This complexity, Taylor *et al* (2014) suggest, points to the need to review services provided to disabled children during and following child protection enquiries to ensure they are appropriate to their needs. Their suggestions include adapting child protection conferences to include disabled children and increasing the number of foster carers able to provide placements for disabled children. These recommendations are particularly important in light of other evidence that disabled children are over-represented among children in out-of-home care and also experience higher levels of placement instability than non-disabled children in care (Baker, 2007; Kelly *et al*, 2016). The lack of evidence regarding effective interventions to prevent and respond to maltreatment involving disabled children also represents an important direction for future research (Mikton, *et al*, 2014).

Studies regarding children’s own perspectives of maltreatment have shown the crucial need to understand their experiences in order to improve child protection practice with disabled children (Smeaton *et al*, 2015; Shah *et al*, 2016; Jones *et al*, 2017). However, research on this topic remains scarce. Moreover, two of the four studies cited, (Jones *et al*, 2017; Shah *et al*, 2016), although UK based, drew primarily on disabled adults retrospective accounts of maltreatment during their childhoods up to 20-30 years previously. These studies therefore have very limited ability to shed light on how the considerable policy changes during the intervening period might have impacted child protection practice with disabled children. This underlines the pressing need for research, such as that explored in this dissertation, exploring disabled young people’s perspectives of child protection processes while they are still children and actively receiving support from children’s social care.

Chapter 3 - The voice of the (disabled) young person within child protection processes

Introduction

The preceding chapter reviewed evidence for disabled children's increased risk of maltreatment and how their needs are met within child protection processes. Disabled children have the same rights to express their concerns about maltreatment and have these taken seriously during child protection enquiries (UNCRC,1989). This is important to disabled young people themselves (Jones *et al*, 2017; Franklin and Smeaton, 2018), and is crucial to keeping them safe (Munro, 2011; Working Together, HM Government 2018). Research suggests that disabled children's opportunities for their maltreatment to be recognised and responded to are fewer and less robust than those afforded to other children, despite their additional vulnerability and greater need for family support (Kelly and Dowling, 2015; Taylor *et al*, 2016).

Children's right to participate in all decisions affecting their lives is also a core right within the United Nations Convention of the Rights of the child (Article 12, UNCRC, 1989), alongside the right to protection and the provision of support (Reading *et al*, 2009). This is especially important during child protection procedures, given that the decisions made can dramatically alter the course of children's lives, resulting, for example, in their being placed in out-of-home care. Disabled children's right, in view of their impairment needs, to receive information and communicate their views in a variety of forms in order to take part in decision-making processes is specifically addressed by Article 13 of the UNCRC (1989) and practice guidance to the Children Act (Department for Education, 1991).

Despite this policy rhetoric what represents an appropriate level of involvement for an individual child in various types of decision-making has been the source of considerable debate. These debates, influenced by the differing ideas about children and childhood outlined in chapter 1, are summarised in the first part of this chapter, before moving on to review the evidence regarding how children's right to be involved in decision-making is upheld within social work practice. This provides important background to this study's research question concerning disabled children's experiences of taking part in child protection decision-making processes. However, in the absence of studies focusing on disabled children's own views of their participation in child protection enquiries and decision-making processes (Stalker and McArthur, 2012), research concerning non-disabled children's views about their involvement in child protection decision-making is first reviewed, and the insights gained applied to what is known about disabled children's participation in other decision-making processes.

What is participation and why is it important for disabled children?

Participation is a broad term which potentially refers to children's involvement in many different types and levels of activity. It can involve children contributing to decisions that affect them individually or as a group, for example, where children contribute to service planning at a local or national level. However, like disability and maltreatment, what constitutes children's participation is neither straightforward nor easily defined (Sinclair, 2004). Nonetheless, attempting to pin down what participation means in any given context would appear to be especially important for disabled children given Kirby *et al's* (2003) statement that:

> "*Participation is a multi-layered concept whose complexity needs to be understood and applied if participation is to be inclusive of all young people and in all decision-making*"
>
> Kirby, *et al* 2003, p. 3.

As already touched on in chapter 1, there have been a number of different drivers towards the increased policy and practice emphasis on children's rights and participation from the 1990s onwards (Sinclair, 2004). These include theory and research highlighting children's competence and capacity to influence the course of their own lives (Prout and James, 1998; Alderson, 1993); increased policy emphasis on service users' involvement in planning and delivering services; and political campaigning by marginalised groups, including disabled people (Mitchell and Sloper, 2011). The most important development for children's participation in decision-making has been the UNCRC (1989), especially Articles 12 and 13, although other legislative and policy changes affecting children's social care such as the Children Act (1989), Children Act (2004), Every Child Matters (2003) and Working Together (HM Government 2010) have also been influential. In addition, the Mental Capacity Act (2005) has also been important for decision-making involving young people over 16 (Franklin and Sloper, 2009).

Although children's participation potentially serves a wide range of different purposes, these are often grouped into legal, political or social reasons (McNeish and Newman, 2002; Willow, 2002). Sinclair and Franklin (2000, p.1), usefully summarise the aims of children's participation as being important to uphold children's rights; fulfil legal responsibilities; improve services; improve decision-making; enhance democratic processes; promote children's protection; enhance children's skills; empower children and enhance their self-esteem. This highlights the diverse impacts that children's participation can potentially have on improving services and the functioning of society, as well as promoting children's individual welfare and active citizenship (Sinclair, 2004).

It is also important to acknowledge that children's involvement in individual and strategic decision-making are not unconnected (Willow *et al*, 2004), particularly in view of disabled children's high levels of service use and their increased risk of social exclusion (Franklin and Sloper, 2009). However, given this study's focus on disabled children's participation during child protection enquiries and decision-making, children's involvement in decisions affecting their own lives necessarily forms the basis of discussion here.

The types of decision that children can be potentially involved in within their own lives is also very broad. These can range from making informal everyday decisions about their daily routine to being involved in formal decision-making, such as when parents separate and cannot agree where and with whom children should live (Thomas, 2012). Moreover, children having regular opportunities to participate in informal decision-making is essential to promoting their ability to participate in formal decision-making in a meaningful way (Sinclair, 2004). This is especially important for disabled children given the additional barriers they face participating and being included in other areas of their lives (Franklin and Sloper, 2009; Raghavendra *et al*, 2012).

Typologies of children's participation

Children's level of participation in formal decision-making likewise differs, depending on the degree to which children share power and influence over decision-making with adults (Kirby *et al*, 2003). Various typologies have attempted to categorise and capture children's differing experiences of participation, which is seen as ranging along a continuum with different levels, usually arranged hierarchically. There is little agreement as to at what “level” of involvement children can be thought of as having ‘participated’, and the term’s precise meaning is often contested (Lansdown, 2010). Most typologies differentiate between consultation, defined as children simply being given information and being asked their views, and more active forms of participation, where children “have reason to believe that their involvement will make a difference” (Sinclair 2004, p. 111). More active forms of participation are viewed as necessarily involving children sharing influence or power over the outcomes of decisions with adults, rather than simply being consulted during the process with adults deciding whether or not children’s views are taken into account.

Among typologies of children’s participation, Hart’s (Hart, 1997) ‘Ladder of participation’ (Figure 5), adapted from Arnstein’s (1969) ‘Ladder of Participation’, categorising citizenship involvement in community development, is probably the best known (McNeilly *et al*, 2015). In this model, the lowest three levels are termed ‘non-participation’. These levels represent situations where children do not understand the reasons for their participation and/or are not provided with information about the process or possible outcomes. At the fourth level, children are informed but not asked their views, progressing to the fifth level where children are informed and consulted but do not directly influence decision-making. In the top three levels children are allowed to share in adult initiated decision-making and may progress to initiating and directing decision-making themselves with support from adults.

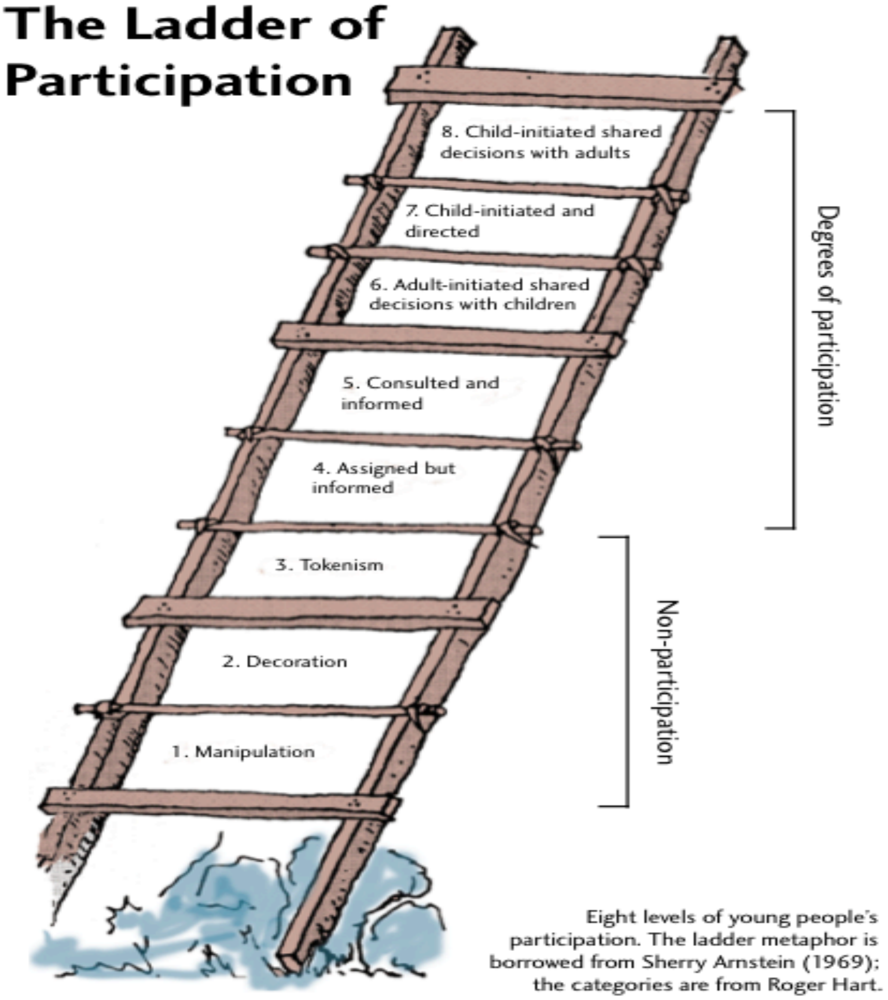

Figure 5: The Ladder of Participation (Hart 1997, p 8)

Other typologies have adapted and applied Arnstein's (1969) and Hart's (1997) ideas to various practice contexts, including within health and social care (e.g. Thoburn *et al* 1995; Alderson and Montgomery, 1996; Shier 2001; Wright *et al*, 2006; Thomas, 2007). Shier (2001), for example, intended practitioners to use his "pathway to participation" to examine their current practice and think about how the next level of participation could be achieved:

1) Children are listened to
2) Children are supported in expressing their views
3) Children's views are taken into account
4) Children are involved in decision-making processes
5) Children share power and responsibility for decision-making

Criticisms of hierarchical typologies

The difficulty with Shier's (2001) approach, and other hierarchical typologies, is the underlying assumption that the higher levels are both achievable and desirable for all children and in all decision-making processes (Treseder, 1997). Whereas in some contexts, especially within children's social care, over-emphasising children's participation risks children inappropriately bearing the burden for decision-making (Schofield, 2005), or being exposed to potentially harmful experiences, such as hostility between parents and professionals during child protection meetings (Healy and Darlington, 2009).

In addition, such typologies run the risk of greater weight being given to the views of children who are more confident and articulate, rather than those of children who have more difficulty expressing themselves (Franklin and Sloper, 2006) or who may hold ambivalent views, such as those in care (Schofield, 2005). Hierarchical typologies do not easily account for the additional barriers disabled children face in participating because of a lack of access to appropriate forms of communication (VIPER, 2013).

Hierarchical typologies are also problematic in situations where the basis for children's participation is involuntary (Gallagher, 2012). Within child protection, for example, the 'top' rungs of the 'ladder' would rarely be desirable or achievable, since it would be unlikely to be appropriate for children to initiate or direct decision-making (Thoburn *et al*, 1995). Notwithstanding that children sometimes trigger child protection enquiries through disclosing abuse, safeguarding practice guidance in England emphasises professionals' responsibility to notice and to ask children when something appears to be troubling them (Working Together, HM Government 2018, p. 10). Professionals' over-arching responsibility for decision-making about how children can be kept safe within the child protection system is likewise spelt out. Though, the importance of children and their families being informed and involved as much as possible is also acknowledged.

These criticisms have led some authors to devise non-hierarchical typologies in an attempt to over-come these difficulties (Treseder, 1997; Kirby *et al,* 2003). These reflect the fact that the appropriate level of participation will vary according to the decision being made and the capabilities and preferences of the children concerned (Franklin and Sloper, 2006). Kirby *et al's* (2003) model, for example, has similar categories to Shier (2001) but is presented in a non-hierarchical form (Figure 6).

Figure 6: A [non-hierarchical] model of the level of participation, Kirby et al, (2003) p. 22.

Non-hierarchical typologies potentially offer a more flexible understanding of participation. They may therefore be more applicable to examining disabled children's participation or participation during child protection enquiries and decision-making (Franklin and Sloper, 2009). If Kirby *et al's* (2003) model is applied to child protection practice, for example, children's views should always be taken into account. However, children's degree of involvement in decision-making will vary according to the context, their age and understanding, and the circumstances surrounding their need for protection. Therefore, even within a non-hierarchical approach, there is still a danger that children's perceived vulnerability, immaturity or lack of understanding will be used to exclude them from decision-making, an issue that seems especially likely to be an issue for some disabled children

A further advantage of non-hierarchical typologies is the equal value placed on the different ways that children contribute to decision-making (Kirby *et al*, 2003). However, this also makes it more difficult to understand how children's different levels of participation relate to each other. As Franklin and Sloper (2009) point out, disabled children being provided with appropriate information in an accessible format is a necessary pre-requisite to their accessing other forms of participation that allow them to influence decision-making. Likewise, non-hierarchical approaches to participation do not facilitate easy analysis of the degree to which power is shared in decision-making between children and adults (Thomas, 2012).

The relative merits of hierarchical versus non-hierarchical typologies has been the subject of considerable debate (McNeilly *et al*, 2015). Neither can in themselves, however, provide a satisfactory model of children's participation since they do not adequately capture the complexities and tensions inherent in children's participation (Thomas, 2012), especially in the context of child protection enquiries (Cossar *et al*, 2014). Nor do they take account of how disablist attitudes among practitioners and a lack of investment of time and resources restrict disabled children's opportunities for participation (Franklin and Sloper, 2009; McNeilly *et al*, 2015). To better understand these issues a closer examination of the relationship between participation, ideas about childhood, including childhood disability as well as other children's other rights is required. This highlights the need for this dissertation's study research questions exploring disabled children's views of their participation in child protection decision-making processes.

Participation, children's rights and citizenship

As alluded to in chapter 1 due to continuing concern regarding children's capacity to make 'rational' decisions owing to their biological immaturity, children's rights have developed more slowly and in a different way to those of other marginalised groups of adults (Therborn, 1993). First and foremost, children's rights legislation was developed to afford children the right to protection, an emphasis which is almost entirely absent from comparable adult human rights legislation (Quennerstedt, 2010). This reflects dominant understandings of children as dependent and of childhood as a protected stage of development (Freeman, 2000). The Preamble to UNCRC (1989) reaffirms the UN declaration on Human Rights (1948) designation of childhood as a period of development that is "entitled to special care and assistance" (paragraph, 4), adding that "the child by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection" (UNCRC 1989, paragraph, 9). Hammarberg (1990) argues that the UNCRC (1989) remains stronger on children's rights to protection and welfare provision than participation, since children's participatory rights continue to be mediated by their age and maturity.

Moreover, children’s right do not extend to political rights such as voting or in general the right to self-determination, which effectively undermines any sense of them as having full citizenship (Tisdall, 2012).

Following the Gillick ruling English case law goes further than the UNCRC (1989), in recognising children’s competence to make autonomous decisions in specific circumstances, based on their ability to demonstrate their capacity for understanding rather than their age (*Gillick vs West Norfolk and Wisbech Health Authority,* [1986] AC112). Consequently, the Children Act (1989) requires professionals’ to take children’s wishes and feelings into account according to their “age and understanding”, rather than their “age and maturity” (Article 12, UNCRC, 1989).

Nevertheless, a professional’s paramount responsibility under the Children Act (1989) is to ensure children’s welfare and make decisions in their best interests. Consequently, in practice children’s rights to participate in decision-making is often seen as needing to be ‘balanced’ with their right to protection. Consequently, the requirement to promote children’s best interests is sometimes used as a justification for disregarding their views and limiting their involvement. Since as a principle it remains linked to a view of children, and perhaps especially disabled children, however understanding and capable, as intrinsically vulnerable and in need of protection (Sandman, 2017).

This position is often viewed as inherent within the field of developmental psychology (Cossar *et al*, 2014). However, several authors have questioned the extent to which children’s rights of participation and protecting their best interests necessarily cancel each other out (Schofield and Thoburn, 1996; Munro, 2011; Gallagher, 2012). Rather, they argue that a more nuanced understanding of child development can help contextualise children’s views and contribute to their protection (Schofield, 2005; Munro, 2011). Through applying attachment theory, for example, children’s apparent loyalty and contradictory views regarding parents who abuse them can be seen as an understandable response to abuse and trauma, rather than as evidence of irrationality or a lack of competence (Schofield, 2005).

Moreover, children’s participation in decision-making can itself promote children’s healthy development (Schofield, 2005), by helping to lessen their feelings of anxiety about child protection involvement through the provision of clear and understandable information (Woolfson *et al*, 2010). Children's participation can also help promote children's self-efficacy and self-esteem, including among disabled children (Raghavendra *et al*, 2012). Equally, evidence suggests that children experience being excluded from participating in decision-making as frustrating and disempowering (Bell, 2002; Davey, 2010).

This last point is especially relevant for disabled children as in order to participate they often require information in a different format or need additional support expressing their views due to their impairment needs. The UNCRC (1989), UNCRPD (2006) and the Children Act (1989) each require practitioners to meet disabled children's specific needs and uphold their equal right be involved in decision-making. Practice guidance to the Children Act (1989) states that "if the child has complex needs or communication difficulties arrangements must be made to establish his views", and that "no assumptions should be made about 'categories' of children with disabilities who cannot share in decision-making" (Department for Education, 1991, p. 14-15).

A closer examination of children's rights and of child development therefore contributes to a more nuanced understanding of the complexities surrounding children's participation in decision-making than offered by typologies alone. Evaluating research evidence regarding how children's rights to participate are realised is also of upmost importance, however, since children's experiences of decision-making logically depends on how practitioners seek to address these tensions and complexities in practice (Cossar *et al*, 2014). It is to this that I now turn.

Disabled and non-disabled children's experiences of participating in social work decision-making processes

In this section research relating to disabled and non-disabled children's participation in decision-making within children's social care is reviewed. Studies relating to disabled children's participation within children's social care are still relatively scarce, and it is an area of social work practice repeatedly highlighted as in need of further research and development (Franklin and Sloper, 2009; VIPER, 2013; Prynault-Jones *et al*, 2017). I was also unable to find any studies specifically focusing on disabled children's own views of their involvement in child protection decision-making processes, underlining the important contribution made by the research that is the subject of this dissertation's findings.

By contrast a number of studies have been conducted regarding non-disabled children's experiences of child protection decision-making processes (Bell, 2002; Woolfson *et al*, 2010; Cossar *et al*, 2014). Since many of the themes identified by these studies may equally apply to disabled children the findings of these studies are first reviewed and then compared with what is known about disabled children's participation in other decision-making processes, either as children in need (Franklin and Sloper, 2009; Mitchell and Sloper; 2011; McNeilly *et al*, 2015) or as looked after children (Morris, 1998; Kelly *et al*, 2016).

The majority of research concerning both disabled and non-disabled children's participation in decision-making within children's social care has been conducted in the UK. This includes 17 of the 21 studies included in a review of research relating to children's participation in child protection decision-making (van Bijleveld *et al*, 2015) and 22 of the 27 studies on disabled children's participation in decisions about their health and social care identified by McNeilly, *et al* (2015). Moreover, despite the potential difficulties of comparing findings between countries with different approaches to child welfare, van Bijleveld *et al* (2015) reported the research themes relating to children's involvement in child protection decision-making to be broadly the same across all countries.

There is also a tendency for studies relating to disabled and non-disabled children's participation in decision-making to employ qualitative research methods. Although the largest study (Thoburn *et al*, 1995) used a questionnaire survey with managers and practitioners to quantitatively map how children's and parents' views were represented in 220 child protection cases. Franklin and Sloper (2006, 2009) similarly surveyed participatory practice with disabled children across 71 Local Authorities in the UK, as well as seeking the views of practitioners, parents or carers and children in 6 case study authorities. Most other studies utilised either focus groups, semi-structured interviews or both to explore the views of children, parents and practitioners.

Many studies used creative participatory methods, particularly those involving disabled children with cognitive or communication impairments, (e.g. Franklin and

Sloper, 2006; Cossar *et al*, 2011; Mitchell and Sloper, 2011). Some projects, including a few with disabled children (e.g. VIPER 2013), also included children and young people directly as co-researchers. Actively involving children in the research process and analysis helps address an important criticism regarding the authenticity of 'children's voices' based on data collected and analysed solely by adults (Tisdall, 2012; Carpenter and McConkey, 2012). However, this issue is more difficult to address in research with disabled children who communicate non-verbally (Wickenden, 2011).

Most studies report having relatively modest sample sizes which limits the possibilities for applying their findings more generally (Gallagher *et al*, 2012). Studies exploring children's participation in child protection decision-making had between 4 (Leeson, 2007) and 45 participants (Buchanan *et al*, 1995). Those concerning disabled children's participation in decision-making involved between 14 (Preece and Jordan, 2009) and 32 participants (Kelly, 2005). Studies seeking social workers' views regarding children's participation had generally larger sample sizes which ranged from 16 to 86, perhaps explained by the greater use of surveys and focus groups rather than individual interviews.

Unsurprisingly, given the practice-focused nature of these topics, much research was found within the policy and practice literature (Cavet and Sloper, 2004; Cossar *et al*, 2011). Though, encouragingly reviews by van Bijleveld *et al* (2015) and McNeilly *et al* (2015) identified a larger number of studies in peer review journals than identified by earlier reviews (Schofield and Thoburn, 1996; Cavet and Sloper, 2004). van Bijleveld's *et al* (2015) exclusive focus on peer-reviewed research meant some influential studies were not considered, including: Thoburn *et al's* (1995) large study, commissioned by the Department of Health to evaluate practice following the Children Act (1989); and Cossar *et al's* (2011) study for the Children's Commissioner which helped inform Munro's review of the child protection system in England (Munro, 2011).

Research exploring disabled children's participation and that concerning children's participation in decision-making during child protection processes were found to identify similar themes. Gallagher *et al* (2012), reviewing both areas of practice, summarises children's participation, whether or not they are disabled, as dependent upon the quality of information and communication afforded to children during decision-making; the nature of relationships between children, parents and practitioners; and the availability of appropriate support. These factors are also described as acting either as ‘barriers’ or ‘facilitators’ to disabled children’s participation (Franklin and Sloper, 2009; VIPER, 2013).

Despite significant overlaps, there are also some differences between these two areas of research. Research regarding disabled children’s participation is scarcer and has taken longer to appear than that concerning non-disabled children. This perhaps reflects negative attitudes and assumptions regarding disabled children’s capacity to participate in research or decision-making (Davy, 2010). Unlike during child protection procedures or arrangements for children in care, disabled children’s involvement in decision-making in social care is discretionary, so possibly seen having less priority (Priestley, 2000). This makes the lack of studies focusing on disabled children’s participation during child protection enquiries and decision-making all the more surprising, and underlines the need for the research reported in this dissertation, particularly given disabled children are at increased risk of maltreatment (Jones *et al*, 2012) yet apparently under-represented among children who have child protection plans (Ofsted, 2012).

As these areas of research are generally considered distinct fields of enquiry they are also discussed separately here. Research concerning children’s involvement in child protection decision-making processes is reviewed first, according to the themes identified by Gallagher *et al* (2012). These findings are then compared and contrasted with research concerning disabled children’s participation in other decision-making processes within children’s social care and the implications for this study exploring disabled children’s experiences with child protection processes is discussed.

The voice of the child in Child Protection

Many children report experiencing child protection involvement positively (Thoburn 1995; Cossar *et al*, 2011; Woolfson *et al* 2010). However, evidence suggests children’s views are commonly not represented during child protection enquiries and decision-making (La Valle *et al*, 2012). Learning from serious case reviews similarly identifies professionals’ not seeing or speaking enough to children as frequently significantly contributing to the incident leading to the review (Ofsted, 2010). Children themselves likewise consider greater effort to engage them in child protection processes would help improve outcomes (La Valle *et al*, 2012). These findings are discussed in more detail below.

Information and Communication

Children's access to information

Schofield and Thoburn's (1996) assertion that children need clear understandable information during child protection enquiries has been echoed by the findings of subsequent research. Young people in Woolfson *et al* 's (2010) study said that being provided with clear information at an early stage had helped to reduce their feelings of anxiety during child protection enquiries. Children in Thomas *et al* (2002) study emphasised clear explanations as being especially important where decisions were made against their wishes. Children in several studies, by contrast reported that not feeling well informed during child protection enquiries and decision-making processes had left them feeling anxious about what would happen and confused about the reasons for the changes in their lives (Bell, 2002; Leeson, 2007; Bessell, 2010).

Cossar *et al's* (2014) study similarly identified wide variation in children's understanding of the child protection system, especially according to age. Younger children (6-10 years) often had little or no understanding of the reason for professional involvement or how their views were represented in child protection meetings, and some were unaware that such meetings took place, a description strikingly akin to Hart's (1992) levels of non-participation in his 'Ladder of Participation'. Other children were partially aware of professional concerns but, lacking clear information from professionals, had often pieced together information themselves gleaned from parents and other family members, which was consequently liable to mis-interpretation and wrong perception. Similar difficulties were identified by young people in Woolfson *et al's* (2010) study, one of whom commented "everything that happened, I only knew in bits" (p. 2078).

Having access to appropriate information has been frequently highlighted as an essential pre-requisite to children participating in child protection decision-making. Older children in Cossar *et al's* (2014) study who had a clear understanding of child protection processes were usually able to say whether or not they agreed with professional concern for their families and many were able to describe the decisions made in some detail. Providing accessible papers and clear explanations was similarly a core finding of Creegan *et al's* (2006) research concerning children's involvement in children’s hearings in Scotland.

Studies have emphasised the need for information provided during child protection enquiries to be tailored to children’s individual needs, a finding which is especially relevant to disabled children (Gallagher *et al*, 2012). Whitehead *et al* (2009) found that being sent too much, inaccessible or irrelevant information was intimidating for some children. Creegan *et al* (2006) likewise observed that professionals’ use of jargon impeded children’s participation in decision-making processes. Moreover, children being told inappropriately detailed information about their parents’ personal lives is potentially damaging to family relationships (Whitehead *et al*, 2009).

Opportunities and ways of participating

Not wishing to expose children to conflict between their parents and professionals is frequently cited by social workers as a reason for excluding them from attending child protection meetings (van Bijleveld *et al*, 2015). However, children in Cossar *et al’s* (2014) study who had a clear understanding of child protection processes were much more likely to have attended a children protection conference or core group, and also saw meetings as their main opportunity to express their views. Young people in Woolfson *et al’s* (2010)’s study spoke about wanting to attend child protection meetings for similar reasons.

However, evidence suggests that attendance at meetings does not in itself assure that children’s participation in decision-making will be positive or meaningful (Thomas and O’Kane, 1999; Bell, 2011). Children also report having very mixed views and experiences of going to meetings (Bell, 2002; Cashmore, 2002). Children who attended meetings in Leeson’s (2007) study, for example, described ‘being present’ rather than participating in decision-making. Children in Cossar *et al’s* (2014) study described attending meetings as difficult and stressful, and reported finding it hard to ask questions and make their views heard. Children in several studies report feeling overwhelmed by the large numbers of often unfamiliar professionals present at child protection conferences (Cashmore, 2002; Woolfson, *et al* 2010) and as affecting their ability to contribute (Creegan *et al*, 2006). A lack of preparation beforehand and not having access to the same information as adults during meetings further hinders children’s willingness to take part during meetings (Buchanan, 1995; Bell, 2002; Cashmore, 2002). Children also understandably say they find it upsetting to talk about their family’s difficulties in front of their parents (Cossar *et al*, 2014).

Despite these difficulties, some children want to attend child protection conferences or core group meetings (Bell, 2002; Woolfson, 2010). However, they often say this is because they see it their main or only opportunity to gain information or contribute to decision-making (Cossar *et al*, 2014; Woolfson *et al*, 2010). Vis and Thomas (2009) found that children who had attended one or more child protection meetings were three times more likely to have participated in decision-making than those who had not. This effect may have been mediated by age, as appeared to be the case among participants in Cossar *et al* (2014) study. However, both studies indicate that children's opportunities for participation during child protection enquiries and decision-making are unlikely to be meaningful unless they also have a trusting relationship with their social worker or another professional.

Relationships between children and practitioners

From the child's perspective

Children consistently report that the quality of their relationship with their social worker largely determines their experience of participating in child protection decision-making (Thoburn *et al* 1995; Bell 2002; Vis and Thomas 2009). However, the challenges inherent in children's relationships with practitioners are equally often highlighted (van Bijleveld *et al*, 2015). The large number of adults involved in statutory rather than everyday decision-making represents an unusual situation for children (Bell, 2002). Some of these professionals may not have met the child before and often have little knowledge of what matters to them (Cashmore, 2002; Donnelly, 2010). Children may also be understandably reluctant to share information with unfamiliar adults, especially when they cannot be sure of the consequences (Sanders and Mace, 2006).

Given the strength and importance to children of their family relationships, it is also unsurprising if children sometimes ally themselves with their parents against professionals, including their social worker during child protection processes (Schofield and Thoburn, 1996). Maltreated children are also much less likely to have formed secure attachments to their caregivers, further hindering their ability to make informed decisions (Schofield, 2005). These children's caregivers, in turn may be less likely to be able to support their children's participation in decision-making, due to their own, often conflicting needs. This creates a situation where children need to rely on professionals for their voices to be heard (Bell 2002).

Having a good relationship with professionals, especially their social worker is frequently highlighted by children as important during child protection enquiries (Bell, 2002; Leeson, 2007; Winter, 2010). Children tend to view social workers as powerful figures in decision-making (Munro, 2001; Cossar *et al*, 2014) and where this relationship is experienced positively children tend to see their social worker as an important ally (Bell, 2002; McLeod, 2010).

Children in studies by Munro (2001) and Bell (2002) said they valued social workers who they saw as available, reliable and who were good at sharing information. Children in Leeson (2007) and Cossar *et al's* (2014) studies appreciated social workers who showed concern for their welfare, respected their views without being judgmental, while those in Healy and Darlington's (2009) study appreciated social workers who were honest and transparent with them regarding the possible outcomes of decision-making during child protection enquiries. The quality children most valued in their social worker, however, was being able to trust them, as one young person in Cossar *et al's* (2014) study put it, "you've got to trust her, and she's got to trust you, otherwise there's no point" (p.5).

Despite these positive examples, children often report having a poor relationship with their social worker during child protection enquiries (van Bijleveld *et al*, 2015). Children particularly highlight social workers' lack of time and availability as a significant barrier to their meaningful participation in child protection decision-making (McLeod, 2007; McLeod, 2010; Cossar *et al*, 2011). Children in Leeson's (2007) study, for example, described their social worker as a remote figure whom they usually only saw at meetings. Children additionally report disliking social workers who are hard to contact, are late for or who cancel appointments and who do not make enough effort to keep them informed or listen to their views, since this gives the impression of not caring (Munro, 2001; Leeson, 2007; Bessell, 2010). Children in Cossar *et al's* (2014) study likewise said they resented feeling interrogated by their social worker and being treated as a source of information. Children cite frequent changes of social worker as common and as leaving them feeling confused, abandoned and wary of trusting future workers (Bell, 2002; Cossar *et al*, 2014).

From the social worker's perspective

Children frequently emphasize social workers' working in partnership with them in overcoming their family's problems as forming the basis of good relationships (Bell, 2002; Cossar *et al*, 2014). However, deciding how to promote children's best interests is almost always complex and challenging from the social worker's perspective (Cossar, *et al*, 2014). It often involves practitioners having to choose the least detrimental among a range of options that each enable some, but not all, of the child's needs to be met (Schofield and Thoburn, 1996).

It is often not appropriate to burden children with these adult concerns and complexities (Healy and Darlington, 2009), however they inevitably often impinge on social worker's ability to form trusting relationships with children during child protection enquiries (van Bijleveld *et al*, 2015). Social workers also report particular difficulties discerning children's true feelings due to concern about the ongoing influence of parents or other adults on children's views (Holland, 2001; Archard and Skivenes, 2009). These issues can also make it difficult for practitioners to create an environment in which the child feels able to talk freely (Horwath, 2010).

Social worker's attitudes towards children and their participation also inevitably affects their approach to involving them in child protection decision-making. Social workers in most studies see children's participation as important in terms of children's rights (Vis and Thomas, 2010), but have differing views about what this looks like in practice (Sanders and Mace, 2006; Vis *et al*, 2010). Some interpret participation as simply giving children information (Archand and Skivenes, 2009) or even only as a need to 'see' the child (van Bijleveld *et al*, 2015). Although most social workers report seeing participation as consulting children regarding their views, many practitioners view this as primarily a way of improving the accuracy of assessments (Vis and Thomas, 2009; Archand and Skivenes, 2009).

Children being consulted does not necessarily mean that their views are allowed to influence decision-making. Holland (2001) identified considerable variation in the weight social workers gave to children's views even where these were included in assessments. Vis and Thomas (2009) report that children's views influenced decision-making in less than half the child protection cases they examined, while Archand and Skivenes (2009) found children's views were given less consideration where these differed from those of their social worker. Although it is important to acknowledge that it may not always be appropriate for children to influence decision-making, children who social workers perceive as especially vulnerable or in need of protection, including younger and disabled children, are less likely than other children to be consulted or allowed to contribute to decision-making following child protection enquiries (Sanders and Mace, 2006; Vis *et al*, 2010).

Support for children's participation

Developing child-centred practice

The quality and amount of support provided to children also affects their opportunities to participate in child protection and other decision-making processes in children's social care (Gallagher *et al*, 2012). For example, Thomas (2002) found children were better able to contribute to decision-making when they received adequate support and information at the start of and throughout child protection involvement, which sometimes included an adult speaking on the child's behalf. Healy and Darlington (2009) also found that using creative child-centred approaches such as play, visual arts, writing and story-telling helped children contribute to child protection decision-making, but emphasised that these techniques needed to be tailored to individual children's age and understanding. Winter (2009) likewise reports creative methods as allowing even young children in care to discuss emotive topics, seemingly without adverse consequences.

These and other authors have highlighted social workers' need for training in order to develop their knowledge and skills engaging children in child protection decision-making (Wright *et al*, 2006; Winter, 2009). However, there is also evidence that professional attitudes sometimes limit children's opportunities for participation. Holland (2001), for example, found that the weight given to children's views in decision-making depended largely on the extent to which these were seen as rational or sensible in relation to adult views. This has led some to suggest that social workers and other professionals involved in child protection should receive training on children's rights in order to help challenge the prevailing view of children as lacking capacity and in need of protection (van Bijleveld *et al*, 2015).

Gallagher *et al* (2012) and others likewise recommend that child protection processes would greatly benefit from being adapted to meet children's needs. Suggestions to promote children's experience of participating in child protection decision-making include; making child protection meetings more child friendly by reducing the number of professionals attending (Vis and Thomas, 2009); children being better supported during child protection conferences (Bell, 2002); skillful chairing; a respectful attitude towards children attending from conference members and children having the opportunity to discuss the decisions made immediately afterwards with their social worker and/or the conference chair (Schofield and Thoburn, 1996).

Children often indicate having some awareness that their participation in decision-making is sometimes circumscribed by the nature of child protection concerns (Bell, 2002: Cashmore, 2002). Nevertheless, Shemmings (2000) found practitioners offering children choice and control even within these limits helped them to feel empowered and promoted the development of trust within relationships. For instance, many children have expressed a preference for participation occurring within a one-to-one relationship rather than attending meetings and having their views represented (Bell, 2002; Cossar *et al*, 2014). Children also report wanting more to say in decisions that are important to them, rather than only those that their social worker considers appropriate (Munro, 2001; Leeson, 2007).

Wright *et al* (2006) further suggest that a whole system approach is necessary to improve children's experiences of participation in decision-making within children's social care. This includes building an organizational culture committed to children's participation, as well as the appropriate planning and resourcing of participation activities to ensure that these become embedded. They further suggest organisations appointing Participation Champions as a way of ensuring children's participation is prioritized.

Independent advocates

As discussed, children's participation in decision-making is especially problematic in child protection where the basis for involvement is involuntary (Gallagher *et al*, 2012). Power differentials between adults and children, as well as social workers' conflicting roles and responsibilities have led some to argue that independent advocates may be better placed to support children's participation under such circumstances (Boylan and Dalrymple, 2011; LaValle *et al*, 2012). Advocates, as well as helping children access adequate complaints procedures, it is argued, can help strengthen children's position within child protection decision-making processes, by supporting them in putting their views across or speaking on their behalf (Thomas and O'Kane, 1998; Boylan and Dalrymple, 2011).

To date, however, children's advocacy services have tended to focus on the needs of looked after children (Holland and Scourfield, 2004). Moreover, although there has been little research on the use of advocates during child protection enquiries (La Valle *et al*, 2012), the available evidence suggests that the quality of the relationship with the child is key to children's effective participation in decision-making, whether the professional involved is an advocate or a social worker (Vis and Thomas, 2009).

Benefits of participation for children

Research has repeatedly highlighted the positive impact of participation in decision-making on children's welfare and development. Cashmore (2002), for example, found children were positive and felt valued if they felt their social worker had listened to their views during child protection enquiries even when the decisions made meant things did not work out the way they wanted. Other studies similarly report that being allowed to contribute to decision-making helps promote children's sense of self-efficacy and self-confidence (Leeson, 2007; Schofield, 2005).

Conversely, children describe feeling frustrated when their views are overruled, and feel powerless when professionals' ignore their concerns during decision-making (Munro, 2001; Leeson, 2007). Winter (2010) similarly found feelings of guilt, anger, sadness and anxiety were associated with a lack of consultation among young children. A further response by some children to their views being disregarded is to employ more subversive methods of expressing themselves, such as withdrawing or rebelling to avoid engaging with professionals (Bell, 2002; Leeson, 2007). Each of these responses to a lack of participation in decision-making seems likely only to increase the chances of adverse outcomes for the children concerned.

Moreover, since maltreatment concerns an abuse of power, some have pointed out that participation in decision-making following maltreatment is not only a right, but also potentially part of the remedy (Schofield and Thoburn, 1996). For example, being involved in decision-making may help re-dress the power imbalance for these children associated with their experiences of maltreatment (Reading *et al*, 2009). Equally, not supporting maltreated children's participation in decision-making may compound or re-activate their feelings of powerlessness (Bell, 2002).

Barriers to children's participation

Despite research evidence that children benefit from being involved in decision-making, Gallagher *et al* (2012) caution that promoting children's participation "*may have substantial and un-realistic resource implications. It may also create conflicts with statutory social workers' legal and professional duties, particularly in risk-averse professional cultures"* (p.76). In spite of policy rhetoric about the need for practitioners to focus on children's views, (Working together, HM Government, 2018 p.10) Gunn (2008) similarly questions the extent to which children's participation really empowers them or simply serves the needs of organisations. Social workers themselves highlight the procedural focus on risk management as adversely affecting their relationships with children and ability to support their participation in decision-making, alongside other organisational factors such as high case-loads, inadequate staffing and paperwork requirements (Winter, 2009; Barnes, 2012). Given the scarcity of resources and the UK government's focus on further cuts to public spending at the time of writing, greater prioritisation of children's participation in child protection decision-making seems unlikely, notwithstanding its benefits to children and its centrality to upholding their human rights (Article 12, UNCRC, 1989).

The voice of the disabled child in decision-making

Research specifically examining disabled children's perspectives regarding their participation in child protection decision-making is currently lacking (Stalker and McArthur, 2012). However, as discussed in the preceding chapter the available evidence suggests that practitioners' frequently struggle to adapt procedures to meet disabled children's needs, particularly during child protection enquiries (Taylor *et al*, 2014). In this section, what is known about disabled children's participation in other decision-making processes is compared and contrasted with research concerning non-disabled children's participation in child protection decision-making processes. This is considered necessary in order to anticipate the potential challenges disabled children in this study might experience in contributing to child protection decision-making.

Information and communication

Disabled children's access to information

Access to understandable information has been repeatedly identified as an essential pre-requisite to all children's participation in all decision-making (Kirby *et al*, 2003; Sinclair, 2004). It is therefore particularly important for disabled children since, as a group, they are likely to experience higher levels of professional involvement and intervention than other children because of their impairment needs (Morris, 2005; Franklin and Sloper, 2006). As already discussed, Article 13 of the UNCRC (1989) and Article 7 of the United Nations Convention of Persons with Disabilities (2006) specifically requires practitioners and organisations to recognise and provide for disabled children's right to receive information in a range of different formats and communicate in a manner consistent with their impairment needs.

Despite these provisions, studies repeatedly identify disabled children as lacking adequate and accessible information within children's social care. This includes information about specialist and inclusive leisure activities in their local area (Beresford and Clarke, 2009); the availability of advocacy services (Franklin and Knight, 2011) and leaving care provision (Priestley *et al*, 2003). The transition from children to adult services has been highlighted as an area where information is especially poor (Beresford *et al*, 2004; Abbott and Carpenter, 2010). For example, 70 % of disabled young people and their parents in Sloper *et al's* (2010) study reported a lack of information about independent living, benefits and finance, employment opportunities, and adult relationships and sex education.

Dixon-Woods *et al* (1999) noted a lack of evidence about how to design information materials for children in order to include them in decision-making. A range of initiatives have focused on specifically addressing this issue for disabled children as part of the 'Aiming High for Disabled Children' programme and the 'Every Disabled Child Matters' Campaign (Council for Disabled Children, 2008-2015). Nevertheless, studies report that documents used to include disabled children's views in short breaks or looked after children's reviews are routinely provided in written question and answer format (Kelly *et al*, 2016; Wilson, 2016). This reflects Franklin and Sloper's (2009) finding that local authorities tend to adopt a "one-size fits all" approach to supporting children's participation, based on an underlying and disablist assumption that children are able to express their views on paper (Carpenter and

McConkey, 2012). Consequently, disabled children often had limited understanding of decision-making processes, either because they had received no explanation or information had not been provided in an accessible format (Franklin and Sloper, 2009). Though, by contrast social workers in Kelly *et al's* (2016) study with looked after disabled children in Northern Ireland, aware of the limitations of these forms said they used more creative approaches to seeking disabled children's views in practice.

Communicating and consulting disabled children

Research suggests that professionals' similarly tend to prioritise verbal over other forms of communication when seeking to involve disabled children in decision-making (Holland, 2011). Franklin and Sloper (2009) found only small numbers of disabled children were taking part in decision-making processes in children's social care, but those who were tended to be the most confident, articulate and able to communicate. Morris (1998) found practitioners made little effort to find alternative ways of consulting disabled young people living in residential care who communicated non-verbally. Franklin and Sloper (2009) found the majority of social workers were unaware of the specific communication needs of disabled children on their caseloads. While disabled children who use alternative communication systems are often only able to access these at school. This limits their opportunities to contribute to decision-making in other settings (VIPER, 2013).

Other evidence suggests that disabled children with communication impairments do not always have sufficient people in their professional or personal support networks able to understand or accurately interpret their views (Morris, 2003; Raibee *et al*, 2005). Studies indicate that the communication needs of deaf children (Young *et al*, 2008), younger disabled children (Dixon, 2004) and those from minority ethnic backgrounds (Marchant and Jones, 2003; Read *et al*, 2009) are also often overlooked. This is particularly concerning given that deaf children in Jones *et al* (2017) study identified access to registered interpreters as a key enabler to their having disclosed abuse.

Research has also identified evidence of good practice in relation to how disabled children's communication needs are met in social work practice. Ofsted's (2012) review of child protection practice in England found several examples of practitioners using creative communication techniques to include disabled children's views in assessments, including the use of participant observation with children with complex cognitive and communication impairments. Social workers in Prynault-Jones *et al*'s study (2017) similarly stressed the need to use visual, art-based and sensory related activities, as well as observations of behaviour and facial expressions when consulting disabled children who communicate non-verbally. Although practitioners' have also raised concern about the challenges and potential ambiguities of interpreting the views of children who communicate non-verbally, particularly where there are child protection concerns (Taylor *et al*, 2016; Kirton, *et al*, 2009).

Opportunities and ways of participating

Overall, evidence suggests that practitioners' efforts to consult disabled children and involve them in decision-making is patchy and inconsistent (Ofsted, 2012; VIPER, 2013). Consequently, disabled children's opportunities to express their views about services are often limited and even when consulted are seldom involved in decision-making processes in children's social care (Dickins, 2008; Franklin and Sloper, 2009). Studies by Kelly (2005) and Wilson (2016) found that children with learning disabilities did not attend review meetings, and their views were rarely considered in decisions about whether they should attend residential short breaks, despite some saying they did not enjoy going, indicating these children's participation was "tokenistic" at best (Hart, 1997).

By contrast, most of the disabled children in out-of-home care in Kelly *et al's* (2016) study said they were aware that decisions about their lives were made at their looked after children reviews. Some of the older children also attended these meetings. However, these children's experience of their involvement in decision-making was mixed, with some expressing frustration that their views were not listened to. This would appear to suggest that although some disabled children are consulted their level of involvement rarely extends to being allowed to influence decision-making, reflecting the experience of most non-disabled children (Cossar *et al*, 2011).

Studies also indicate that disabled children's opportunities to participate in decision-making are often mediated as much by the attitudes and skills of professionals as by their impairment needs (Ofsted, 2012; McNeilly *et al*, 2015; Kelly *et al*, 2016). McNeilly *et al* (2015) found professionals as well as parents in their study often questioned the value of giving disabled children information because they assumed, they would not be able to understand. Professionals' and parents' similarly frequently under-estimate disabled children's capacity to be involved in decision-making

(McNeilly *et al*, 2015; Kelly, 2005), especially those with additional communication needs (Holland, 2011).

Disabled children themselves, by contrast, repeatedly emphasise wanting to be informed and involved, even where they are happy for adults to take the lead in decision-making (Mitchell and Sloper, 2011; McNeilly *et al*, 2015). Studies also indicate that even children with complex communication and learning needs are able to express preferences and make choices when information is presented in an accessible way (Mitchell and Sloper, 2011; Canella *et al*, 2005; Lanciono, 1996).

A further difficulty is professionals' tendency to place greater emphasis on children's' participation in formal decision-making processes rather than the informal ways of contributing their views valued by disabled children themselves (Martin and Franklin, 2010). Though, as already discussed, a similar tendency has been noted in non-disabled's participation in child protection decision-making (Vis and Thomas, 2009) these attitudes are even more problematic for disabled children because the different ways they express their views are less likely to be seen as a 'valid' form of participation by practitioners (Franklin and Sloper, 2009).

This has led some to call for a more nuanced understanding of what 'participation' means for disabled children and greater recognition of the significance of children contributing to decision-making at a level appropriate for them (Franklin and Sloper, 2009). This also confirms the view that non-hierarchical typologies (Kirby *et al*, 2003) are more applicable to promoting disabled children's participation than those based on a hierarchical approach.

Relationships between disabled children and practitioners

From disabled children's and their caregivers' perspectives

Disabled children's accounts of their relationships with professionals, especially social workers differ from those of non-disabled children in several ways. Though non-disabled children often describe difficulties in their relationship with their social worker during child protection enquiries, including a lack of contact, disabled children often do not have an allocated social worker even when they are receiving short breaks (Connors and Stalker, 2003; Preece and Jordan, 2009). Where disabled children do have social workers, they often report having little or no relationship with them (Franklin and Sloper, 2009). Of the ten children with ASD in Preece and Jordan's study (2009), for example, eight had met their social worker but only two recognised them from their photograph, and none understood their role. Children with communication impairments in Mitchell and Sloper's (2011) were similarly unable to distinguish the role of a social worker from that of other professionals in their lives.

Although, these disabled children's understanding of their social workers' role may be influenced by their age as well as their impairments, this is rarely acknowledged. Younger children in Cossar *et al's* (2011) study, for example, tended to have less understanding of their social worker's role as well as of child protection processes. However, most of these non-disabled children still identified their social worker as a significant person in their lives or saw them as supporting their participation in decision-making, whereas only one of the 27 disabled children in Mitchell and Sloper's (2011) study mentioned their social worker as someone who had helped them to make decisions about "growing up".

By contrast, disabled children in out-of-home care in Kelly *et al's* study (2016) did identify their social worker, along with teachers, carers and birth parents as someone who they could turn to if they had a problem. Several identified their social worker as having been a key source of support at difficult periods in their lives. They also valued similar qualities in their social workers to those mentioned by non-disabled children during child protection enquiries and decision-making, such as making an effort to spend time with them, being non-judgemental and listening to their views.

The differences in disabled children's accounts of their relationships with social workers may be due to the higher level of contact that disabled children in Kelly *et al's* study (2016) had with their social worker as a result of being in care. This view is supported by evidence that disabled children in Wilson (2016) and Preece and Jordan's (2009) study were more likely to discuss their relationships with residential social workers at the short breaks provision they attended, whom they saw regularly, than with their allocated social worker.

Parents have similarly highlighted allocated social workers' lack of contact with disabled children receiving short breaks as insufficient to allow them to develop a relationship or meaningfully involve them in decision-making (Connors and Stalker, 2003; Franklin and Sloper, 2009). As one parent in Franklin and Sloper's (2009) study said “The social worker has seen M about five times in five years. I don’t think they had a relationship in which she’s got any chance of getting any views from M” (p. 8).

However, research also suggests that factors other than level of contact also influence the quality of disabled children’s relationships with their social worker. Disabled children in Kelly’s (2005) study felt social workers mostly talked to their parents and/or only focused on their views about services, which some interpreted as a sign that their social worker disliked them or were not interested in other aspects of their lives. Disabled children in McNeilly *et al*’s(2015) study by contrast appreciated individual practitioners making an effort to build a relationship with them and helped them feel included and that their views were important in decision-making. This highlights the importance of social workers having a positive attitude, making time to get to know disabled children and understand what is important to them in supporting their participation (Kelly, 2005; Franklin and Sloper, 2009).

Social workers’ perspectives

Practitioners and managers consistently indicated their awareness of and commitment to disabled children’s equal right to be consulted about decisions affecting their lives (Taylor *et al*, 2016; Prynault-Jones *et al*, 2017). However, they also identify a number of barriers to undertaking direct work and developing the relationships with disabled children required to achieve this in practice.

Like disabled children and their parents, practitioners’ report a lack of time to visit disabled children regularly as the main barrier to their being able to gain a holistic picture of their lives. They highlight similar pressures on their availability as those affecting social work practice with non-disabled children, including high caseloads and the need to complete statutory tasks and assessments within prescribed timescales (Munro, 2011; Ferguson, 2010;). However, practitioners’ also blame management systems for failing to take into account the additional time and resources required to build relationships with disabled children and include them in decision-making due to their learning and communication needs (Prynault-Jones *et al*, 2017; Taylor *et al*, 2016).

Practitioners’ suggest that the lack of time to regularly undertake direct work with disabled children further limits their opportunities to practice their communication skills with children with a wide range of impairments (Prynault-Jones *et al*, 2017;

Taylor *et al*, 2016). They consistently identify a lack of access to specialist training on how to communicate with disabled children, including on social work degree programmes, as preventing them from improving their confidence and skills consulting disabled children directly (Prynault-Jones *et al*, 2017; Taylor *et al*, 2016; McNeilly *et al*, 2015).

For social workers in child protection teams and in teams supporting looked after children, knowledge of and access to training about how to communicate with disabled children has been described as especially poor (Kelly and Dowling, 2015). They noted that this caused particular difficulties during child protection enquiries, with practitioners with no specialist skills undertaking joint-protocol interviews with children who communicate non-verbally. Taylor *et al* (2016) similarly identified a commitment to treat all children equally and a lack of awareness of disability issues as contributing to practitioners' failure to tailor child protection procedures to disabled children's impairment needs.

Sharing of resources and expertise between practitioners in disabled children's and child protection teams has been identified as helping to address these issues (Taylor *et al*, 2016; Kelly and Dowling, 2015; Ofsted, 2010). Social workers in disabled children's' teams also say that successfully consulting disabled children involves networking with professionals with specialist skills and those who know individual children well, particularly teachers in special schools, as well as being willing to try a range of creative techniques to engage individual children (Prynault-Jones, *et al*, 2017; VIPER, 2013; Ofsted, 2012). However, practitioners' also report that arrangements for multi-disciplinary working are inconsistent, meaning that their access to these specialist resources to support their practice with disabled children is unreliable (Taylor *et al*, 2016). As a result of these pressures and restrictions many social workers describe themselves as "muddling through" when it comes to involving disabled children in decision-making (Prynault-Jones *et al*, 2017; Taylor *et al*, 2016).

Practitioners' acknowledge that their lack of time, skills and resources frequently results in them relying on parents' and carers' proxy views rather than seeking disabled children's views directly. Three-quarters of the social workers in Kelly's (2005) study admitted that disabled children did not really participate in decision-making and that they rarely consulted them directly. However, several also said that even with more time and training they would still view it as often more appropriate to consult parents and professionals rather than communicating with disabled children themselves. Other studies similarly report that practitioners' negative attitudes and assumptions about disabled children's ability to understand and communicate strongly influences the efforts made to involve them in decision-making (Prynault-Jones *et al*, 2017; McNeilly *et al*, 2015; Ofsted, 2012).

Supporting disabled children's participation

Family-based or child centred practice?

It is also important to acknowledge that parents and caregivers are often both a vital source of information and key enablers to supporting disabled children's participation in decision-making. McNeilly *et al* (2015) found that disabled children's participation was strongly grounded in a family-based model of participation, with parents often directly or indirectly advocating on children's behalf. Disabled children themselves often express a clear preference for adults, most often their parents or caregivers, to support them to express their views or to take part in decision-making. Mitchell and Sloper (2011) found young people with communication impairments wanted and valued parents and carers being actively involved in supporting them to make decisions about their lives, challenging the implicit assumption of some hierarchical typologies that children necessarily want to be the main decider (Mitchell and Sloper, 2011).

Practitioners' likewise have a responsibility to work in partnership with parents, including in supporting children's participation in child protection decision-making (Working Together, HM Government 2018). However, as already discussed in the case of disabled children this often appears to be at the expense of children participating themselves (Prynault-Jones *et al*, 2017; McNeilly *et al*, 2015; Kelly, 2005). This is especially concerning given: disabled children's views and priorities often differ from those of their parents' (Dickenson, *et al*, 2007; Welch *et al*, 2014); studies report that parents' tend to under-estimate disabled children's ability to contribute to decision-making (McNeilly *et al*, 2015; Franklin and Sloper, 2009); and that parents' over-protective attitudes can themselves act as a barrier to disabled children's participation (Prynault-Jones *et al*, 2017; McNeilly *et al*, 2015).

Research has also highlighted that parents and caregivers supporting children's participation in decision-making is especially problematic where there are child protection concerns (Kelly and Dowling, 2015). This is particularly where this reflects a lack of effort to focus on the child's needs due to pressures of time. As one practitioner in Prynault-Jones *et al's* (2017) study reflected "I think we can rely on parents and carers too much, to give you all the answers you need quickly, and in child protection cases this may not be the best way" (p.18).

Independent advocates

Several authors have argued that disabled children may particularly benefit from being supported by an independent advocate, given the additional barriers they face contributing to decision-making (Cavet and Sloper, 2004; Martin and Franklin, 2010). Morris (1998) highlighted access to independent advocacy as being especially important in helping to maintain a focus on the needs and rights of disabled children living away from their families in residential schools. Independent advocacy can also help to challenge negative attitudes concerning disabled children's participation among parents and professionals (VIPER, 2013). For example, research has shown that access to independent advocacy improved disabled children's understanding of and confidence taking part in decision-making and contributed to the development of more open and honest relationships with professionals (Franklin and Knight, 2011).

Despite its potential benefits in supporting their participation in decision-making, independent advocacy services for disabled children are lacking. Research by Franklin and Knight (2011) found that less than 3% of disabled children had access to an independent advocate, and that a third of advocacy services had only one advocate able to work with disabled children. Oliver *et al* (2006) also found that children in foster care and those with complex communication needs had particular difficulties accessing advocacy. Independent advocates themselves report similar problems accessing specialist training to help them to communicate with severely disabled children to those identified by other practitioners' (Franklin and Knight, 2011). Independent advocacy is also time and resource intensive and, though children themselves emphasise the benefits of long-term relationships and involvement, a lack of research regarding outcomes can make funding hard to justify (Franklin and Knight, 2011).

Benefits of participation

Disabled children themselves highlight similar benefits to having the opportunity to contribute to decision-making as those identified by non-disabled children. These include an increased sense of confidence and self-esteem when their views are listened to as well as improved self-efficacy extending to other areas of their lives (McNeilly *et al*, 2015; Murray, 2012; Franklin and Sloper, 2009). Though, these studies also highlight that further research is required regarding the longer-term benefits for disabled children of participating in decision-making.

Disabled children in Mitchell and Sloper's (2011) study emphasise that the level of support they require to participate depends on the decision being made. Like other children, disabled children say they want and expect to become more involved and be able to move towards greater autonomy in decision-making as they get older (Mitchell and Sloper, 2011). However, research also shows that when younger disabled children are supported and informed of their rights, they want more say in decision-making and become more confident about participating (McNeilly *et al*, 2015). This demonstrates that age should not be necessarily be seen as barrier to children's participation in decision-making, whether or not they are disabled (Franklin and Sloper, 2009).

Disabled children especially value opportunities for participation when they are "drawn into decision-making processes by adults and recognised as partners in interactions with professionals" (McNeilly *et al*, 20015, p.1). The features of their experiences of participation disabled children mentioned especially valuing include: receiving adequate preparation information and support to enable their participation in formal decision-making processes (VIPER, 2013): and being involved in making choices and feeling that their views are respected, even where they are not the main decider (Mitchell and Sloper, 2011). Disabled children in Franklin and Sloper's study also said they appreciated being kept informed and given feedback by practitioners throughout the decision-making process (Franklin and Sloper, 2009).

Barriers to participation

Like other children, disabled children report feeling frustrated when their views are not respected, and/or they do not receive adequate support to participate in decision-making. For example, when adults do not allow them sufficient time and support to communicate and/or end up speaking for them (VIPER, 2013) Similar issues have been raised in relation to non-disabled children's experiences during child protection enquiries where children are similarly often seen as vulnerable or lacking the competence to participate in decision-making (Holland and Scourfield, 2004). However, Russell (2003) contends that disabled children are seen as less able to participate in decision-making not only on the grounds of being a child but also through being disabled. In practice this often means, due to the continued dominance of the medical model, being defined by what they cannot do, rather than what they can (Watson *et al*, 2005; Raibee *et al*, 2005), as reflected by evidence of practitioners' negative attitudes and assumptions concerning disabled children already discussed.

These same attitudes and assumptions also restrict disabled children's opportunities to make choices and decisions in their everyday lives. Disabled children often experience higher levels of adult surveillance and control both at home and at school, which re-enforces their greater dependency on adults (Raghavendra *et al,* 2012; Priestley *et al*, 2000). This in turn, inhibits disabled children from developing the confidence and skills required to contribute their views within more formal decision-making-processes (Raghavendra *et al,* 2012; Beresford, 2002), such as during child protection enquiries.

As a result of these additional barriers to their participation in other areas of their lives, Franklin and Sloper (2009) to identify a need for disabled children to receive support and training to improve their confidence and skills participating in decision-making, as well as practitioners' receiving training in how to communicate better with them. As others have also pointed out, such activities need to be embedded within an organisational culture of participation, one which recognises disabled young people's equal rights to receive support to participate in decisions affecting them and the redistribution of resources required to achieve it (McNeilly *et al*, 2015).

Conclusion

The research reviewed in this chapter suggests that while both disabled and non-disabled children value and report positive benefits from taking part in decision-making in children's social care, disabled children generally have fewer opportunities and face additional barriers to their participation than those experienced by non-disabled children (Franklin and Sloper, 2009). Disabled children's opportunities for participation are strongly influenced by the nature of their impairments, with those who communicate non-verbally or who have severe learning disabilities being least likely to be informed or consulted during decision-making (Mitchell, 2011).

Practitioners' report a lack of time, training and resources and other organisational factors as restricting their ability to support disabled children's direct participation in decision-making, frequently resulting in an over-reliance on parents' and carers' proxy views (Taylor *et al*, 2016). Though, parents' and professionals' negative assumptions and attitudes regarding disabled children's capacity to understand and express themselves also limits their opportunities for participation (McNeilly *et al*, 2015). Studies also suggest these factors may particularly affect disabled children's right to participate in decision-making being upheld in child protection processes (Taylor *et al*, 2016; Kelly and Dowling, 2015). This provides a strong rationale for the choice to focus on disabled children's own accounts of their participation in child protection decision-making for the research discussed in this dissertation (Stalker and McArthur, 2012).

Summary of themes identified by the literature review

The literature review presents disabled children and young people as a small, but significant group of children within the population, whose needs and perspectives have been relatively neglected as the subject of theory, research, policy and practice. The recurring themes highlighted by the literature reviewed in each chapter include:

- Disabled children and young people's heightened vulnerability to a range of personal and social issues within their families and wider communities

- Disabled children and young people's marginal position as members of society, reinforced by the continued prevalence of segregated service provision

- Evidence of disabled children and young people's aspirations and capacity for agency but of this often being restricted by disablist attitudes and negative assumptions regarding their capabilities.

- The complex nature of the relationship between these personal, social and attitudinal factors and disabled children's increased risk of maltreatment and the inconsistent policy and practice responses regarding this issue.

- The impact on disabled children's sense of self of their limited opportunities to express their views and have these taken seriously. This includes evidence of less support for their participation in decision-making in children's social care

- Research evidence of an inadequate professional response to disabled children's experiences of possible maltreatment.

Box 1 – Summary of themes identified by the literature review

This list is not exhaustive but emphasises the main issues identified that are pertinent to the study's research questions. The literature reviewed suggests that the specific needs of disabled children are not adequately attended to by child welfare services aimed at either their support or protection. It also confirms that little is known about how this is experienced from the disabled child's perspective, underlining the need for the research undertaken for this dissertation.

Part 2

Methodology

Chapter 4 – Methodological considerations

Introduction

This chapter discusses how the study was designed and conducted. It starts by outlining the study's aims and how the methods chosen and the overall study design, were informed by the theoretical perspectives on childhood disability discussed in chapter 1. In view of the sensitive topic and participants' vulnerability, particular attention is paid to explaining how ethical issues were attended to and access to the study sample negotiated. The approach taken to collecting and analysing participant data is then described, including the challenges that arose and how these were addressed. The chapter concludes with a discussion of the study's limitations and my reflections on the impact on me of the research process, both personally and as a researcher.

Study aims

The study's main aim was to explore disabled young people's social worlds and their views and experiences of child protection enquiries and their aftermath. It was guided by the following research questions:

- How do disabled young people see themselves within their families and wider social worlds?
- What are disabled young people's experiences of child protection enquiries and taking part in decision-making?
- What are disabled young people's experiences of receiving help and support following initial child protection enquiries?

These questions were informed by the findings of similar studies involving non-disabled children (Bell, 2002; Cossar *et al*, 2011). However, this study also aimed to tease out whether, and in what ways, being disabled impacted on young people's experiences of child protection enquiries and receiving help. This premise was informed by the social model of disability, which draws attention to the structural and attitudinal barriers disabled children face due to their impairments that result in their social exclusion and limit their participation (Davis *et al*, 2003; Connors and Stalker, 2007). However, in view of critiques of the social model of disability's limitations (Shakespeare and Watson, 2001), in conducting the study account was also taken of variation in participants' identities and experiences of impairment and their agency in negotiating their day-to-day lives (Davis *et al*, 2003).

The intention to capture disabled young people's sense of themselves, their families and their wider social networks was likewise founded on an understanding of them as holders of rights (UNCRC, 1989; UNCRPD, 2006) and reflexive "social agents who actively negotiate their lives" (Watson, 2012, p194). This approach is also consistent with Carpenter and McConkey's (2012) appraisal of existing research that disabled children's perspectives are best understood by considering their lives "as a whole, including their friendships and developing identities … not just their involvement with the "service world" of professionals and agencies" (p. 258). Such an approach allows an exploration of how the tensions between the structural, process driven demands of childrens' social care and young people's autonomy and agency play out in their individual lives (Cossar *et al*, 2011).

Theoretical influences on choice of methodology and research design

The four theoretical perspectives identified in chapter 1 as relevant to understanding disabled children's lives (developmental psychology, childhood studies, disability studies and human rights perspectives) have each been applied to previous research with disabled children (Davis *et al*, 2003; Kelly, 2005; Connors and Stalker, 2007; Larkins *et al*, 2013). However, as Carpenter and McConkey (2012, p.256) argue, the links between theory and methodology have not always been made explicit, creating an obligation for future researchers to better explain the rationale for their choice of methods and the theoretical positions underpinning them.

Drawing on the insights set out in chapter 1, Figure 7 conceptualises the similarities and differences between these theoretical perspectives. I will explain how each informed the study design and the choice of a qualitative participatory methodology.

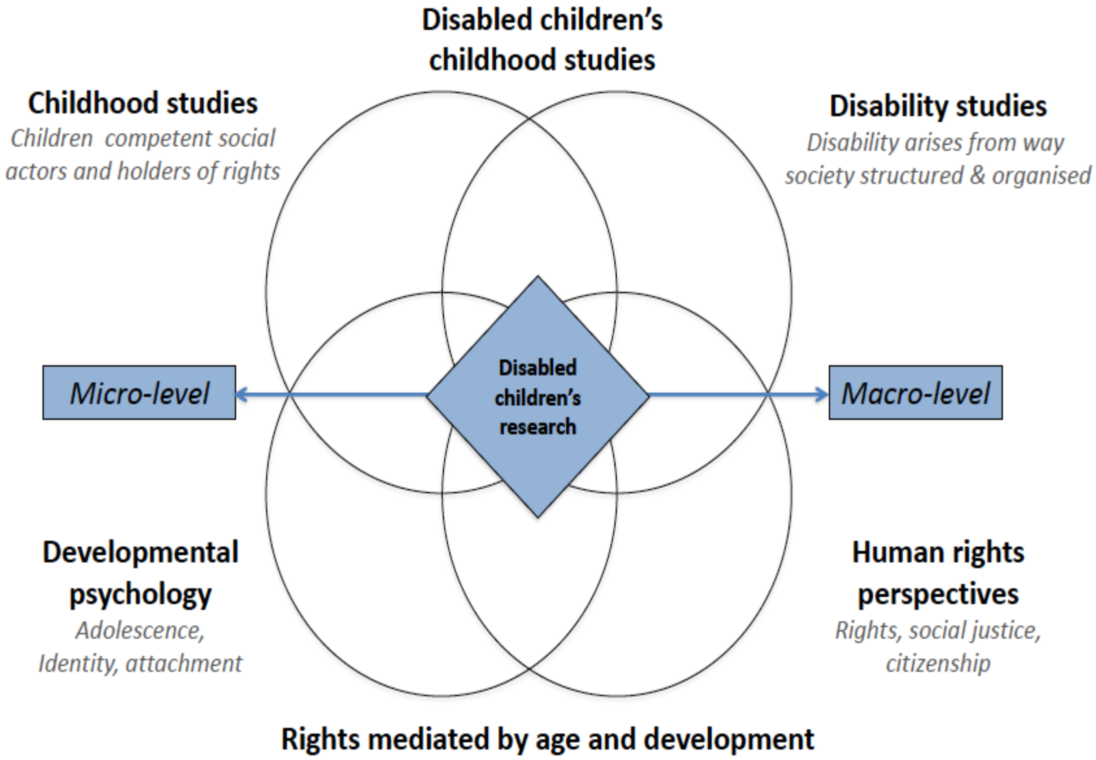

Figure 7: Theoretical perspectives informing the study design

Despite their different emphases on "micro" or "macro-level" processes, disability and childhood studies share an ontological view of reality as socially constructed through subjective experience. This is consistent with a qualitative or interpretative research paradigm which seeks to understand how individuals and groups make sense of particular events, processes and relationships (Braun and Clarke, 2013). In addition, a qualitative methodology was felt likely to be the most effective in capturing the interplay between young people's "micro-level" needs experiences and the "macro-level" driven priorities of the child protection system. This was partly informed by theoretical developments within disability studies outlined in chapter 1, which view disability as arising from complex interactions between the individual, their impairments, and wider factors in the environment (Shakespeare and Watson, 2010).

Qualitative methods are further considered particularly appropriate for giving voice to those whose views have previously been marginalised. They are therefore consistent with a human rights approach, since they help to challenge the macro-level "hierarchy of credibility" (Becker, 1967) within which the views of those with greater social power have traditionally been given more weight in research (Beresford, 1997). This reflects this study's aim, influenced by the emerging field of disabled children's childhood studies, to redress the tendency of previous research on this topic to prioritise professionals' and caregivers' perspectives and instead place the views, priorities and aspirations of disabled children at the heart of the research enquiry (Curran and Runswick-Cole, 2014).

The use of participatory methods, using activities tailored to young people's individual needs, was also informed by developments by researchers within childhood studies (Christensen and James, 2008) and also disabled children's childhood studies (Kelly, 2007; Wickenden, 2011), as well as an understanding of participants' developmental needs and trajectories. A participatory approach allowed me to pay attention to young people's emerging adolescent identities, interests and aspirations. It also allowed young people some opportunity to influence the course of the interview and the topics discussed, informed by an understanding of them as competent social actors, reflecting the approach taken within childhood studies (James and Prout, 1990). Undertaking activity-based interviews additionally helped me to uphold disabled children's equal right to take part in research by overcoming disablist assumptions that, owing to their impairments, they lack the capacity to meaningfully participate in research, since they create too many challenges for conventional methods to be used (Beresford, 1997).

The inherent flexibility of a qualitative and participatory methodology also allowed me to include questions and activities that would allow young people to express their experiences of macro-level processes and relationships in a non-threatening and age appropriate manner, e.g. by constructing an eco-map. I was also interested in gaining an in-depth understanding of the organisational and attitudinal factors affecting young people's experiences of child protection enquiries and decision-making processes. As I anticipated some participants might have less awareness of these issues due to their developmental stage, I also decided to interview their caregivers, albeit that this data was viewed as supplementary to young people's accounts. The decision to interview parents and carers was also partly influenced by difficulties recruiting participants early on in the research process, as discussed later on in the chapter.

Taking a qualitative approach was also appropriate for methodological and ethical reasons. Firstly, methodologically the paucity of previous research regarding child protection practice with disabled children and young people would have made the design of quantitative measures difficult to achieve. Wide variation in disabled young people's level of understanding and preferred method of communication would have made the use of questionnaires or existing measures problematic. Moreover, the heterogeneity of disabled young people would have made it difficult to recruit a representative sample. An additional consideration was the particular suitability of qualitative methods for eliciting participant views concerning sensitive topics. This is reflected by most existing studies concerning non-disabled children's experiences of child protection processes having used qualitative methods (Bell, 2002; Leeson, 2007; Cossar *et al*, 2014).

Epistemological tensions and challenges

Despite the obvious suitability of qualitative and participatory methods for eliciting disabled children's perspectives, there are also tensions and challenges associated with this approach. Careful preparation and planning were therefore required, prior to and during data collection and analysis to take account of these to ensure that the study's research design was robust and methodologically sound (Beresford, 1997; Kelly, 2007).

For example, research focusing on children's "voice" has been criticised for tending to privilege verbal communication, with the risk of prioritising the views of the most articulate and marginalising the views of those who communicate little (Lewis, 2010), or rely on non-verbal methods of communication (Komulainen, 2007). Since these risks are particularly relevant to disabled children's involvement in research (Tisdall, 2012), a range of recruitment and interview materials were developed for participants to use during interviews in order to take account of individual young people's communication and learning needs.

Critics have further questioned the validity of findings generated by qualitative methods due to the influence of researchers' personal assumptions regarding childhood and disability when interpreting participant data during the analysis (Davis *et al* 2000; Kelly, 2007). It also needs to be acknowledged, however, that all research whether quantitative or qualitative is value laden and open to bias (Silverman, 2011), and qualitative research is understood as a subjective process within which participants and researcher are understood as engaged in co-constructing meaning (Braun and Clarke, 2013).

Nevertheless, the intrinsic bias created by adult researchers selecting quotes that are supposedly representative of children's voices creates added difficulties in legitimising research involving children (Tisdall, 2012). This required me to take a reflexive approach throughout the research process, in order to limit and/or show my awareness of the bias created by my involvement (Taylor and Bogdan, 1998). The steps taken included; being transparent regarding my personal and theoretical standpoint, as outlined above; writing fieldnotes and memos throughout the research process in order to keep track of and reflect on my own thoughts and responses to participant data, as well as exploring these issues further in supervision (Braun and Clarke, 2013); making sure to report negative or contradictory findings alongside recurring themes in the analysis (Silverman, 2011); and creating opportunities for participants to comment on the analysis (Kelly, 2007).

Research design

For the reasons outlined a small-scale investigation using qualitative methods was chosen to explore disabled young people's social worlds and experiences within child protection processes. Semi-structured interviews were decided upon as the most appropriate method of data collection, since it was felt that participant confidentiality and any emotional distress would be more appropriately managed within an interview setting, given the sensitive nature of the topic.

Semi-structured interviews also allowed the inclusion of topics relating to the research questions, particularly in view of my intention to use thematic analysis to explore participants' accounts, while still allowing young people themselves to influence the direction of the interview. This creates opportunities for researchers to explore "the texture and weave of everyday life, the understandings, experiences and imaginings of our research participants [*research question 1*], the ways social processes, discourses or relationships work, and the significance of the meanings they generate [*research questions 2 and 3*]." (Mason, 2002: page 1).

As already discussed, participatory tools and activities were incorporated within interviews to maximise young people's active involvement in recognition of their rights and agency (Christensen and James, 2000); to make taking part as engaging and fun as possible and promote the inclusive involvement of young people with cognitive or communication difficulties (Morris, 1998; Connors and Stalker, 2003).

In view of the additional time often required to build rapport with disabled young people, especially those with communication impairments, I planned to arrange to hold more than one interview with individual participants where this seemed necessary. I was also aware, however, of the need to balance this with the risk of causing participants undue distress, given the emotive nature of the topic being discussed. Young people's parents or caregivers were interviewed separately, in order to help contextualise their accounts.

Development of Research Materials

Activities used in previous studies (Christensen and James, 2008; Cossar *et al*, 2011; Thomas and O'Kane, 1998; Connors and Stalker, 2003) were used as a starting point for devising an initial interview and activity matrix based on this study's research questions. A separate, much briefer interview schedule, for use with parents was also designed covering broadly the same topics, after the decision was made to interview them. The activity matrix and interview schedule for parents are included at Appendix 4 and 5.

Consulting a group of disabled young people to test out recruitment materials and activities used during interviews with young people also seemed essential to: ensure what the research was about and would involve was communicated to young people in as resonant and engaging way as possible (Christensen and James, 2008); improve the validity of the research design (Morris, 1998) and help mitigate unequal power relations between the researcher and researched (Beresford 1997).

A local Youth Forum run by a disabled people's organisation agreed to be involved. Members were aged between 14-25 and had a range of impairments. Lewis *et al* (2008) identify advantages to consulting existing reference groups in terms of avoiding recruitment and timing problems and providing greater continuity for young people once the research ends. However, these authors stress the need to establish ground rules regarding young people's involvement and how they will be rewarded even when using an existing reference group. Therefore, I met with the group's project officer prior to meeting group members to discuss my aims, the terms of reference for the consultation and an information sheet which he shared with members beforehand (Appendix 6 and 7). Members also received a £10 voucher and a certificate to thank them for taking part.

We had two sessions together, each session was attended by seven young people supported by two project officers, an interpreter for one young person and two volunteers. During the first session the group commented on draft copies of two types of recruitment materials (one easy read/picture based). Group members, several of whom had learning difficulties and/or visual and communication impairments, made valuable suggestions on the use of symbols, photographs, layout, colour-scheme and wording of the materials (noted in Appendices 8 and 10).

Materials were re-drafted and further alterations made following members comments at the second session (draft/final copies are included in Appendices 8 to 11) during which members also tried out and made suggestions about interview activities. These included using Widgit symbols (a widely used visual communication system) with the '*My week tool'* (Christensen and James 2008) to make it accessible for young people who have difficulties reading or writing. Members felt the "pots and beans" activity to talk about meetings (O'Kane, 2008) was too complicated and should be left out as it would be better to ask young people simple questions instead.

Youth Forum members' involvement undoubtedly made an important contribution to making the research more accessible. However, there were some limitations to their involvement. Firstly, members' participation was facilitated and sometimes prompted by the Project Officers and other adults present meaning it was sometimes difficult to distinguish their contribution from those of young people. This could have been overcome by appointing individual disabled young people as project advisors (Kelly, 2007) or establishing a specific reference group (Taylor *et al*, 2015).

Secondly, none of the group to my knowledge, had direct experience of child protection processes and very few had a social worker. This was partly overcome by asking for feedback on recruitment materials and interview activities from the pilot interview participant Nicola, who told her social worker that she "*got a lot from seeing the symbols on your sheet; and thought you looked nice".* Nicola's comments and my own reflections on this pilot interview are included at Appendix 12.

Sampling considerations

A purposive sampling strategy (Spradley 1979) was used to identify disabled young people as potential research participants for this study. The initial sampling criteria were:

- Disabled young people aged 11-18
- Subject of a Child Protection Conference or Plan within the past 2 years
- Not in public care

The age range was chosen as previous studies have shown that older non-disabled children generally have a greater understanding and ability to discuss their experiences within child protection processes (Cossar *et al* 2011). The study sought to recruit approximately 20 disabled young people with a diverse range of impairments. Based on the experience of researchers in previous studies (Kelly 2007, Connor and Stalker, 2003) it was anticipated that the cognitive abilities required to understand the abstract concepts involved in discussing their experiences of child protection enquiries and decision-making processes might preclude some disabled young people from taking part, however. Although not intended to be representative, it was also seen as desirable to seek to achieve a reasonably diverse sample of participants of different ages, gender and cultural backgrounds.

It was also seen as preferable for young people's experiences of child protection enquiries and decision-making to be current or within the previous year, to aid recall of the details of their experiences and minimise bias associated with retrospective accounts. Initially, the decision was made to exclude young people in care, to avoid young people confusing their experiences of child protection procedures with those associated with becoming a looked after child or young person.

Ethical considerations

Ethical considerations are heightened when undertaking any research with children and young people, given their relative lack of power and also often of knowledge and understanding (Alderson and Morrow 2011). In view of the intended sample such concerns were particularly likely to apply in this study given participants' potential greater vulnerability and limitations arising from their impairments and alleged experiences of maltreatment.

Seeking participants' views and experiences of child protection enquiries and their aftermath was considered justified, however, in view of the study's aim to increase knowledge and policy and practice sensitivity to disabled young people's needs. This is particularly important given that disabled children are known to be especially vulnerable to maltreatment (Jones *et al*, 2012). Their views and concerns remain marginal within childhood research and society in general (Stalker, 2012) and there is evidence that their rights are frequently inadequately upheld by service providers, including those within child protection processes (Cooke and Standen, 2002; Ofsted, 2012).

Ethical approval

I sought to minimise the potential risks to participants while upholding their right to take part by maintaining the highest ethical standards throughout. Accordingly, ethical approval for the study was obtained from the University of East Anglia School of Social Work Ethics Committee on 18th July 2013 (Letter confirming ethical approval included at Appendix 13). I additionally obtained Research Governance approval from participating local authorities as required by their procedures.

Managing risk and distress

Owing to the particular vulnerability of potential study participants I decided to contact them via their social workers. This was because, knowing the young person's circumstances and needs well, I considered them well placed to assess the potential risks to them of taking part. It also meant they could be contacted and provide support in the event that participants made a new disclosure of abuse, requiring an exception to be made to their confidentiality.

I remained mindful that the study's topic represented an emotive issue for all participants, however. As an experienced social worker, I felt confident in my ability to interview sensitively, respond appropriately to young people's distress, reduce potential conflict and signpost them to support services. However, I also emphasised participants' choice not to answer certain questions, take a break when needed, or to terminate the interview at any stage. I remained alert to participant's non-verbal cues during interviews and checked with them that they were happy to continue if they appeared anxious or distressed.

I took care to debrief participants to minimise any distress arising from taking part by providing information at the end of interviews on how to complain if they were unhappy with any aspect of the process and regarding other sources of support (Appendix 14 for an example debriefing sheet). I also asked young people to identify a professional able to provide on-going support (Morris, 1998) and checked they knew how to contact them.

As a lone researcher undertaking home visits, I also considered safety issues for myself and others. I telephoned young people's caregivers usually more than once before interviews and also spoke to their social worker to discuss any issues that might arise. On the day of interviews, I made sure others knew where I had gone and expected to be finished. I kept a mobile phone with me and arranged for someone to phone me if I had not contacted them by the agreed time. I additionally resolved to terminate any interview if it appeared that to continue would exacerbate a risky or distressing situation for the young person, another person or myself. When upsetting information was raised by participants, I subsequently sought support from my primary supervisor.

Informed assent and caregiver consent

Prior to gaining young people and their caregivers' agreement to take part they were made aware that their participation in the study was voluntary and that they could withdraw at any time without giving an explanation. Information in a range of formats was provided in advance of arranging interviews, including easy read and separate information for parents and carers (Appendices 7, 9 and 12).

I went through this information with young people and their caregivers again at the start of interviews: checked that the arrangements met the young person's individual needs; that they were still happy to take part; understood what would happen; how information will be used and that their identity would be kept confidential. I also explained to young people that they could stop the interview at any time, skip any questions or activities they did not wish to answer/ take part in. I provided a stop-go card to young people to make it easier for them to indicate this to me during the interview. Finally, I checked with participants whenever they appeared upset, bored or tired that they still wanted to continue.

Wherever possible written agreement to take part in the study was obtained directly from young people themselves, using an agreement form appropriate to their needs (Appendix 16). Those with learning and communication difficulties were asked to indicate their willingness to take part verbally or using their usual communication method, verified by their parent or an interpreter where appropriate. Many participants were likely to be 'Gillick' competent to independently consent to taking part in the study. However, it was difficult for me to be confident of this without prior knowledge of their level of understanding. Therefore, consistent with the approach taken in similar studies (Kelly, 2005; Cossar *et al*, 2011) young people's agreement was treated as their assent, meaning that their parent or carer's written consent was additionally required for them to take part in the study (Appendix 17). Participants were given a certificate and £10 gift-card in recognition of their contribution and invited to comment on a summary of the study's findings at a later stage.

Confidentiality and data storage

Young people and their carers' were asked to give permission for interviews to be tape-recorded. I explained that the recording would be kept safe, used only by myself for research purposes, and deleted once transcribed. I also explained that no identifying information would be kept by myself as the researcher, that their contributions would be anonymised, and pseudonyms used to prevent them from being identified in the final report and any presentations or publications arising from the study.

While young people were assured of their anonymity and confidentiality while taking part in the study it was also made clear that an exception to this would be where they raise concerns to the researcher that either they or another child or young person is at risk of or experiencing abuse or harm. A protocol for managing any disclosures of risk or abuse to young people arising during the study was agreed with participating local authorities beforehand.

Throughout data analysis interview transcripts have been stored in NVivo in password protected files. Participants' identifying data such as names, addresses and contact numbers remain stored in a paper file in my office, locked when not in use, and will be destroyed once the thesis has been submitted.

Negotiating access to participants

Recruitment process

Having designed the study and gained ethical approval, initial approaches were made to six Local Authorities seeking their support to recruit study participants. Three authorities eventually agreed to take part, including two large county councils and one London borough. A further participant was recruited via a national impairment specific charity, due to my role as advisor in a project they were running. Information regarding the study was then presented to senior managers and child protection and disabled children's social work teams (Appendix 18). The approach used to negotiate access to individual participants varied, as shown in Figure 8. overleaf. However, telephone calls and face to face meetings with team managers and individual practitioners were generally more effective than letters, emails or contact with senior managers.

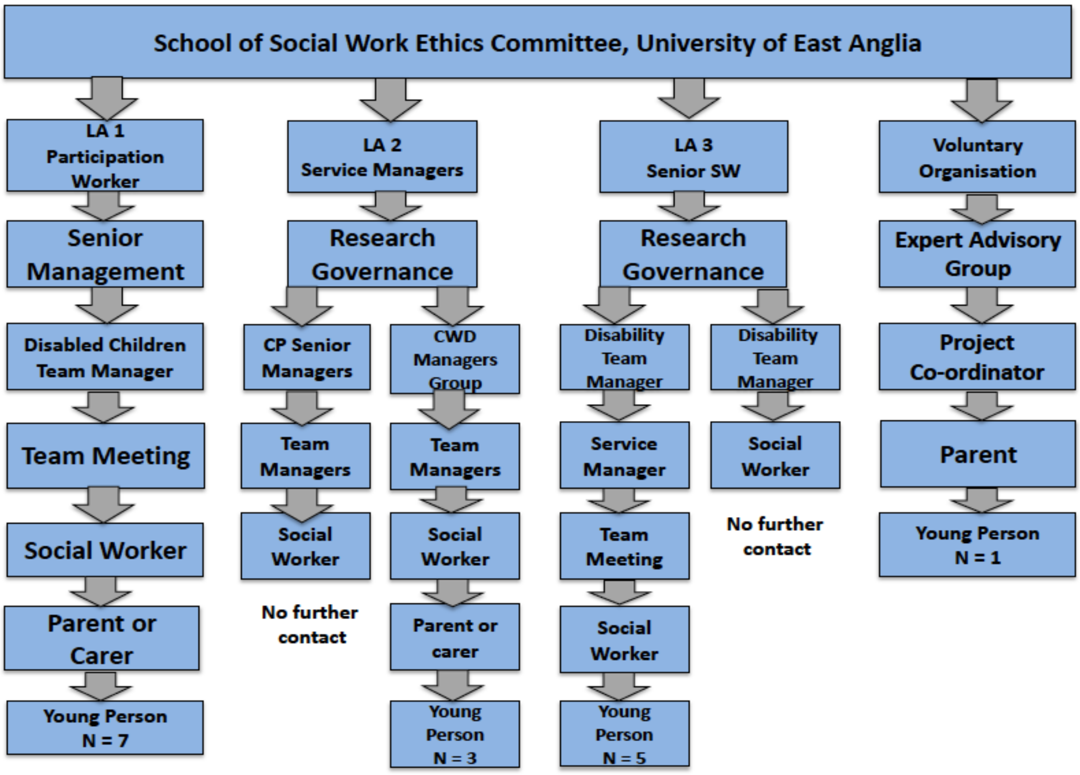

Figure 8: Recruitment process

Once teams had identified potential participants their social workers were asked to pass on an information pack to them and their parent or carer inviting them to take part. This included: a flyer introducing the study (Appendix 9); a letter to parents and carers; a leaflet providing full information regarding study aims and procedure (Appendix 15); a version of the information sheet for young people (Appendix 11).

Social workers were asked to contact young people's parent or carer 1-2 weeks later to enquire if they wanted to take part. With their permission, interested participants' contact details were passed onto me as the researcher. I then phoned the young person's caregiver to arrange a suitable time and place to meet.

Recruitment challenges

The difficulties I encountered identifying and recruiting potential participants are similar to those reported by researchers in similar projects (Cossar *et al*, 2011; Taylor *et al*, 2015) and are summarised in Appendix 19. Social work teams in all local authorities commented that the number of potential participants was limited by the low numbers of disabled children with child protection plans, a trend that has been reported nationally (Ofsted, 2012).

The response from team managers of child protection teams was notably poor, with most failing to respond. It may simply have been that these managers were too busy to respond due to high caseloads and/or the intensive nature of their work. However, those who did respond said they worked with disabled children only very occasionally or not at all, indicating that it may also reflect a tendency to define 'disability' in terms of eligibility for specialist support. This is despite disabled children's team managers in these same authorities stating that the number of potential participants was limited due to the fact that they only worked with severely disabled children.

Consequently, this study generally concerns disabled young people's experience of involvement with specialist disabled children's teams. Commitment to the study also varied between disabled children's teams, however. One team who initially agreed to take part, later withdrew due to workload pressures. Two out of three disabled children's teams in another authority said as they could only identify one or two potential recruits, they did not see any point in my attending their team meeting to discuss further.

Despite my efforts to promote an inclusive recruitment strategy several social workers raised concerns about the ability of some young people to understand the research, further limiting the pool of young people they were willing to approach. In addition, several parents who social workers approached declined saying they were too busy or were concerned that taking part might disrupt the progress their family had made. These difficulties highlight the tensions and challenges of relying on adult gatekeepers to facilitate access to disabled young people to participate in research. Some young people may themselves have wished to take part in the research, for example, but were not given the choice due to their social worker or caregiver's reservations.

These difficulties also inevitably created delays to the research process. Consequently, I decided to broaden the scope of the sample to include any young person who had been the subject of child protection involvement, including those in care and whose involvement had been more than two years previously. The decision to include young people in care was based on the understanding that living away from their families represents an important part of child protection processes for many disabled children. These young people are also likely to have experienced maltreatment of a more serious nature and therefore likely to be in greatest need of support from social workers to help them recover from their experiences of trauma and abuse. By contrast, studies have shown that young people tend to become less negative about child protection processes as time passes (Thoburn, *et al*, 1995). These changes were therefore felt likely to facilitate the inclusion of a broader range of disabled young people's views and experiences of child protection enquiries and their aftermath.

It was also at this point that I decided to interview parents and carers in addition to young people themselves. This decision was the result of conversations with other researchers and noting from articles that supplementary data from caregivers represents a valuable source of contextual data in research with disabled young people (Franklin, *et al*, 2015). In view of this, caregiver interviews were recorded, transcribed and the data used to inform the analysis of young people's accounts using the approach outlined later in the chapter, though young people's accounts remained the primary focus of analysis. It was also hoped that interviewing parents might allay their concerns about how data would be used and support and encourage their children to take part, since previous researchers have noted that caregivers of disabled children tend to be more protective about their children getting involved in research (Kelly, 2007; Abbott, 2012).

Data collection

Who took part?

These changes eventually led to 16 disabled young people, 14 parents and 4 carers taking part in the study. The young people were all aged between 11 and 17 (mean age 14.7 years). The sample of young people was reasonably balanced in terms of gender (10 girls and 6 boys) and included 4 young people from minority ethnic backgrounds. Participants had a range of impairments (11 had learning difficulties, 5 had Autistic Spectrum Disorders, 4 had physical disabilities and 4 with a long-term health condition). Ten young people were living with their birth families at the time they were interviewed and 6 were living in care.

Data collection was focused on the perspectives of young people themselves. However, as already outlined in common with similar studies (Connors and Stalker, 2003; Kelly, 2005; Franklin and Smeaton, 2018) interviews with caregivers helped me establish rapport with young people and gain a better overall sense of their lives and relationships, particularly as I did not seek to access their children's services files. A total of 14 parents (9 mothers and 5 fathers) and four foster-carers (3 females, 1 male) were interviewed. Two participants living in residential care were supported by care staff during interviews, but these staff members were not interviewed separately.

Undertaking interviews

Establishing parameters – Where, when, how?

Setting and timing

Apart from the pilot interview, I initially met young people where they were living. This was also where nearly all interviews took place. Being interviewed in their home environment seemed to help most young people to relax in my presence after a while. It also provided an added sense of context to their accounts. The main downside was the lack of privacy associated with the usual interruptions and routines of everyday life and negotiating a space to speak with young people alone, a difficulty noted by previous researchers (Abbott, 2012; Cossar *et al*, 2011). In one case these difficulties led to my visiting one young person at school instead.

I adopted a similarly flexible approach to arranging a second interview with other participants, due to my awareness that building rapport with disabled young people can take more time (Morris, 2003; Boggis, 2011). Most young people and their families opted to be interviewed only once, however. With hindsight this was appropriate as the emotive nature of the topic contributed to some participants becoming upset during interviews. Researchers involved in previous studies with disabled young people on sensitive topics report taking a similar approach (Abbott and Carpenter; Taylor *et al*, 2015). Like them, I do not feel that interviewing participants only once significantly affected the quality of interview data, although for some young people it may have been preferable on reflection.

Moreover, spending an extended period (between 2-3 hours) in the family home due to interviewing young people and their caregivers on the same day provided greater opportunities to build rapport with young people than may otherwise have been the case. Over half of interviews were during the school summer holidays, which perhaps also contributed to participants' taking a more relaxed approach to the length of my visit. Though, I was also careful to observe signs that I had outstayed my welcome.

Caregiver involvement

Caregivers involvement was also often instrumental in helping me engage young people, especially at the start of interviews when explaining the study and gaining young people's agreement to take part. As well as being ethically necessary, this often felt like a rite of passage, since it allowed participants to decide about my credentials, what Abbott (2012) terms "overall niceness". Following this interaction most young people confirmed their willingness to talk with me alone, partly perhaps in response to the cue from their caregivers that this was ok.

A few young people opted for their caregiver to be present during interviews. This meant that the data produced involved a degree of co-construction and associated risk of bias that is perhaps not ideal from a research point of view, albeit outweighed by the need to respect young people's wishes. Although it may have proved possible to speak to these young people alone by offering to do a second visit, I was also aware that disabled young people commonly prefer their parents to support their participation in decision-making in practice (Mitchell and Sloper, 2011), and may otherwise choose not to take part. All participants, whether interviewed alone or not, were in any case likely to be influenced in what they shared by knowing that their caregiver was nearby and maybe listening.

Developing rapport - activities and agency

I started interviews by sharing with participants the box of activities that could be used during interviews. I asked them to choose a stop/go sign (with words or happy/sad face) to use if they wanted to stop, take a break or skip questions at any point and also allowed participants to familiarise themselves with the digital recorder. Several took the opportunity to ask questions and most seemed to appreciate setting ground rules in an active way rather than just signing a form.

I then asked young people about their interests using the “My week tool” (example Appendix 20). Most appeared to enjoy talking about themselves and their achievements, some also took the opportunity to ask questions about me, which also helped to establish rapport. This usually led quite naturally onto completing an eco-map of people participants’ considered important and using the ‘helping people cards’ (Cossar *et al*, 2011) to talk about their relationships with professionals. Activities using visual prompts, photos, pictures, symbols or stickers generally worked better than those involving writing, especially with younger participants and those with learning disabilities. I overcame this by asking participants if they wanted me to write on their behalf, for example, when asking them to think of 5 things about their social worker using the ‘Hand Tool’ (Appendix 21). Writing activities also helped prompt a more relaxed interviewing style with older young people without learning disabilities, for whom visual activities seemed less appropriate.

An important and unanticipated benefit of using activities was that it often prompted participants to show me certificates or medals from their activities and/or photos of themselves and their families. As well as creating a more natural feeling to the interview, it also allowed young person to exercise their agency and allowed a sense of creativity and collaboration to develop between us, which I felt went some way towards re-dressing the power differentials between them and myself (Christensen and James, 2008). One young person showed me the incentive system used at his residential placement, for example, prompting a lively discussion about fairness and his difficulties managing his behaviour. Although, I was careful not to allow such opportunities to detract from the focus of interviews.

Building understanding

Aware of the importance of good communication when interviewing disabled young people (Morris, 1998), I tried to learn as much as possible about individual participants' preferred method of communication and level of understanding from their caregivers and social worker beforehand. For one participant with complex communication needs I visited the manager of the short breaks unit he attended and arranged to use family photos and symbols from his communication passport to tailor the interview to his specific needs (Appendix 22).

With all participants I also took time to check back with them during interviews that I had understood their responses correctly if I was unsure what they meant. In order to take account of increased suggestibility among young people with learning difficulties (Sigelman *et al*, 1981), I used a range of different questioning styles, focused on using simple language and avoided asking leading questions (Lewis and Porter, 2004). I also ensured questions related directly to young people's everyday lives rather than reflecting my own interests (Pilnick *et al*, 2010).

In practice building understanding between myself and individual young people was very much a process of trial and error. This was the main drawback of usually only undertaking one interview. However, young people were usually very accommodating when difficulties arose, perhaps partly as a result of being used to collaborating with adults to make themselves understood. One young person with cerebral palsy used her iPad to type words or phrases when I found it difficult to understand her, and also appeared to find a self-depreciating joke I made comparing myself with her social worker funny, leading to a useful discussion about how much she valued her social worker taking time to get to know and understand her well.

I encountered particular difficulties during one of the research interviews communicating with one BAME participant. Mark's family are Chinese. However, I was surprised to see an interpreter arranged by his social worker when I visited as she had not told me Mark's father spoke little English. Mark appeared very comfortable with the interpreter, who apparently regularly interpreted the family during child protection visits and meetings. However, Mark was very reluctant to engage with me. There were other difficulties during the interview each of which may also have played a part. Mark was one of the youngest participants, he was clearly tired from the school day and also has autism. However, although Mark alternated between using English and Chinese, the interpreter's presence severely reduced my ability to establish rapport with him and also made it extremely difficult to estimate the effect on how he responded. This experience forcibly highlighted for me the additional and multi-layered barriers disabled children from BAME backgrounds face being involved in research or practice (Marchant, 2003), including during child protection.

Handling difficulties and distress

Despite my best efforts to engage young people some participants gave very limited responses during interviews. This was possibly due to difficulties understanding or articulating their thoughts because of their impairments; being unused to adults asking their views as a result of the negative assumptions often made regarding disabled young people's competence (McNeilly *et al*, 2015); a lack of confidence related to maltreatment experiences or the emotive nature of the topic. Aware of these reasons I tried to avoid using closed questions due to the likely tendency for young people to respond affirmatively (Sigelman *et al* 1981; McAuley, 1996).

Participants' unresponsiveness did result in my sometimes needing to employ a more direct interviewing style, however. While I simultaneously adopted a flexible and inclusive understanding of communication (Boggis, 2011) by remaining attentive to young people's non-verbal cues and behaviour, and responding reflexively to participants' silences (Lewis, 2010), especially if it appeared to be a sign of their anxiety or distress.

A few participants also became visibly upset during interviews. I attempted to reassure them and asked them if they wanted to continue, which they generally said they did. This presented me with a dilemma, wanting to respect their wishes but not wanting to cause further distress and also being aware of disabled young people's tendency towards acquiescence (Sigelman *et al*, 1981). My response was to continue but to switch to a neutral topic and seek to draw the interview to a close if their distress continued. I also took care to acknowledge their distress at the end of interviews and asked if they wanted to seek support from their caregiver or nominated professional.

Due to my concern for her emotional welfare, with her permission, I did decide to mention one young person's distress to her foster-carers at the end of the research interview. Another young person became anxious due to her mother becoming distressed while I was interviewing her (the young person was in the next room). Her mother and myself both attempted to reassure her, and I also spent some time talking with them together at the end of the interview to make sure they were OK and did not wish to contact anyone for support. I did not contact the social worker for either of these participants as their distress did not directly relate to maltreatment concerns. In reaching this decision I was also mindful of the need to avoid using my professional judgement in a research context.

Data Analysis

After the interview

I made fieldnotes directly after interviewing each participant. This helped me reflect on issues and challenges that had arisen for participants and myself during interviews. Making fieldnotes also helped me to note similarities and differences between individual participants and other study participants' accounts. This, in turn, helped me to start asking questions of the data in relation to each of the study's research questions, in preparation for the process of analysis (Silverman, 2013). The process of making fieldnotes also helped me identify areas to explore further in subsequent interviews, and to build up an overall sense of participant data from the outset (Charmaz, 2006). Though I did not formally code fieldnotes, I found them a useful and important source of supplementary data to refer back to during the process of analysis and interpretation. The questions I used to guide to my writing of fieldnotes and a sample fieldnote are included at Appendix 23 and Appendix 24.

Translating speech into text

I made time to listen back to the audio recording as soon as practicable after every research interview. This process was important in allowing me to reflect more fully on the experience of interviewing each participant. I made careful notes on particular silences during each interview, as well as noting any moments I specifically recalled as being accompanied by strong emotion for either myself or the participant. I viewed listening back to participants' interviews as important, given Riessman's (1993, p. 11) observation that the record of the interview encapsulated in audio form is, itself, only a partial representation of the actual experience. Therefore, I considered it imperative to record these subtle poignancies, in order to reduce the risk of these becoming lost in the process of converting talk into text through transcription.

As I had already decided that my main focus during data analysis would be on the meaning of speech rather than on sounds or individual words, each participant's interview was transcribed verbatim. This meant that rather than inserting every discourse marker (as in discourse or conversational analysis) punctuation was used to represent pauses and delays in speech during interviews. I additionally noted any prominent non-verbal cues, such as participants' laughter and any relevant actions. For example, I noted when participants referred to their drawing, or the use of visual materials during interviews, such as photos or pictures of professionals. I recorded each of these instances in square brackets. My interpretation of strong emotions expressed by participants during interviews were also inserted where this was considered relevant. My recording of participants' emotions was based on fieldnotes, my notes from listening back to the audio recording, as well as my own recollections of the interview.

As far as possible I transcribed participants' interviews myself, as I recognised it was important to interact with participant data, especially during the early stages of the analysis, in order to gain an overall sense of the themes emerging from disabled young people's accounts. In total I transcribed around a quarter of participant interviews. However, I made the decision to have later interviews professionally transcribed. This was because I felt that the time the process of transcribing interviews was taking, due to my lack of experience, meant I was at risk of becoming "lost in transcription" (Silverman, 2013, p. 293). In view of the delays already caused by my difficulties recruiting participants, I was also concerned to leave sufficient time for the process of conducting the analysis. In addition, I felt my time could be more productively spent carefully checking interview transcripts for accuracy, especially given that some participants' comments, particularly those with communication impairments, were difficult to understand. I also felt that the process of repeatedly listening back to audio-recordings allowed me sufficient opportunity to familiarise myself with each participant's account. This process of familiarisation with the data is, in itself, an important first step in the process of data interpretation and analysis (Braun and Clarke, 2013).

Analytic approach

Thematic analysis was the approach chosen to guide the process of interpreting participant data in this study (Braun and Clarke, 2006; 2013). Although, a range of analytical approaches could potentially have been used, thematic analysis was selected on the basis that the approach used to guide data analysis needed to be flexible. This was given the variation in the data collected, both in terms of the richness of individual participants' accounts and the additional use of visual methods and activities in interviews with participants with communication and cognitive impairments. Thematic analysis also offered the flexibility to use both an inductive “bottom-up” and deductive “top-down” approach during the analysis. This involved developing themes inductively from participant data, as well as deductively from the study’s research questions and existing research and theory as shown in Figure 9 (Braun and Clarke, 2013; Ritchie *et al*, 2014). This was considered important in view of the study’s participatory approach and emphasis on young people’s agency, based on an understanding of them of as experts on their own lives. This is consistent with the theoretical approach taken by disability and childhood studies, both perspectives that had strongly influenced the study’s aims and design.

The visual data generated by participants, alongside spoken data during interviews, precluded my use of either Conversational Analysis or Discourse Analysis. This is because the focus of analysis in both these methods is on how language is structured and produced. Grounded theory, following the approach developed by Charmaz’s (2006), was initially considered due to its complementarity with the study’s social constructivist theoretical stance, consistent with the approach adopted by disability and childhood studies. Grounded theory’s emphasis on thick rich data would have made it difficult to incorporate the views of less articulate participants. This would have run counter to the study’s aim to be inclusive of young people with a range of impairments and experiences.

Either Interpretative Phenomenological Analysis (IPA) or Narrative Analysis could have accommodated the study’s aim to understand participants’ perspectives of their lives and relationships alongside their experiences of child protection processes. However, IPA was felt to lack sufficient theoretical flexibility due to its psychological theoretical foundation (Smith *et al*, 2009). Also, disability and childhood studies give greater emphasis on the need to incorporate sociological perspectives within the analysis. In addition, IPA is usually considered more appropriate for smaller numbers of participants (Braun and Clarke, 2013). A purely narrative approach (Riessman, 1993) was decided against since most participants’ accounts were felt to lack a sufficiently coherent narrative. This may partly relate study participants’ young age, as longitudinal research, using narrative methods with learning disabled participants noted that their sense of identity had matured when they were interviewed as young adults (Kelly, 2013).

Analytic strategy

This section sets out the analytic strategy used to complete the process of thematic analysis of participants' accounts that informed the study's findings. It draws on the "within case" and "across case" approach to data analysis set out by Mason (2002), as well as the six-stage process of thematic analysis described by Braun and Clarke (2006). A coding framework was also developed to help provide a consistent and coherent approach to the coding and analysis of participant data (Ritchie *et al*, 2014). How each of these different stages and elements of the analysis relate to each other and the study's research questions is set out in Figure 9. Each of these stages is described in more detail in the paragraphs that follow.

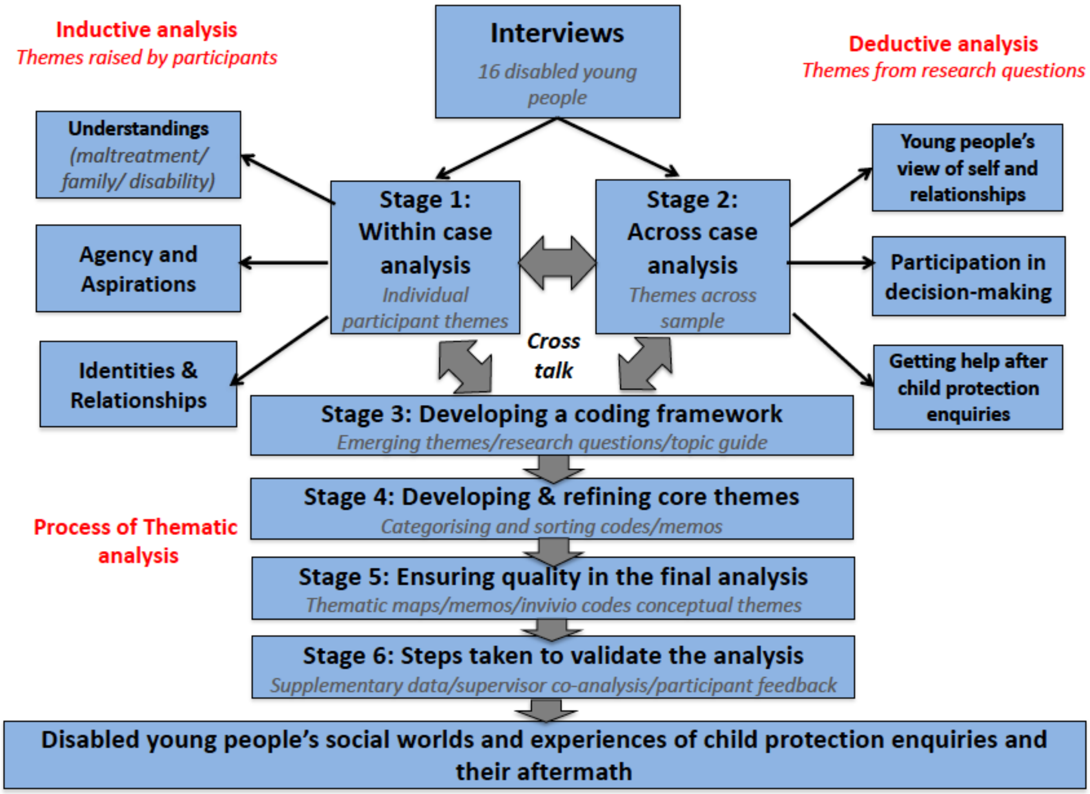

Figure 9: Analytic strategy informing Thematic Analysis of participant data

Stage 1: 'Within case' coding and analysis

An important aim of the study was to understand how individual participants make sense of themselves, their lives and relationships. Therefore, in order to retain a focus in the analysis on participants' lives as a whole, interview data for each participant was first analysed narratively via a process of 'within case' coding and analysis. This first stage of the analysis involved repeated close reading of individual participants' interview transcripts. This was in order to familiarise myself within the depth and breadth of content. To assist in this process I also made notes about my initial impressions of each participant via a series of memos (Braun and Clarke, 2006, p. 16).

Once this process had been completed, participants' interview transcripts were loaded into NVivo 11, a software package widely used to assist with qualitative analysis. Line by line coding, also known as 'complete' coding was then used to analyse individual interviews. Braun and Clarke (2013) describe 'complete coding' as working systematically through each interview searching for sections of data that may be relevant to addressing the study's research questions (page 211). Consistent with this study's focus on participants' agency and expertise on their own lives, *invivo* codes (i.e. those named using participants' own words or phrases) were used whenever feasible. Some of these invivo codes were later used to name key themes in the final analysis (e.g. '*only speaking softly*' Chloe).

This process of complete coding allowed recurring themes and issues of particular importance for each individual participant to be identified. It also helped me to develop a sense of individual participants' understanding of disability and maltreatment, their identities and family relationships, as indicated by the boxes next to stage 1 in Figure 9. As well as helping to address the study's first research question, treating interview data for each participant initially as a separate unit of analysis also allowed participants' experiences of child protection processes to be better understood within the context of their lives and relationships.

Stage 2: 'Across case' coding and analysis

The emerging themes from this initial "within-case" coding and analysis of participant data was used to help identify similarities and differences between and across participants' accounts. To aid this process I completed another series of memos, noting initial ideas about patterns of potential themes across interviews. These memos were an important part of establishing dynamic "cross-talk" between the different stages of the analysis, as indicated by the arrows between stages 1, 2 and 3 in Figure 9. The aim of this second stage of "across case analysis", to identify important themes in relation to each the study's research questions across the sample as a whole, was also aided by developing a coding framework, as indicated by stage 3 in Figure 9. This coding framework was then used this to further code both the “within case” and “across case” parts of the analysis.

Stage 3: Developing a coding framework

I wished to remain as close as possible to the themes identified as important by disabled young people themselves, as is consistent with the aims of disabled children’s childhood studies (Curran and Runswick-Cole, 2014). However, since this generated between 100-200 codes per interview I began reviewing and merging codes by looking for similarities and differences. This process is variously described as “constant comparison” (Glaser and Strauss (1967), “indexing and sorting” (Ritchie *et al*, 2014) and “searching for candidate themes” (Braun and Clarke, 2013) in qualitative analysis. This process helped me to collate themes from the “within-case” analysis of individual participant interviews, and to merge codes from different participants that appeared to represent the same ideas in the “across-case” part of the analysis. However, I recognised that I was still having difficulty ‘seeing the wood for the trees’. Therefore, in order to maintain coherence and consistency between these two, albeit closely related stages of thematic analysis, a coding framework was developed, based on the approach set out by Ritchie *et al* (2014).

This coding framework was initially developed from the themes that emerged from the “within case” inductive analysis of data from first four participant interviews (Nicola, Jack, Chloe and Louise), and “deductive” analysis of the topic guide, based on the study’s research questions used during interviews. The validity of the coding framework was also confirmed by incorporating the insights from “blind-coding” of a further three participant interview transcripts (Jon, Ethan and Mathilde) completed by my primary supervisor, who is a very experienced qualitative researcher. The coding framework developed was then applied to the complete coding of participant data, generated during both the “within case” and “across case” parts of the analysis.

The decision to develop a coding framework as part of the process of Thematic Analysis was felt to have a number of advantages. Firstly, it meant a consistent approach was used to analyse all participants’ interviews. Secondly it helped ensure that study’s aims were met as topics relevant to each research question could be incorporated within the coding framework. Thirdly, using consistent headings helped me identify recurring themes for individual participants as well as across the sample as a whole. This also helped provide a structure for the process of "cross-talk" between the two strands of the analysis. Finally, using the same headings to analyse caregiver interviews allowed me to see where their data complemented or contradicted the young person's account, and identify potential bias where their accounts overlapped.

Stage 4: Developing and refining themes

The use of a coding framework helped me to systematically categorise, organize and further develop candidate themes in relation to each of the study's research questions based on the "within-case" and "across-case" coding of participant data. To assist with this next stage of the analysis "developing and refining themes" (stage 4 in Figure 9), I created a hierarchy of folders within NVivo that reflected the categories within the coding framework I had developed (set out in Appendix 25). I then arranged relevant codes under each category of the framework in folders for each individual participant. Once this process was complete, I created the same framework of categories in separate folders within NVivo for the sample as a whole. I was then able to copy the codes stored under each category of the framework for individual participants into the corresponding folder of the framework for the sample of participants as a whole. Through this process I was able to begin identifying patterns within the codes for different participants and develop candidate themes for the "across case" part of the analysis.

While some participant codes and candidate themes collated under each category of the framework were largely descriptive, others were already more analytic in orientation. These more "analytic" codes proved very helpful with the next stage in the process of thematic analysis, that of sorting and merging the candidate themes for each category of the framework across the sample as a whole (Braun and Clarke, 2013, p. 233). This process was necessary to develop and refine the core themes that represented the study's key findings. During this process of developing and refining themes, attention was also paid to convergent and divergent themes among participants. This ensured rigour and improved the validity of the analysis (Silverman, 2013). To assist with this process I also continued to write memos exploring possible reasons why some participants' experiences seemed more similar than others. An example of one of these memos is included at Appendix 26.

Stage 5: Ensuring quality in the final analysis

As the analysis progressed, I also drew 'thematic maps'. Braun and Clarke (2013, p.232) described thematic maps as a useful visual aid during Thematic Analysis, for exploring relationships between codes and themes, core themes and subthemes as well as helping researchers to identity over-arching, "conceptual themes" in their data. Used alongside memos, I found thematic maps help me to see more clearly the connections between codes and themes identified during the analysis, as well as to interrogate similarities and differences between participants and groups of participants.

The use of thematic maps also enabled me further to test out and refine 'candidate' themes, eventually leading to the identification of higher level 'conceptual' themes, that seemed to help account for the patterns observed in the data (Braun and Clarke, 2006, p.21). I was not able to draw thematic maps within NVivo. However, I found the process of drawing these out on large pieces of paper by hand was in any case less constraining. This was because writing the different codes out on post-it notes meant I could then freely arrange and rearrange them in order to decide how they best "fit" together. I was also able to add thoughts as annotations on the background paper. An example of a Thematic Map in progress is included at Appendix 27.

A simplified version of thematic maps are presented within the relevant findings chapters. This was in order to aid transparency about how themes and sub-themes had been developed, a common criticism of qualitative research (Shek, *et al*, 2005). Young people whose accounts revealed similar themes were also grouped together in the presentation of study findings. This was to enable discussion of the full range of participants' experiences. As well as including sufficient data extracts to justify each theme (Braun and Clarke, 2006, p.23), participants' words are also sometimes used to name themes to retain closeness to the data. While in other cases a paraphrased version (still in the first person), or an underlying emotion is used, as this was felt to better capture the range of views expressed. Each of the steps outlined above was taken to help ensure quality in the final analysis, as indicated by stage 5 in Figure 9.

Stage 6: Steps taken to validate the analysis

Steps were also taken throughout the analysis process to ensure the validity of the study's findings as an interpretation of participant data, as show in stage 6 of Figure

9. These steps included the “blind-coding” of a purposive sample of 3 participant interview transcripts by my primary supervisor. As already discussed, this process of interpretive validation helped confirm the categories in the coding framework used in the process of Thematic Analysis (Kelly, 2007). Analysis of supplementary data generated from fieldnotes, interview activities and interviews with participants’ caregivers was further used to help confirm and/or interrogate the themes from the analysis of disabled young people’s interviews, an approach used by researchers in previous similar studies (Wickenden, 2011; Franklin and Smeaton, 2015). Research colleagues in my department were also asked to comment and give feedback on a powerpoint presentation of my initial findings. Feedback from these colleagues, and further comments and suggestions made by my supervisory team on initial drafts of my findings chapters were also used to refine and validate the final analysis.

To further enhance the validity of the study’s findings, an easy-read summary of the initial findings was produced and sent to participants who had expressed an interest in providing feedback. The response to this request for participant feedback was disappointing, however, perhaps partly due to the length of time that had elapsed since they had taken part in research interviews. It also did not seem appropriate to discuss the summary of the findings with members of the Youth Forum who had been consulted regarding the study design, as none, to my knowledge had been the subject of child protection enquiries. I was, however, eventually able to speak to one participant directly via her social worker, and this young person’s helpful comments were incorporated into the analysis and discussion of the study findings.

Limitations and challenges

A better response from participants in commenting on the analysis may have been possible had they been involved throughout the research process. While this is one of the study’s limitations this was considered too ethically challenging given the emotive topic and participants’ ages.

A further limitation was that, despite my best efforts, it did not always prove possible to include the views of participants with the most complex impairments in all parts of the analysis, due to their difficulties understanding the topic or articulating their views. It might have been possible to partly overcome this using participant observation, as used in research studies specifically exploring the experiences of this group of children (Boggis, 2011; Watson, *et al*, 2018).

Better use could perhaps also have been made of visual data especially with this group, including photos of family members and professionals as well as pictures and symbols (Clark and Moss, 2001). Whereas, among more articulate participants activities tended to act as a prompt to discussion and help engagement rather than generating data in themselves.

It was also difficult at points during the analysis to clearly differentiate between the views of young people and those of their caregivers. Despite the measures taken to prioritise young people's views, these did not always help disentangle the strongly co-constructed nature of participants' accounts. Similar difficulties with interpretation arose when there were large discrepancies in young people and their caregivers' subjective views. Nicola and her foster-carer strongly disagreed about where she could go in the community by herself. However, it was difficult to gain an in-depth appreciation of the complex issues involved based on a one-off encounter. Although, these difficulties might have been eased by prolonging my involvement, this might have been difficult due to the sensitive nature of the disagreement. Moreover, such issues are also part and parcel of adolescence, albeit heightened by the presence of maltreatment and impairment.

The decision to include young people in care whose involvement in child protection processes was historic provided some useful comparisons. However, it also limits the specificity and generalisability of the study's findings to other disabled children's experiences of child protection enquiries and decision-making processes. Not being able to include the views of disabled young people receiving support from child protection rather than specialist disabled children's teams likewise represents an important omission, given that evidence suggests that practitioners' in these teams often have less knowledge and awareness of disabled children's needs (Kelly and Dowling, 2015)

Concluding reflections

Reflecting on the study overall, I consider that, despite the inevitable limitations of a cross-sectional design, the methods used, and the approach taken to the analysis was robust. As a researcher the childhood studies perspective helped me to see participants as young people with interesting things to say about their lives, rather than through the equally stigmatising lenses of impairment and maltreatment. While the emphasis on disability studies challenged me to continually question my assumptions and adapt my approach to ensure I neither patronised nor excluded them, even where this uncomfortably highlighted the deficits in my own skills and understanding.

I did, however, experience a great deal of frustration regarding my own limitations as a researcher, particularly my skills and abilities in understanding and communicating with young people with complex impairments. This, as discussed in the introduction to this thesis, is one of the factors which motivated me to embark on the study. Spending more time with and undertaking multiple interviews with individual disabled young people or using participant observation would perhaps have allowed me to gain a deeper understanding of these young people's lives. These factors, almost ironically, closely mirror the pressures social workers, myself included, frequently cite as precluding them from working effectively with disabled children and their family's within child protection processes (Prynault-Jones, *et al*, 2017).

At the same time, interviewing the majority of disabled young people involved many of the same skills as those I developed in my practice with non-disabled children (Connors and Stalker, 2003). This suggests that the barriers to involving disabled children in both research and practice often more reflect the capacities and attitudes of adults than children themselves. I was also extremely humbled by participants' willingness and openness in sharing their, often upsetting, stories with me, as well as by their resilience and determination not to be defined by their impairments or their experiences of child protection processes.

Having spent a number of years working as a children's social worker, I was, however, unexpectedly taken aback by the emotional impact that researching disabled children's experiences had on me. The interviews themselves were emotionally draining, particularly those where young people or their caregivers became angry or distressed. However, I was equally surprised at how vulnerable and impotent I found bearing the responsibility of listening in to their stories and continuing to hold their distress as I worked on the analysis, without having the possibility of intervening to try and assist them, or of becoming reabsorbed in the business associated with my role as a professional social worker. Ultimately, this re-doubled my determination to allow these young people's views and voices about their lives and experiences of child protection enquiries and their aftermath to be heard. It is to the analysis of their accounts that we now turn.

Part 3

Findings

Introduction

This introduction gives a brief overview of this study's findings and explains how these are arranged within the three findings chapters that follow.

The accounts of the disabled young people presented in this study paint a rich and compelling picture of their experiences of disability, identity and adolescence. This is set against a backdrop of often difficult and complicated family relationships and social disadvantage. Although participants' views and experiences were informed by their unique circumstances and family background, a number of consistent themes emerged concerning both their identities and relationships and their interactions with social workers and other professionals within child protection processes.

The reader is introduced to the participants in chapter 5. An overview of participants' circumstances and characteristics is provided first. This gives a strong indication of their relative social and economic disadvantage and the complexity of their family circumstances. This followed by participants' own reflections on their experiences and priorities of managing risks, identities and aspirations during adolescence. The importance of their families, their desire for friendship and opportunities to explore the world, along with struggles with stigma, self-esteem and self-efficacy, often associated with their impairments and/or their family's difficulties, and for some their experiences of maltreatment.

All of this provides important context for understanding disabled young people's views about their experiences of child protection processes, explored in chapters 6 and 7. Chapter 6 specifically focuses on disabled young people's experiences of taking part in child protection decision-making processes. Participants' identified many of the same barriers and enablers to supporting their understanding and involvement in child protection decision-making as identified by non-disabled children in similar studies, most notably their relationship with their social worker. However, some additional barriers and enablers to young people's participation in decision-making were also noted, related to their own lack of self-confidence expressing themselves, practitioners' attitudes towards them and the way they responded to their impairment needs.

In chapter 7, disabled young people's overall experiences of child protection enquiries and the support and intervention they and their families had subsequently received are explored. For some participants their experiences were partly informed by their experiences of taking part in decision-making outlined in chapter 6, while others described very different experiences of support and interactions with social workers, often as they moved on to receiving services as children in need or as looked after children. That said, it was also unusual for participants to describe either an entirely positive or wholly negative account of their experiences within child protection processes, with their relationship with their social worker identified as being key to their experiences of both support and protection processes within childrens social care.

Chapter 5: Understanding participants' lives and their perspectives on their identities, families and wider social worlds.

Introduction to the young people

This chapter introduces the reader to the disabled young people whose lives and experiences are the focus of this thesis. It is set out in two parts. The first part describes the sample of disabled young people's circumstances and characteristics, in order to locate them within the wider literature concerning childhood disability and maltreatment. The second part, by contrast, begins to explore participants' lived experiences: their identities, interests and relationships, at home and at school, in their families and in their communities; their priorities, as well as what worried or frustrated them. For many young people this included issues related to their impairment and/or the reasons for their family's involvement with the child protection system.

Interviews with disabled young people themselves are used as the primary source of data, whenever possible. However, supplementary information gathered from young people's social workers and caregivers was also helpful in trying to make sense of their lives and experiences. A similar approach has been used to gather supplementary information in previous research exploring disabled children's experiences of maltreatment (Taylor *et al*, 2015; Franklin *et al*, 2015).

Participant characteristics and circumstances

Demographic characteristics

The demographic characteristics of the sixteen disabled young people who took part in this study are summarised in Table 1.

Name	Age	Gender	Ethnicity	Religion	Location
Allison	11	Female	White British	None stated	City
Ashia	13	Female	White European	Muslim	City
Chloe	17	Female	White British	None stated	Shire Rural
Hannah	15	Female	White British	None stated	Shire Rural
Louise	17	Female	White British	None stated	Shire Town
Mathilde	17	Female	Black African	None stated	City
Nataly	13	Female	White European	None stated	City
Nicola	16	Female	White British	None stated	Shire Town
Rebecca	17	Female	White British	None stated	Shire Town
Stevie	13	Female	White British	None stated	City
Ben	13	Male	White British	None stated	Shire Rural
Ethan	16	Male	White British	None stated	Shire Town
Jack	16	Male	White British	None stated	City
Jon	16	Male	White British	Christian	Shire Rural
Liam	14	Male	White British	None stated	Shire Rural
Mark	11	Male	Asian Chinese	None stated	Shire Town

Table 1: Participants' demographic characteristics

Age and gender

Participants were aged between 11 and 17, and the study sample included a fairly even mix of older and younger children within this age range (mean age, 14.7 years, median age 15.5). Ten of these young people were female and six were male, with females being very slightly older than males (mean age 14.9 vs 14.3 years). Five participants had a sibling who was also a study participant. These participants were: Nicola, Stevie, and Allison, who were sisters, and Louise and Ben who were brother and sister.

Ethnicity and religion

Three quarters of the study participants were White British (n=12), and a quarter (n=4) were from black and ethnic minority backgrounds (BAME). Nataly and Ashia were White European; Mathilde, was Black African; and Mark, was Asian Chinese. Only two young people mentioned their religion: Ashia, described her family as non-practising Muslims; and Jon said his family were practising Christians.

Location

Nine study participants lived in two Shire Counties, six in a London Borough, and one in the North of England. Of the four young people from BAME backgrounds, three lived in London, reflecting the higher ethnic diversity in that population, and one lived in a Shire County. Two thirds of study participants lived in either a town or a city (n=11), and a third in a relatively rural location (n=5). These latter young people were Chloe, Hannah, Liam, Jon and Nicola.

Impairment and Disability

Impairment type

Study participants had a diverse range of cognitive, physical and communication impairments and conditions, as shown in Table 2.

Name	Learning Disability	Autistic Spectrum	Physical Disability	Chronic Health	CAMHS Support	Dyslexia
Allison	Severe			x		
Ashia	Moderate		x			
Ben	Severe		x			
Chloe	Moderate		x			
Ethan				x	x	
Hannah			x		x	
Liam	Severe					
Louise				x	x	x
Jack	Mild	x			x	
Jon		x			x	
Mark		x			x	
Mathilde	Moderate	x			x	
Nataly	Severe	x			x	
Nicola	Moderate				x	
Rebecca	Severe			x		
Stevie	Mild				x	
Total	**11**	**5**	**4**	**4**	**10**	**1**

Table 2: Participants' impairments by type

Learning disability was the most prevalent type of impairment among study participants, with over two thirds of young people (n=11) described by their social worker or caregiver as having either a severe (n=5), moderate (n=4) or mild learning disability (n=2). Approximately a third of young people had reportedly been diagnosed as having an Autistic Spectrum Condition (ASC) (n=5), a quarter had physical disabilities (n=4), and a quarter had a chronic health condition (n=4).

Ten participants or their caregiver additionally reported having received support from Child and Adolescent Mental Health Services (CAMHS). Of these young people only one, Louise, described herself as having a diagnosed mental health condition (anxiety and depression). Moreover, for all of the five young people diagnosed with Autistic Spectrum Conditions their involvement with CAMHS was described as mainly related to diagnosing and monitoring of their condition.

Multiple impairments

Over half of study participants were additionally described as having multiple impairments (n=9). Apart from Louise, all of these young people, according to their social worker or caregiver, had learning disabilities and another, in some cases related, impairment. For example, three young people were described as having learning disabilities and an Autistic Spectrum Condition (ASC) (Nataly, Mathilde, and Jack); three as having learning disabilities and physical or communication disabilities arising from their cerebral palsy (Chloe, Ben, and Ashia); and two as having congenital or genetic conditions which, as well as causing their learning disabilities, affected their health or development in other ways (Allison, Rebecca).

Comparison with other studies

It was not my intention to recruit a representative sample of disabled young people. However, it is interesting to note that none of my participants had sensory impairments. This is in marked contrast to Taylor *et al* (2015) study exploring disabled young people's experiences of child protection, where 7 of the 10 participants were deaf. By comparison, my study participants' characteristics more closely matched the 27 participants interviewed for Franklin *et al* (2015) study of learning-disabled young people's experiences of sexual exploitation, who were aged between 12 and 23 years, and where almost one in five (18%) were from BAME backgrounds. In

Taylor *et al* (2015) study only three participants were under 18, and only one was from a BAME background.

Special Educational Needs

Fourteen participants in my study were described as having a statement of special educational need by either their social worker or caregiver. Most of these young people also attended special schools (n=12). The two participants with a statement of special educational need attending mainstream schools both had Autistic Spectrum Conditions; one received additional support with his learning from a learning support assistant (Mark) and the other via a specialist unit for children with Autistic Spectrum Conditions attached to his school (Jon). In addition, one of the two participants who did not have a statement of special educational need mentioned that a learning support plan had recently been put in place for her dyslexia at her mainstream sixth form college (Louise).

Participants' alleged experience of abuse and neglect

This study's main objective was to understand disabled young people's views about their experiences within the child protection system, rather than their experiences of abuse and neglect. Therefore, I did not seek access to participants' childrens services files. However, participants' social workers did share some limited background information about young people's alleged experiences of maltreatment when discussing their eligibility for the study. Participants' or their caregiver usually also referred to these experiences during research interviews, and the information obtained from these two sources is combined in Table 3.

Alleged type of abuse	Neglect	Emotional Abuse	Sexual Abuse	Physical Abuse	Family Violence	Types of alleged abuse
Allison	x		x	x		3
Ashia	x			x		2
Ben	x		x		x	3
Chloe	x					1
Ethan	x				x	2
Hannah	x					1
Jack	x					1
Jon		x				1
Liam	x		x			2
Louise	x		x		x	3
Mark		x		x		2
Mathilde	x			x		2
Nataly	x		x			2
Nicola	x		x			2
Rebecca	x		x			2
Stevie	x		x			2
Total	**14**	**2**	**8**	**4**	**3**	**mean = 1.9**

Table 3: Participants' alleged experience of abuse and neglect

Prevalence of types of maltreatment

Neglect was mentioned as having been part of the professional concern leading to child protection enquiries for all but two participants, either by their social worker, caregivers or young people themselves (n=14). While for Mark and Jon, emotional abuse was described by their caregivers as having been the main concern. This finding is consistent with neglect and emotional abuse being the most commonly identified forms of child maltreatment. For example, these two forms of abuse together regularly comprise the main categories for over 80% of child protection plans in England (DfE, 2016).

Multiple types of maltreatment

However, three quarters of the young people in this study were additionally described by their social workers as considered at risk of or to have experienced more than one type of maltreatment (n=12). This reflects previous studies indicating that disabled children are more likely to experience multiple forms of maltreatment (63% compared to 54.9% for non-disabled children, Sullivan and Knutson, 2000).

For just under half of these participants these additional concerns related to alleged incidents of physical abuse by a parent (n=4), or exposure to violence (n=3), which for siblings Louise and Ben reportedly involved witnessing their father's murder. There was, however, a particularly high co-incidence of professional concern about participants' actual or potential exposure to sexual abuse (n=8), alongside other forms of maltreatment. Interestingly all but one of these participants had learning disabilities, a factor that several other studies have previously identified as increasing young people's risk of exposure to child sexual exploitation (Beckett, 2011; Smeaton, 2013).

In addition, a higher proportion of participants living in out-of-home care had allegedly experienced multiple forms of abuse, compared to those living with their families. Young people in care, or one of their siblings were also more likely to have directly disclosed to professionals that they were being abused triggering child protection enquiries. Although, other multiply maltreated participants had remained living at home (Ashia, Mark), or had subsequently returned to their parent's care (Mathilde, Jack), despite alleging abuse.

Current child protection status

Although all of the participants in this study had been the subject of a child protection conference or plan, their current child protection status varied. This is perhaps unsurprising given some young people were living with their families while others had been in out-of-home care for some time. This is outlined in Table 4.

Name	**Child Protection Plan**	**Child Protection last 12 months**	**Child in Need**	**Living in out-of-home Care**
Allison				x
Ashia	x			
Ben		x		
Chloe		x		
Ethan	x			
Hannah				x
Liam				x
Louise		x		
Jack			x	
Jon			x	
Mark	x			
Mathilde			x	
Nataly				x
Nicola				x
Rebecca		x		
Stevie				x
Total	**3**	**4**	**3**	**6**

Table 4: Participants' current child protection status

For example, eight of the ten participants living with their families currently had a child protection plan or had been the subject of a child protection conference or plan during the past year. By contrast none of the six participants living in out-of-home care currently had a child protection plan. Though five of these participants, including sisters, Nicola, Stevie and Allison, had become the subject of a full care order, as a result of care proceedings following on from initial child protection enquiries. By contrast, Hannah had only recently entered care under a voluntary arrangement, after her relationship with her father and stepmother had broken down. But, according to her social worker, Hannah had moved to live with her father and his family four years earlier following previous child protection enquiries due to concern that her mother was neglecting her.

Family circumstances and relationships

Coming into care had inevitably had a significant impact on these young people's lives. The family circumstances of participants' still living with their families were also often quite complicated, however, and there were a number of notable similarities as well as differences between these two groups of participants' family relationships as shown in Table 5.

Name	Lives with	No contact non-resident parent (s)	Non-resident siblings	No contact with non-resident sibling	Disabled parent	Disabled sibling
Ashia	Mother & Father					
Ben	Mother + 2 sibs	Deceased	1			1
Chloe	Mother & Stepfather +1 sib	x	2		1	
Ethan	Mother & partner +1 sib		1			
Louise	Mother +2 sibs	Deceased	1			1
Jack	Mother	x				
Jon	Mother & father +1 sib					
Mark	Father, PGM +3 sibs	x				
Mathilde	Mother, MGM +3 sibs				1	2
Rebecca	Mother & Father		3		2	
Allison	Foster care + 1 sib		4		1	4
Hannah	Childrens home	x	5	x		1
Liam	Childrens home	x	2	x		2
Nataly	Foster care	x			1	
Nicola	Foster care		5		1	4
Stevie	Foster care + 1 sib		4		1	4

Table 5: Participants' living arrangements and family relationships

Disrupted family relationships

Most young people had experienced significant separations and losses within their family relationships, whether they were living at home or in out-of-home care. This disruption was also often related to child protection enquiries and subsequent decision-making, though the effect on young people in out-of-home care was usually more profound, since all were living apart from their birth parents, and in most cases their siblings as well. In addition, these young people had inevitably had to forge new relationships within their foster families, or in Liam and Hannah's case, with staff and other young people in their residential placements.

Of the ten participants living with their families, however, only three were still living with both their biological parents (Ashia, Jon, Rebecca), and five were living in households headed by a single parent carer. Moreover, three of these participants reportedly did not currently see their non-resident parent, in two cases this was allegedly because of safeguarding concerns (Mark and Jack). Furthermore, Ben and Louise were siblings in the same family whose father had reportedly been murdered, triggering initial child protection enquiries with their family due to concern for the children's safety.

Some participants living in out-of-home care had similarly also not seen one or both of their birth parents for some time. Liam, for example, reportedly currently had no contact with either of his parents, and Nataly and Hannah had not seen their birth mothers for more than two years. Though in Hannah and Nataly's case this lack of contact was reportedly mainly to do with their mothers' living elsewhere, rather than because of on-going child protection concerns. Hannah, for example, whose mother now lives overseas, said that they speak by phone once a fortnight.

By contrast, although Nataly said she sees her father regularly, according to her carers these visits are supervised, because of previous allegations of abuse. The remaining participants in care, sisters Nicola, Stevie and Alison, also reported that their contact with their birth parents is supervised. These visits, which take place three times a year, also include their two older brothers and other members of their extended family. Outside of these visits Allison and Stevie live together with the same foster carers, and see Nicola and their younger sister, each living with different carers, approximately every six weeks.

Allison and Stevie were the only participants in out-of-home care placed with any of their siblings. However, half of the participants living with their families also had siblings who were living elsewhere. Except for Ethan, whose brother lived with their father but who he saw at weekends, this was because these participants had siblings who were older and had left home. These participants all also said that they saw these siblings fairly regularly, whereas some young people in care reportedly did not currently see one or more of their siblings at all. Liam, for example, reportedly that he did not currently see his sister, which his social worker said was because of allegations he had sexually abused her. Hannah's stepmother also said Hannah had not seen her two stepbrothers since coming into care due to their poor relationship.

(In)-stability and uncertainty

All but one of the participants living in out-of-home care had been separated from their birth families for at least four years. However, in contrast to the disruption to their family relationships arising from decisions made as a result of child protection enquiries, only two of these young people had changed placements since this time (Nicola and Stevie). This would seem to suggest that the living arrangements of participants' living in out-of-home care in this study were more settled than many other disabled young people in care. Kelly *et al* (2016), found almost third of disabled young people in out-of-home care in Northern Ireland, for example, had had three or more placements.

Some of these young people's placements nevertheless showed signs of instability, including those who had been in their placements a long time. Liam and his support worker, for example, both mentioned that the residential care home where he had been living for four years was currently experiencing an exceptionally high turn-over of staff. Nataly's foster-carers similarly said a violent outburst she had had a few days prior to our interview had caused them to question if they could continue caring for her, even though she had been living with their family for more than six years. Hannah, by contrast, had only been in care for six weeks, but was due to move onto a new placement at residential school the following week.

A few of the participants living with their birth families were likewise currently experiencing fluidity and uncertainty in relation to their living arrangements. This was often, but not always, related to their family's recent involvement in child protection enquiries. Mark's mother, for example had recently moved out and separated from Mark's father following professionals' concern about her abusive behaviour towards Mark and his siblings. Ethan's mother described feeling under similar pressure from his social worker to ask her partner, who had been with the family less than six months, to move out due to historical allegations of intimate partner violence.

Mark and Mathilde's circumstances were similarly ambiguous. Each had a grandparent living with them, whom their parents saw as crucial to helping them to continue caring for their children. However, for each of these grandparents there was some doubt as to whether they would be allowed to remain living in the household long term. This was due to uncertainty regarding their immigration status, and whether they would be granted indefinite leave to remain. Mathilde's mother described this situation as particularly acute for her family, because Mathilde's younger brother and sister also have Autistic Spectrum Conditions. Chloe's mother also described feeling overwhelmed by caring for her elderly parents, as well as being a full-time carer for Chloe. These circumstances Chloe's mother felt had exacerbated her own mental health problems, in turn contributing to the safeguarding concerns for Chloe.

Disability and Disadvantage

Overall, just over half of study participants reported having at least one other family member who was also disabled (n=9). Seven participants reportedly had a disabled parent, a proportion comparable with the estimated 45.7% of disabled children in the general population with a disabled parent (Blackburn *et al*, 2010). This figure also included a similar number of participants living with their families (n=3) and in care (n=4).

By contrast, the proportion of participants with a disabled sibling (n=8) was twice the estimated 24.6% of disabled children in the general population (Blackburn *et al*, 2010). Though this figure is admittedly skewed by the fact that five participants had a disabled sibling who was also a study participant, it nevertheless seems noteworthy that this included all of the six participants living in care, and a seventh (Mathilde), who had previously been in care. Four of these participants also had a disabled parent, and five more than one disabled sibling. Therefore, in this study participants who came from families with multiple disabled members were more likely to have spent time in care.

Moreover, many of the participants who were not in care appeared to be living in families on low incomes with access to limited resources. Although not specifically asked about their socio-economic circumstances, 8 out of 10 of these participants or their caregiver mentioned that they lived in rented accommodation, compared with an estimated 47.4% of families with disabled children and 33.3% of families with no disabled children (Blackburn, Read and Spencer, 2010). In addition, 6 out of these 10 participants reportedly lived in households where none of the adults worked, compared with 38% of disabled children and 16% of non-disabled children (Department for Work and Pensions, 2014), and/or in households headed by a single parent, compared with 34.1% of disabled children and 25.6% of non-disabled children (Blackburn *et al*, 2010). Furthermore, only one of these single parents reportedly had a part-time job, whereas three of the four fathers of participants in two parent households was reported as working full-time.

These observations are inevitably limited by the nature of the data collected and the small sample size. However, they appear to indicate that participants in this study were experiencing high levels of socio-economic disadvantage, even compared to other families of disabled children, a group known to be at increased risk of disadvantage (Blackburn *et al*, 2010).

Participants' perspectives regarding their lives and families

Having a disability, being exposed to maltreatment or growing up in care tend to be constructed and categorised as 'problems' by society at large. However young people in this study did not necessarily see themselves or their experiences this way. Rather, in common with previous research with disabled children, these young people described themselves as having the same interests and aspirations as their peers (Foley *et al*, 2012). Since all were just entering or part way through adolescence, like other young people of their age they were more interested in talking about their friendships, achievements and becoming more independent than talking about their impairments, family difficulties or experiences of abuse or neglect.

In addition, very few participants considered themselves disabled. Although many participants felt frustrated by the way their impairments affected how other people saw them, and/or restricted their opportunities for friendship and autonomy. Young people's view of their family's difficulties was likewise often very different from how their social workers and caregivers described these issues (Butler and Williamson, 1994). Therefore, it seems fitting, in the second part of this chapter, to explore young people's own perspectives on their lives and relationships, before examining their views and experiences of child protection enquiries and their aftermath in the chapters that follow.

Identity, development and impairment

Interests and sense of self

Most disabled young people in this study talked positively about themselves, their interests and achievements. Liam, for example said he liked where he lived, got on *"fine"* with staff and the two young people he lived with, and did not mind being the youngest because, "*I like who I am*"; Chloe talked proudly about winning a trophy in a dance competition and Jack said:

> *[I've] got like my own music, currently I'm doing piano work, I've learnt quite a lot … [my friends] think it's too hard to play, but obviously, I got a YouTube video of it, and you just keep repeating that until you get it, I've been trying to learn Grenade that's my newest one, Bruno Mars so…*

Many participants of both genders were also interested in pop music, as well as going to the cinema and looking after pets. However, many of young people's other interests appeared somewhat influenced by socially accepted gender 'stereotypes'. For example, several female participants but none of the males mentioned cooking and dancing among their interests, whereas all but one male participant, but very few female participants, said they were interested in computer games, and several were keen football supporters. Liam and Ben for example both mentioned football teams they supported, and Mark said: "*Football is not boring, it's awesome! I play football at Kids Club".*

Several female participants, particularly those who were older, were very interested in and took pride over their appearance. Mathilde, for example carefully drew her hair on a picture of herself and seemed pleased when I commented that it looked nice. She then drew herself with shopping bags, adding that her favourite shops were Primark and New Look, because *"they have got accessories, clothing, handbags, …*

oh and shoes". Nicola was similarly interested in clothes shopping and styling her hair, which her foster-carer felt showed her growing self-esteem:

> *When Nicola first come to me, wouldn't even look in a mirror, didn't care how she looked, anything. Now she drives me mad, because it's the other way round! She has got so many clothes it's ridiculous, and she's always looking in the mirror! So, she does take a lot more pride, she has just learned to put her hair up and has got quite a bit more confidence, so she's getting there, it's just a long slow process.*

By contrast none of the male participants mentioned feeling their clothes or appearance were important. Though, Ethan's mother felt his health condition had contributed to him feeling self-conscious about how he looked:

> *Ethan has not got the confidence to be standing out when people are looking at him, and I think the CF [Cystic Fibrosis] has been part of it because he has got self-body issues. He is wearing his T-shirt now and then at home, but when we go out this afternoon, he will have a jacket on. He doesn't like showing his arms because they are really skinny and [at school] he wouldn't wear the PE shorts and that because he didn't want to show his legs, so he refused to do PE.*

Jon and Jack seemed similarly conscious of how their interest in computer games might affect others' perception of them. Jon, for example, described himself as "*a bit of a nerd*", and Jack likewise seemed keen not to be defined by this interest: *"I don't do [computer games] for 24 hours constant like! I um, split in between sometimes, I do some music, some practicing".* Both these participants have Autistic Spectrum Conditions, which is associated with obsessive interests, which may have contributed to their sensitivity about this issue.

Jon also talked enthusiastically about setting up a gaming club at school, however, and described this as a way of connecting with others, something he admitted finding difficult as a result of his condition. Other participants' likewise felt that their interests had helped them cope with their difficulties. Chloe, for example, showing me her posters of the boy band JLS said:

As you can tell I am a big fan, and I would like to say a massive thank you to the boys because they helped me get through a difficult time. They helped me get out of hospital quite quickly, I had five operations in total, but have been alright since.

While Nicola appeared to feel that having a pet rabbit at her foster carers' helped provide her with a sense of continuity: *"because I have had rabbits since I was little, since I was a little baby, [Mum and Dad] had one wild one once".*

Becoming a teenager

Disabled young people's age and stage of development additionally affected their interests and priorities. For example, Allison and Mark, both aged 11, enjoyed going to the park or watching television, while older participants were more interested in social media and going out. Stevie, Hannah and Mathilde, for example, all mentioned using social media to keep in touch with friends or family, and Jack texted his granddad and friends during our interview to let them know he was not going to youth club that evening.

These participants' interest in social media is unsurprising given the majority of young people in the UK own a mobile phone by age 11, and 99% of 16-24 year olds report using social media for an average of 2 hours a day (Ofcom, 2016). Young people in this study additionally viewed having access to this technology as an important part of becoming a teenager and how they liked to spend their time, as illustrated by Ashia's efforts to persuade her Dad to replace her stolen iPhone:

Ashia: Dad bought me an iPhone, and my Mum took it with her when she went out and she got it stolen, I swear I begged my Dad for another phone, seriously I wasn't in the mood for stolen, it was my phone!
Dad: But I buy you this other one.
Ashia: And then I didn't like it.
Dad: Ashia you are too small for this phone.
Ashia: I don't really care! I am a teenager! Come on Dad think! And if there was an emergency, this will be useful.
Dad: And music, long time, four, five hours a day.
Ashia: Yes, that is true! And most of the time I play Candy Crush.

Like Ashia's father, other caregivers were similarly concerned about how young people were using this technology, and their potential vulnerability. This was a particular source of tension between Mathilde and her mother. Though Mathilde herself also admitted, despite wanting to be on Facebook, that she needed help managing her online identity and relationships:

Mathilde: There are people on Facebook they keep texting me. They can't stop it. It is too terrible.
So, do you like Facebook or not?
Mathilde: A little bit, yes. But now I can't use it anymore, because I don't want to talk to them anymore, they keep asking me many questions I had to turn it off, the chat … [my social worker] did talk to me about the Facebook account, she did sort me out. I needed to get rid of, I needed to get rid of their addresses and their phone numbers, I didn't have any calls, but I needed to get rid of them.

As well as social media, many older participants described other aspects of youth culture as important to them. Hannah and Chloe, for example, talked enthusiastically about attending their first music festival as the highlight of their respective summer holidays, and most mentioned liking bands whose music was currently in the charts. Some participants living in London also mentioned how youth gang culture impacted them. Jack, for example, said gang members hanging around the youth centre he attended made the area feel less safe, while Nataly viewed being part of a gang as a 'normal' part of becoming a teenager:

Nataly: Just normal stuff what teenagers do, just do normal stuff, you know gangsters, like with weed and like that stuff? That is what I will be like when I am grown up. You know gangsters like, you can do rap and then – that's the same as, 'yow bro, how you are yow bro' that stuff.
And does anyone talk like that round here?
Nataly: No. I just know it, I just know stuff?

Although most young people in this study identified with and wanted to be part of mainstream young culture, participants with more significant learning disabilities were usually less aware of these issues. Rebecca, who was aged 17 and Ben aged 13, for example, said their favourite television programmes were Scooby-Doo and Mr Tumble, programmes that are usually popular with much younger children. Rebecca also described playing in her garden and riding her bike among her interests. However, like most older participants, she also aspired to become more independent, had a boyfriend and was aware of needing to develop her skills to reach her goal of going to residential college:

I think I'd like to be a bit more independent, so I could be at home and at college as well. 'Cos they usually help me [at school] so I don't need to get burnt and that, so I need to do stuff in school to get really independent because I'll be leaving when I'm nineteen.

Similarly, Mathilde (17), although interested in getting her hair done and using Facebook also enjoyed reading Rainbow Fairy Books, which are aimed at children aged 7-9. Both these young people's examples highlight the varied, often uneven nature of disabled young people's development and identities. These issues can also have challenging implications for practice. Jack's mother, for example, expressed concern that his tendency to form friendships with much younger children had contributed to him being seen as a potential abuser following an alleged incident of inappropriate touching at school:

I was just worried in case Jack did something, and the boy's younger, you know and you can see from the parent's point of view it's not right, even though I know it will have been harmless, Jack didn't know, he's basically turned 16, sometimes he can act older but sometimes he can act like a 9 year old on certain things, like he connects a lot with 9 year olds cos' they've got the same sort of like interests, [he's] always them few years behind.

Sexual relationships and identity

Sexual relationships and identity were similarly highlighted as an important issue for several other participants or their caregiver. Though, interestingly this topic was more often raised by female than by male participants. Nicola, Allison and Rebecca, for example, all talked about having boyfriends, and Mathilde was embarrassed when her sister said, *"Mathilde has had a kiss with a boy"* and responded by telling her *"can you stop saying that please, it is very rude".* Nicola and Rebecca also talked about how having a boyfriend affected their aims and other friendships. Rebecca wanted to go to college, because her boyfriend was going there; while Nicola said, *"when I go back to school, I am going to spend more time with my mates instead of spending* *time with my boyfriend*". Nicola was worried, however, how her boyfriend might react: *"Mmm, he will probably hate it, but oh well he can piss off".*

Nicola's comments could be interpreted as quite assertive. However, her carer was concerned about her lack of confidence in this relationship. She also described Nicola's frustration at being denied access to contraceptives, as well as her own views about the ethics and potential consequences for Nicola (16) of this decision:

Nicola likes the boys, they won't let her have contraception that can be a big issue for Nicola because Nicola has a boyfriend … [and] you know she is getting on for seventeen, just because she has got special needs doesn't say she hasn't got the same wants and needs as a normal teenager and it should be, Nicola is asking, she wants the implant and everybody agrees bar her Manager. Do we want Nicola to get pregnant? You can't force Nicola to have a termination, it's against her human rights but they can take that baby away [and] that is what they'll do, they have already said that. So why put her through that? Why not just give her the implant? It doesn't make sense to me and it doesn't make sense to Nicola.

Perhaps unsurprisingly, given the sensitive nature of these issues, neither Nicola, nor any of the other participants, talked about the sexual side of their relationships. This may also help explain why none of the male participants mentioned sexual relationships or identity. Though, conversely this was an issue several of their caregivers were worried about, as already highlighted by Jack's mother. Ethan's mother also talked similarly about wanting him to feel accepted by her, and by society, after telling her that he is gay:

I mean and the other thing is he has turned round and said he has got no interest in girls, he is gay, and I have fully supported him in that and I have said to him it makes no difference to me you are still my son, I love you and whether you bring home a boyfriend or a girlfriend it doesn't matter they will still be welcome as long as they treat you with respect. So, you know he has still got my full support with that. He is him at the end of the day and why should he change just to fit in with … I mean what is normal these days, what is the norm? There is no such thing anymore. It is very diverse now isn't it, really diverse, there is a lot more relaxed view.

Cultural and racial identity

There was some, albeit limited evidence, regarding how BAME participants felt their cultural background and experience affected their sense of self. Ashia, whose family are Turkish, for example, said she considered herself "*both Turkish and English, because I speak both*". She later remarked to her father that her English was better than his, "*because I was born here, Dad*". Mark, whose family are Chinese, conversely seemed intrigued by his cultural background, for example, commented "*Wow!*" when his Father talked about coming over to Britain from China in 1997. He also asserted his preference to answer interview questions in Chinese, saying "*I don't want to talk English because I want to talk China – we are Chinese",* further suggesting that he saw his linguistic and cultural background as an important part of his identity.

Identity and impairment

By contrast, though many participants mentioned their impairments, very few described themselves as disabled, or saw this as an important part of their identity. As a group, young people with learning disabilities were the least likely to talk about or recognise their impairments. Liam, for example, said he thought of people in wheelchairs as disabled, rather than himself, adding "*I feel sorry for them, because they can't do what I can do … 'cos they can break bones"*. Only Nicola, directly referred to herself as having a learning disability, though several others mentioned needing additional help with their learning, and Jack and Stevie described themselves as having 'special needs'.

When describing their difficulties managing their emotions or behaviour, some young people with learning disabilities did link this to their impairments, however. Nataly, for example, said "*maybe I have difficulties sometimes, like anger disabilities … like all the time I have that cross, fed up, like that, that's why I have disabilities",* and Stevie said *"if I don't take my medicine, I don't concentrate and I bang into things … that is why I need my medicine for.* Though this could be interpreted as Nataly and Stevie having internalised an individualised medical view of disability, their carers' both viewed their behavioural difficulties as related to their experiences of maltreatment, highlighting the complexities involved in disentangling the consequences of each factor for individual children's development.

Young people with physical impairments or conditions tended to talk much more openly about their conditions but downplayed or rejected this as part of their identity. Ashia, for example, said "*I have got cerebral palsy, but I know it's perfectly normal and it doesn't bother me. I feel like it is not part of me so, it is just okay"* and Chloe describing her frustration that others allowed her impairment to obscure other aspects of her personality, said: '*when I go out to the shops with Mum, people always stare [and] I always think "have you never seen a chair before" [and] it makes me really upset when people don't actually see like I am here, so sometimes with strangers they make me feel really invisible",* adding that this was one reason she did not yet feel confident enough to go out alone.

Young people with less visible impairments were similarly aware of the potential stigma associated with their conditions. Ethan, for example, as already described, chose to dress so that his condition remained hidden. Jon, despite feeling that he had begun to accept having autism, similarly felt relieved that this was not always obvious to others:

When you think about it, you are mentally disabled so it is not really a nice kind of thing to have on your person but it is different, you know it is just kind of Jon really, you get used to it and you know it [but] there are some people who when I tell them I have autism say they wouldn't have had an idea, the first thing that would come into their head was just weird, not really autistic which is fine, it is nice to know that you don't literally portray and kind of parade it.

Jon went on to acknowledge that there were also sometimes benefits to his autism being recognised:

So, it's good in that way to not come across with it, but if you are trying to prove to somebody that you are [autistic], it is a bit harder to do … trying to convince people, like people of authority who can actually do something if they can prove it.

These comments may reflect Jon and his parents' feeling that his delayed autism diagnosis had precipitated child protection enquiries. Whereas having a diagnosis had led to appropriate support being provided, and to Jon becoming a youth ambassador for a disability organisation. Interestingly Jack, who was the only other participant to emphasise the positive aspects of being disabled, had a similar role as disability representative on his local Youth Parliament. These examples possibly highlight that involving disabled young people in service design and provision can help them to develop a more positive disabled identity.

Participants' perspectives on everyday life

Although few young people claimed being disabled as part of their identity, almost all described their impairments as having a significant impact on their daily lives. For most, their impairments had resulted in them attending special schools, mediating their opportunities for friendship and access to social activities both during and outside school; though participants attending mainstream schools similarly described their impairments as influencing their social and learning opportunities. Many participants also talked about having been bullied at, or of having to change schools, and their impairments and/or their family difficulties were often a contributing factor in both cases.

Life at school

Despite these challenges, most disabled young people talked positively about their experiences at school. Many mentioned subjects they enjoyed or teachers who had helped them. Ethan, for example, liked his English teacher because *"she just explained more about stuff than like some of the other teachers, [and] I think it has helped me understand the coursework better*," and Louise felt inspired to further study Art because, *"My teachers say my art work is really good, so I thought I would carry it on in Uni, I am taking A level Art as well and I have just passed the other art."*

Several participants attending special schools also talked about learning life skills alongside academic subjects and about half of participants mentioned receiving individual support with their learning and other needs. Some mentioned their relationships with their support assistant as an important source of support or even friendship. Liam, for example, when asked who was important to him replied, *"Dale, he's a teacher assistant … he's good, he look after me*" and Chloe described keeping in touch with her support assistants from primary school for several years after leaving. A number of other participants similarly identified their teachers or other staff among those they would turn to if they had a problem. Nicola, for example said: "*The only person I would speak to are my teachers, if I was upset",* and Jack, said *"If it's a massive worry, obviously like family stuff, then [I'd] probably tell my Head-teacher or* *the person who, it's a teacher but she looks after people who told her something about family problems."*

Participants' relationships with teaching and support staff weren't always so positive, however. Jon, for example, only liked one or two of the teachers in the mainstream part of his school, because he felt the rest did not understand his Autism, and Louise, similarly felt staff at her previous school had not been sensitive to her learning needs, or her distress when her father had been murdered:

I have got dyslexia and [my old school] never picked it up and I went through my exams struggling with no help at all, also they didn't believe us how Dad actually died, because we went in and said 'we need to take a day off, it is our Dad's funeral tomorrow' and it was like 'you are lying and then they said 'right, we are going to send a teacher to the funeral' … so I was like, that is disrespectful!

Participants attending special schools described similar experiences. Ashia, for example, who is a wheelchair-user, felt her wish to use the toilet independently was not adequately respected by support staff: *"99% of the time I get in trouble because I am wasting time on the toilet, but it is their job, they get paid for it!"* Chloe likewise felt bullied by a particular teacher, whose expectations of her abilities she felt were unrealistic.

Disruptions and transitions

Several young people were anticipating or had recently moved on to a different school or college when I interviewed them, albeit at different stages. Mark the youngest participant, for example, had only recently started secondary school, while Ethan, Jon and Nicola, were about to move on to college or sixth-form. Like any young person starting somewhere new, all described feeling 'scared' or 'nervous', and all were especially anxious about making new friends.

More than half of study participants had experienced disruption to their education outside of these usual transition points, however. Five of the six young people in care, for example, had changed schools since entering care. Though for Allison and Hannah this had involved moving to a school they and their caregivers considered more appropriate for their needs. Allison's foster-carer, for example, described that at her previous school:

Carer: Allison was always sort of separated into Special Needs groups, didn't actually mingle with the kids in the mainstream classroom even to the extent she was still carrying around her sleep blanket, and you are thinking she is a ten year old young girl, she is much more able than you are actually giving her any sort of credit for! … [So] she was learning how to sort of regress back and the teachers either had a very affectionate side for her, or they just didn't know how to work with her.

Allison herself similarly felt: *"that school was not really good for me, and I didn't like it. I always got lots of homework, so annoying!"* Hannah, on the other hand felt she had experienced insufficient learning opportunities at her previous school, where, unlike her, most of the students had learning disabilities. She was therefore looking forward to studying for her GCSEs at her new school.

Nicola and Liam, by contrast, had moved schools because their out-of-home placements were too far away from where their birth families lived. Liam did not see this as a problem, because he had "*loads more friends*" at his new school. Nicola, however, despite moving schools more than three years ago missed her old school: *"I used to have lots of friends. I was the one that was popular in that school then."*

Young people not in care had experienced similar disruption to their education, however, due to their family difficulties or their own impairment needs. Ben and Louise, for example had changed schools after the family relocated to get away from their father's associates following his death. Though Louise and her mother both felt that each of their new schools better met their needs. Jack, Jon and Mathilde, all of who have autistic spectrum conditions, each reportedly experienced delays or disagreement in having their special educational needs recognised, which in Jon's case had reportedly led to him missing two years of school.

Ethan, Ashia, and Rebecca similarly described having missed a lot of school due to illnesses associated with their health conditions. This, Ethan said had resulted in him being *"like a year behind in schooling"*. Whereas Chloe expressed frustration about being unable to transition with her friends from primary onto their local secondary school because parts of the building were inaccessible for her wheelchair. She had recently experienced the same situation at her special school, because she needs a hoist for her personal care this meant she had been put in a different class from her friends.

Friendship and peer relationships

As emphasised by Chloe's example, like other young people, participants' relationships with their peers were a central part of their lives. Almost all talked about their friends at school, and many mentioned particular friends by name. Rebecca, for example, said: *"I meet loads of friends at school"* and described her best friend and boyfriend who go to the same school as important to her. While Ashia described her school friends as a valued source of emotional support: *"If I get into trouble [at school] I go to my friends. I go talk about how it makes me feel*", and Chloe appreciated opportunities to do activities together: "*I was doing [the school dance competition] with my friend Thomas as well, which is a happy experience"*

The nature of participants' friendships seemed to vary, however. Around half, despite identifying their friends as important to them, did not mention anyone they felt especially close to. There was also a tendency among participants with more significant learning difficulties, including Nataly and Liam to simply reel off a list of the young people in their class at school when asked about their friends. Though Louise, Ethan, and Hannah, similarly did not mention any specific friendships and Hannah also said she mainly kept in touch with her friends via Facebook, possibly partly because she had recently moved schools as a result of coming into care.

Several participants, particularly those attending special schools, mentioned being in classes of around only 10 or 12 students. Though Jon said he preferred the smaller classes in the unit he attended for students with Autism to the larger ones in the mainstream part of his school due to his difficulties with social interaction, other young people felt this restricted their opportunities for friendship. This was especially the case for the young women, many of whom described having mainly boys in their class at school.

Consequently, and perhaps unusually for young women their age, Nicola, Ashia, Chloe, Rebecca and Nataly all described having more friends who were boys than girls. This finding, also noted in previous studies (Davis *et al*, 2003), is mostly likely to do with higher prevalence rates of some disabilities among males. Rebecca felt this issue particularly acutely, however, because her best friend, Sarah, the only other girl in her year was now in a different class: *"we don't get to see each other a lot and I feel I'm lonely without Sarah, and the others tease me a bit, that's why it's so really hard".*

Bullying

Other young people similarly mentioned feeling teased or bullied at school, including three of the four participants attending mainstream schools. Most described this bullying as targeting their differences or difficulties coping due to their impairments or family circumstances. Jon, for example, described how taunts made by the pupil who shared his taxi contributed to his difficulties associated with his autism. This affected him both at home and school:

We would have our issues on the way to school … then by the time we got to school we would hate each other and we would just want to like grab each other by the throat … then he started to side with people who didn't like me, and then would tell me what they all say about me on the way home … when I came home I wasn't in a great state, which would then make home life ridiculously difficult. So, there was that occasion where I broke the window in the porch. I smacked it like three or four times and the whole thing just dislodged".

Nataly, who also has Autism, also described feeling similarly bullied by classmates at her special school:

At school the people that are annoying me like I don't know what to do … I get fed up. I told them about screaming and swearing like that and stuff, if I don't listen to them, they say 'Nataly is being bullied. Bo ho ho' just being mean to me. And If I tell 'Miss' they'll be rude to me and then they say 'Ah go tell the teacher boo – hoo, hoo, "who fucking cares" like that.

In Nataly's case her difficulties were exacerbated by not knowing how best to respond to her peers. Jack, by contrast, aware that stigma associated with his family's problems might increase his risk of being bullied, said he would talk to his friends "*just [about] small stuff. It won't be family stuff, obviously yeah … cos that would be spreading like a hawk!"* Conversely Louise felt teasing and bullying had been inescapable, because of the particular circumstances surrounding her father's death*: "I actually got bullied the day that he passed away. Like I got people making up* *rumours and that about what had actually happened saying 'oh he didn't die you are making it up'*

Life outside school

Many participants' sense of isolation and restricted opportunities at school permeated their accounts of their lives and friendships outside of school as well. Most, particularly young people who went to special schools said they rarely, if ever, met up with their friends outside school. Some of these young people lived in a different area from where they attended school, as did many of their friends. Nicola felt this was an issue for her and complained that "*I get bored at week-ends*" as a result. However, she also rejected her carer's suggestion to meet up with a young person at her school who did live nearby, because she felt they did not have much in common, and wanted to be able to choose her own friends.

When participants did describe meeting up with their friends, this was almost always during activities organised and supervised by adults, often at school. This usually meant mixing with the same young people with whom they had just spent the whole day, and though most said they enjoyed these clubs and activities, many also wanted a choice to do other things as well. Ashia's parents, for example, the day I visited, were keen to sign her up for a swimming club during the upcoming school holidays, but Ashia herself said she would prefer to have a lie in or go and visit the local shopping centre.

Most young people did, however, regularly attend social activities other than those at school. Chloe and Ben, for example had regular overnight short breaks at specialist residential units, and many other participants mentioned attending youth clubs for disabled young people. Young people whose impairments made social interaction more challenging seemed to especially value these opportunities. Mark, whose father said he drives him to school because he is too socially anxious to walk because of his autism, by contrast talked enthusiastically about the Kids club for disabled children he had attended that summer and was keen to go back. Chloe did not yet feel confident to go out on her own in her wheelchair, but likewise really enjoyed going along to a Nightclub for disabled young people with her carers.

Comparatively few participants attended mainstream events and activities, however. When they did, this was often with carers and disabled young people who were otherwise not their friends. Some of these young people described very close relationships with their personal assistants, who they viewed more as friends than professionals, particularly those who were close to them in age. This had both advantages and disadvantages: Chloe and Ashia, for example, said they felt able to confide in their personal assistants about problems at home; whereas Jon described his feelings of loss and rejection when his personal assistant moved on after more than two years.

While these young people appreciated having additional support to socialise, others expressed frustration about their caregivers' reluctance to let them go out alone. Nicola, for example, who felt bored at home, wanted to be able spend time hanging out with other young people at her local park. Her foster-carer, however, concerned about her vulnerability, both in terms of her learning disability and prior experiences of abuse, would not allow her to go.

Conversely a few young people reportedly required additional supervision because of their own behaviour. Despite acknowledging that this behaviour was likely linked to their own abusive experiences, these young people's social workers and carers were understandably concerned about the potential risk to others. Liam, for example, was keen to visit the local shop during our interview but was told there were not enough staff on shift to allow him to go, and according to his social worker Liam requires staff supervision at all times because of his sexually predatory behaviour in the past; Nataly's carers similarly reported that she had stopped going to a youth club for disabled children because staff had expressed concern about her sexualised behaviour whilst there.

In contrast to most participants' experience of segregation and supervision, a few did attend mainstream activities or went out on their own. Stevie and Allison, for example, both said they attended Brownies and swimming lessons at their local pool, as well as going to special needs clubs. Jack likewise said he felt included at his local youth centre. He added, however, that although other young people "*do go from my school, they don't say it, if you know what I mean*". This suggests he was aware that there was a risk he and his friends would be stigmatised, if other young people knew they went to a special school.

Participants' perspectives on family relationships

Participants' homes and their families were inevitably a central part of their lives. Almost all expressed how important their families were to them, despite the difficulties and disruption many had experienced within these relationships, as already outlined. Most participants described their main caregiver as their primary source of support, while the majority of those in care identified their birth families as still being very important, even though they no longer played a big role in their daily lives.

Whatever their circumstances, participants also described experiencing tension and conflict in their relationships with parents, carers, siblings and other family members. However, many of these examples appeared comparable with what might be expected in most families, especially during adolescence. A few participants found it upsetting to talk about their families, however, and/or said very little about them, while others felt responsible for family members, or worried about the effect of their disability on family life.

Sense of family

Many participants spoke positively about their families, were grateful for these relationships and how their families had supported them. Louise said, for example, "*I have a strong family bond, I have everything I want and need basically"*. Ben, who I interviewed at the short breaks unit he attends, when asked about his family, replied "*Yes, PLEASE, the taxi home, see Mum*", and expressed a consistent preference for spending time at home; and Chloe also felt hers was a 'close' family.

Young people in out-of-home care also emphasised the importance of their families, and how difficult it was being away from them, even where they felt this had been the right decision. Nicola, for example, said:

Nicola: Being in foster care is a good thing for me and my sisters, though it's really hard when you live with someone, and you're not staying with them anymore and they give birth to you, because I've been there a very long time, at home. But my baby sister didn't … but she still knows that it is her birth Mum, I think … I think I her do knows her birth Mum

Other young people similarly highlighted the importance of their birth families to their sense of identity and valued the opportunity for regular contact. Allison, Nicola's younger sister said for example:

I know who is important to me, my Mum and Dad, Stevie …in October I see all of them, the same day I see my Mum and my Dad and Nicola, [my other sister] and my brothers, and they are all mine!

Young people in foster-care additionally tended to describe their carers as their family. However, most also made a distinction between these relationships and their birth families. Allison for example, referring to her foster-carer as 'Auntie Karen', explained excitedly "*I am going [on holiday] after next week with Auntie Karen and all of my family, but not my Mum and my Dad and my brothers*." Whereas Nataly, who had lived with her foster-carers and their family since the age of six, described her foster-carers, as her 'real' family, and her birth family as her '*pretend*' family.

By contrast, Hannah and Liam, though they both said they got on well with staff at their residential placements, did not give the same sense of feeling part of a 'family'. Liam, for example, only gave brief details about his birth family, which care staff also said was generally the case at his placement. I felt that the care staff present likewise discouraged our discussion of this topic, which also prevented me from exploring Liam's views.

Relationships with parents and caregivers

The majority of participants, whether they were living with their families or in care identified their main caregiver as their primary source of support. For most participants this person was their mother or female foster-carer. This is perhaps unsurprising given that half of those living with their families lived with their mother who was a single female carer. However, regardless of whether they were living in one or two parent families, mothers were generally seen as having a more significant caring role. Jon, for example, described how his Mother supported him emotionally:

when you feel rubbish, Mum gives me Cola depending on how bad it is, [or] sometimes I come home from school and she is sitting in the car with the engine running and says, 'let's just go somewhere', and then we just go and sit, and we just talk about how the day was.

However, he felt that his father had less understanding of his Autism:

Dad has started a bit to learn about [Autism], considering like there is not really a lot of time to get to know me he does try, but occasionally he loses his temper every now and again, or kind of doesn't understand why.

His father reported he often worked away during the week, which Jon implied affected their relationship. Ashia, whose father did shift work, similarly, felt this affected his involvement in her care: *"Most of the things, about 99% of the time, my Mum helps me … [my Dad] goes to work."* Several participants, including some of those in care, perceived their fathers or male carers to be involved in setting boundaries, even when they weren't around much during the day. Nataly, for example, when talking about what she wanted to when she was older said *"I might have a boyfriend or something like that".* But added with a sigh *"if my Dad let me!* Participants were generally less likely to identify their male caregivers as a source of emotional support, however. Nicola, for example, commenting about her foster-carer's partner said: *"he lives with us, er, her partner, but I don't speak to him, we play, but we don't speak"*

Some participants appeared to be very close to their father or another caregiver. Chloe, for example, speaking about her step-father said: "*I love my Dad, I love my Dad very much*", and Mark, whose mother had recently left the household, from my observations of his behaviour during his research interview, appeared to have a close relationship with his father. Mark and Mathilde each also identified their grandmothers, who lived with their families as significant people in their lives.

Other participants' relationships with their mothers and female caregivers were also described as involving varying degrees of difficulty and tension. Many of these examples seemed, however, to reflect the usual ups and downs of family life. Nicola's foster-carer, describing their relationship said, for example "[Nicola] *is quite funny, we do get on well but there are times when we don't like each other very much. I'm afraid we had one of those days yesterday.* Jack was increasingly irritated with his mother for interrupting him during our interview, similarly, said sarcastically*:*

Jack: Mum, this is private, shhh
Mum: No, no I'm not saying things, I'm saying good positive things
Jack: Mum, I think you made yourself clear

Mum: What I was gonna say, you like to help people
Would you agree with that, Jack?
Jack: Mmm, yeah, I'll say it loud!

There were a few participants for whom these relationships appeared to be the cause of significant distress or anxiety, however. Mathilde, for example, was particularly upset and angry with her mother for refusing to allow her to go on a school trip. Chloe, whose mother had recently had mental health problems, said "*I still worry about [my Mum] … when I come home, I always say: 'have you been alright' and 'how have you been' that sort of thing*. Chloe is a wheelchair-user, and also said she felt guilty about the added pressure on her mother, of having to meet all her care needs. But she also felt that her Mother's illness had affected her own mental health: *"Like I'm in a hole, I can't get out, that's how I feel … like listening to Mummy gets me in my hole for a little while, it is very frustrating".*

Relationships with siblings and other family members
Participants described their relationships with their siblings as characterised by similar ups and downs. Allison, for example described her sister Stevie, who lives with her, as *"the cheeky one, my sister, Stevie, she is so annoying"*, and also said about Nicola their older sister: *"Oh you had better watch out with her! Why? She beat my sister Stevie up, she punched her!"* Chloe similarly said about her older sister:

She's a good sister really, but she isn't talking to me at the minute because I don't know if I have done something wrong or not …and she isn't talking to Mum, so like it has been quite hard.

Other participants, by contrast, described their siblings as an important source of support and friendship. Jon, for example, described his sister standing up to the people who were bullying him when they were in primary school together, and also felt that she accepted and supported him in other ways:

[My sister] has been helpful, when I bought my gaming chair she drove and we made a road trip out of it and it was really fun and she is supportive of me … she does really well to help me to deal with [my autism], she is not ashamed of it, so like when people say 'Oh is Jon your brother?' she doesn't kind of say 'yes' in a shameful sort of thing and she is kind of okay to say to them 'this my brother'.

Rebecca, similarly, seemed to value spending time with her two older sisters and their children, who live nearby:

We do all sorts of things really, my family we go down to the [local pub], down the road, with my Mum and Dad, my sister and my other sister, and then there's their three children, they come round and then they can chase me round the garden if they want to, they're all really cheerful.

Ashia also said she enjoyed spending week-ends with her maternal grandmother and aunts, because *"they cook me some Turkish food, I don't always get cooked food [at home], and also if I need a bit of help with my homework, and I stay for the night as well".* But she also mentioned aspects of staying away from home that were more difficult because of her physical needs; *"obviously it is much harder, because I have a commode toilet [at home] … so I mostly have to sleep downstairs when I am there because obviously, getting up to go to the toilet is much harder".*

Participants whose siblings weren't living with them also described missing them. Ethan, for example, recalled a time when he and his younger brother still lived together, and their mother bought them each a budgie:

But then my budgie got to escape but then Jack's one was just hopping from perch to perch just trying to get the other one back I think, because it just kept talking, but the cage door was open and so my little brother's could have escaped if it wanted to but it wanted to be loyal and wanted to stay, [and] ever since I've wanted another parrot yeah.

Some of the young people in care similarly described missing their siblings, who were not living with them. Nicola, for example, also appeared to imply feeling that these birth family ties were more significant than those with her foster family or other young people in care: "*I want to live with them. With my sisters. I want someone who cares about me and makes friends. But like a sister, you can do anything with them".* Whereas Nataly, who had no biological siblings, identified her foster 'sisters' as someone she could turn to when she was upset, and said *"I like to play with all my sisters.*"

Only nine of the fourteen participants with siblings had one or more of their siblings living with them, of whom only three did not also have a sibling or step-sibling who lived elsewhere.

Conclusion

This chapter has given an overview of participants' characteristics and explored disabled young people's views about their lives and experiences outside of the child protection system. These represent important findings in themselves, since participants highlighted many similar themes and experiences to those identified by disabled young people in previous studies. For example, participants tended to emphasise their similarities with other young people, including their interests and aspirations, and downplay the differences associated with their impairments (Wickenden, 2011: Foley *et al*, 2012). Some appeared to have internalised a negative view of themselves due to their impairments, they also described their impairments as affecting their family relationships, restricting their opportunities for friendship and to become more independent (Kelly, 2005; Singh and Ghai, 2009) and increasing their risk of being bullied or experiencing discrimination (Ytterus, 2012).

These findings also identify important themes which help contextualise participants' experiences of child protection enquiries and their aftermath discussed in the chapters that follow. For example, the majority of participants' families experiencing very high levels of need in terms of severity of impairment and numbers of disabled family members, coupled with low levels of social and economic resources, factors that are associated with both cumulative maltreatment risk (Stith, *et al*, 2009) and higher levels of child protection intervention (Bywaters *et al*, 2015). For some participants it appeared hard to distinguish between the effects of maltreatment and their impairment on their behaviour and development. In few cases participants' behaviour or perceived vulnerability related to their experiences of maltreatment was described as restricting their opportunities for friendship and become more independent as well as their impairments. There was also some evidence that participants' impairments might themselves increase their vulnerability to exploitation either online or in the community. Conversely, participants' family difficulties and/or experiences of decisions made as a result of child protection enquiries rather than their impairments appeared more closely associated with the high levels of disruption within participants' family relationships, even among those participants who were not living in care. The key themes identified in this chapter are summarised in Box 2.

- Young people's families reported experiencing very high levels of need, including in terms of disability. However, many appeared to have relatively few social and economic resources to help them cope.
- Young people emphasized having similar interests and aspirations to other young people and tended to downplay their differences related their impairments and/or their family difficulties
- Young people reported having limited opportunities for friendships, to develop their social skills and become more independent. These opportunities appeared influenced both by their impairments and their experiences of maltreatment
- Young people's family relationships were very significant to them, however most had experienced a great deal of disruption in these relationships, sometimes as a direct result of decisions made following child protection enquiries.
- Young people's impairments and prior experiences of maltreatment indicate that they may require additional support to help them manage risks online and in the community.

Box 2 – Key findings - Disabled young people's view of themselves, their families and wider social worlds

Chapter 6 – Young people's views and experiences of taking part and feeling listened to during child protection enquiries and decision-making processes

Introduction

This chapter presents an analysis of disabled young people's views and experiences about their participation in child protection enquiries and subsequent decision-making. As part of the interview discussion and activities young people were asked about what understanding and information they had about what was happening during child protection enquiries; what opportunities they had to say what they thought about it, their awareness of, and involvement in, any meetings held to discuss what should happen, and how far they felt included in decision-making processes, such as at child protection conference or core group meetings.

Most disabled young people described having at least some opportunity to talk to their social worker about their views during child protection enquiries. However, with some notable exceptions, very few felt they had been able to gain a clear understanding of what was happening or might happen to them or their families, or felt their views were taken into account during subsequent decision-making. Some young people gave specific examples of how their social worker had adapted their practice to encourage or facilitate their participation, for example through allowing them to attend or representing their views on their behalf at child protection or other meetings. However, most participants appeared to feel little or no account had been taken of their impairments when seeking their views or attempting to involve them in decision-making.

Understanding disabled young people's views of taking part in decision-making

There were, however, notable differences in how disabled young people described and made sense of their experiences of participating in child protection and other decision-making processes. When examined across the sample young people's views appeared to fall into four different groups depending on the opportunities these participants' felt they had had to express their views and be involved in decision-making. Each of the four groups is also identified by a phrase, used by one of the young people themselves, that appeared to sum up how they felt about their participation.

There were three disabled young people in the first group who felt their participation in decision-making had been limited. Despite some opportunity to talk with their social worker they felt they had little understanding of the reasons for child protection enquiries and their overall view of their participation in decision-making was that "***it just didn't happen***".

The three disabled young people in the second group, despite having a better understanding of what was happening during child protection enquiries, were not confident about expressing their views and taking part in decision-making. It appeared, as one young woman put it, that they were *"**only speaking softly**"*.

Each of the four disabled young people in the third group had attended child protection meetings. They nevertheless felt that their participation in the decisions made at these meetings had not been meaningful because they either felt unable to take part because of the way meetings were organised or that their views did not count because of their age or impairment. They were seen as "***young and dumb***" as one young person said.

By contrast, the four young people in the fourth group were confident about contributing to decision-making. Even though some had not attended child protection or other meetings each appeared to feel supported by their social worker to express their views and have a say in decision-making processes. Consequently, in terms of their participation at least, they seemed to feel that "***it all gets sorted***".

Finally, there were two disabled young people whose participation in child protection or other decision-making could not easily be categorised as belonging to a particular group as they said little or nothing about this aspect of their experience.

Although each group's experience of child protection enquiries and taking part in decision-making varied, they also had four themes in common that may also help account for the differences between them:

How informed they felt about child protection enquiries and if they could choose how to be involved in decision-making
How they felt about the opportunities they had to express their views during decision-making
How they felt adults affected their participation and the weight given to their views
How they felt their relationship with their social worker influenced their participation in decision-making

These sub-themes are used to structure the analysis for each group in the sections that follow, in order to try and better understand the barriers and enablers to disabled young people's participation in decision-making and how practitioners' might better support them in practice.

Group 1: Limited participation – "It just didn't happen"

Why "It just didn't happen"?

"It just didn't happen" captures the limited opportunities for participation during child protection decision-making described by the three disabled young people in the first group (Nicola, Nataly, Mathilde). Though specifically used by Nicola, to describe her frustration at not being allowed to attend her child protection conference, it also conveys the worry and confusion described by all of the young people in the group at not being able to understand what was happening during child protection enquiries or to really say or express what they thought about it.

What was it that made these young people feel that their participation in child protection enquiries and decision-making "just didn't happen"?

There were a number of different aspects of their experiences of participating during child protection enquiries and decision-making which these young people felt ***"just didn't happen".*** These are summarised in Figure 10.

Figure 10: Limited participation – "It just didn't happen" theme and sub-themes

I was not able to understand what was happening

Not feeling they were able to understand what was happening during child protection enquiries was an important reason young people in this group gave for feeling that their participation in decision-making had been limited. Despite opportunities to meet with their social worker, each described their limited understanding about what was happening during child protection enquiries as leaving them feeling upset or confused. Nataly, for example, despite her experience of child protection processes having taken place some years before, remembered her social worker at the time talking to her but recalled this as "*not a good thing*", because she felt she did not explain what might happen to her and her family as a result of the decisions made following child protection enquiries , especially to her Mother once she was in care. She said: *"I was upset, because social workers take me away from my Mum, and I feel I worry about her my Mum".*

Other young people described similar difficulties understanding what was happening during child protection enquiries, despite their experience being more recent. Mathilde, for example despite saying "*a social worker can help me*" did not appear to know why she had one. She likewise found it difficult to say what the purpose of her meetings with her social worker were or to say what is discussed:

Why do you think you have a social worker?
Mathilde: *I don't know.*
Do social workers ever have meetings with you to talk about things?
Mathilde: *Yes …*
And what do you talk about with [your social worker]?
Mathilde: *Nothing, I don't know… it is about, I am not sure*

Mathilde' autism could have affected her ability to answer these questions during the research interview, due to their abstract nature and the potential for the experience of being interviewed to trigger social anxiety (Beresford *et al*, 2007). However, this in itself highlights the need for social workers and other professionals' to check with young people, that they understand what has been discussed when facilitating their participation in practice as well.

Nicola appeared to have a much clearer understanding of child protection enquiries and decision-making processes than other young people in this group. For example, describing her understanding of social worker's role during child protection enquiries she said:

[Social workers] *just care about like, if it is safe for you or not safe. And if it's not safe they have to have plans or have to say stuff to the government or something if they think you're not safe in there.*

She nevertheless felt that her opportunity to contribute to child protection decision-making had been limited by not being allowed to attend her child protection conference, a meeting she seemed to view as important for gaining information about what would happen to her and her family following initial child protection enquiries.

I thought I want to go [to the meeting] *… I just wanted to know stuff what's happening, but they just didn't let me … I know it's gonna be sad, but I would want to know stuff,* *and I think other kids think that too. They wanna know what's happening, if they're going in foster care or not going.*

It was difficult to say how I felt

As well as not being able to understand what was happening during child protection enquiries young people in this group described difficulties expressing their views as limiting their participation in subsequent decision-making. Nicola, for example, was frustrated at being excluded from attending her child protection conference not only because it prevented her feeling informed about what was happening but also because it denied her an important opportunity to tell professionals what she thought:

I really did want to go [to the meeting] to see what they say [and] I would have liked to have told them what I thought, but ***it just didn't happen****. I was young then, I was like 10 or 13 or something.*

Other young people in this group similarly saw their age as limiting their ability to express their views, albeit for apparently different reasons. Nataly recalled talking to her social worker at the time when she came into foster care as a result of child protection enquiries into concerns that she was being left alone and unsupervised for long periods by her mother, however found it difficult to express herself due to her age. She said: *"I was talking to [my social worker] … it was difficult for me … I was too little to understand"*

Other young people similarly seemed to suggest that their impairments also made it harder for them to tell their social worker their views. Mathilde felt her social worker sometimes asked her about her views, for example when she was placed in foster care following child protection enquiries after she alleged that her Mother had hit her. However, she also said that she generally found it very difficult to talk with her social worker about how she felt. She said:

[Social workers] *did ask me about when I was in foster care … [but] it is difficult for me I don't talk and chat, it really is too difficult.*

The difficulties Mathilde describes chatting to her social worker seem likely related to the social and communication difficulties she experiences as part of her autism, especially given research highlighting this as a particular barrier to participating in decision-making for this group of young people (Beresford, 2012).

Nataly and Mathilde's experiences both highlight the additional barriers to understanding and/or expressing views that disabled young people face because of their age or impairments. Moreover, the need for practitioners' to be especially attuned to their developmental needs and preferences and adapt their practice in ways that help disabled young people express their views on an equal basis with other young people during child protection enquiries and decision-making.

My parents did not think I could/should participate

There was also some evidence that how these young people's parents and carers and other adults viewed their understanding and ability to express themselves further limited their participation during child protection enquiries. Some also saw this as having affected the weight given to their views in decision-making. Nicola, for example, as well as her age felt that not being allowed to go to her child protection conference reflected her parents and her social worker under-valuing her contribution and competence to participate:

My Mum didn't want me to go because she didn't want me to get upset, she didn't want me to get involved … I talked to my social worker and my foster carer, and said that I wanted to be there, but they didn't let me.

Nicola asking both her social worker and her foster carer if she could attend suggests she had some confidence in these relationships, but nevertheless felt frustrated by her parents' wishes being given greater credence than her own. Although Nicola said she understood that adults were concerned that attending the meeting might upset her, she did not agree that this was sufficient reason for her to be excluded from attending. Rather she seems to suspect that the adults may be more concerned about her behaviour, or that she might do something wrong if she was allowed to go:

So why do you think they didn't want you to go?
Nicola: *I don't know, I'd probably get angry or something, or I might be scared, or I might do something wrong …*

The experience of other young people in the group also suggested that their parent or carer's views of their competence limited their opportunities to participate or the weight given to their views during child protection enquiries and decision-making. Mathilde's mother, for example, downplays the allegations that led to her spending time in foster-care, and suggests nothing Mathilde says can be believed, because of her emotional problems related to her impairments:

[Mathilde] might say something which is not the truth … the last time there was a problem she was in foster care and I think [social worker's] ask her and she said 'my mother beats me' but you know she might be in trouble when she have this story just come, you think it is true which it is not! … because Mathilde have this hallucination, it is hard to understand, especially she have this emotion problem, since she was young.

Nataly's foster father similarly questions the credibility of what she says, because of her tendency to be inconsistent in her account:

[Nataly] made all sorts of allegations against her father and we're not sure how true they are because she keeps contradicting herself, so she will say one thing one day and something else another day, so you know she's a bad witness …

Decisions about how best to respond to allegations of abuse by any child are often finally balanced. However, such negative attitudes regarding these disabled young people's competence also raises concern about how their participation is currently being supported during child protection enquires. This is particularly given that there was some evidence that these views may also have had a bearing on child protection decision-making. Mathilde, for example, was placed in foster-care which appears to suggest her social worker took her allegations seriously. However, her Mother casts doubt on this assumption when she says: *"I was angry, I did not want her back and I tell Mathilde's [social worker] yes, just tell her she is not coming back*". The fact that Mathilde also returned home shortly afterwards may also suggest that professionals' ultimately attached more weight to her Mother's views than Mathilde's.

My social worker did not help me trust them

These young people's opportunities for participation in decision-making also seemed limited by their difficulties trusting their social worker. Some felt their initial trust in their social worker had been undermined because they had not listened to their views or explained the reasons for their decisions following child protection enquiries. Nicola, in addition to her frustration that her social worker had not supported her wish to attend her child protection conference, felt disappointed because she had not told her that she was leaving:

[My social worker] let me down cos' she just went and left and just never like tell you and yer Mum just tell you, and like I'd been open to her and I trusted her, everything … I guess that was now, I was just angry about it then

Mathilde, despite describing her social worker as someone who "*can help me*", also seems afraid of her and worried about getting into trouble. Although she doesn't directly make a direct connection with the allegations she made against her mother, she says the meeting where she recalls getting told off apparently happened around the same time:

What do you think a social worker's job is?
Mathilde: A social worker can help me…
When does your social worker come and see you?
Mathilde: When they are cross with me … she comes to the meeting in our house. Oh, the social worker is coming round!
Was this when you were living with [foster carer] for a bit?
Mathilde: Yes, and she told me off, it was with [my teacher] as well.
So why did she tell you off?
Mathilde: I am not sure.

Nataly similarly seems to view social workers as powerful figures, and while she appears to have mixed feelings about their becoming involved as a result of child protection enquiries and like Mathilde, seems wary of their authority to intervene in her life:

When I was little, I was so scared and then the social workers take me far away from my Mum, I feel, I used to cry when I was little and now, I am back to here I missed her then.

Group 2: Not confident participating - "Only speaking softly"

Why "only speaking softly"?

There were three disabled young people in the second group (Chloe, Ashia and Stevie) who all seemed to lack confidence participating during child protection enquiries and decision-making. There appeared to be a number of issues that contributed to this, including being more used to their parents speaking for them because of their impairments and a reluctance to trust their social worker. Each also expressed seeing themselves as having played a role in triggering initial child protection enquiries. Moreover, fearing the potential consequences of having shared their concerns with professionals appears to have played a part in their reluctance to contribute to decision-making by "***only speaking softly***", as one young person put it.

What was it that made these young people feel they could "only speak softly" in child protection decision-making?

The factors that seemed to contribute to these disabled young people's lack of confidence contributing to child protection decision-making are set out in Figure 11.

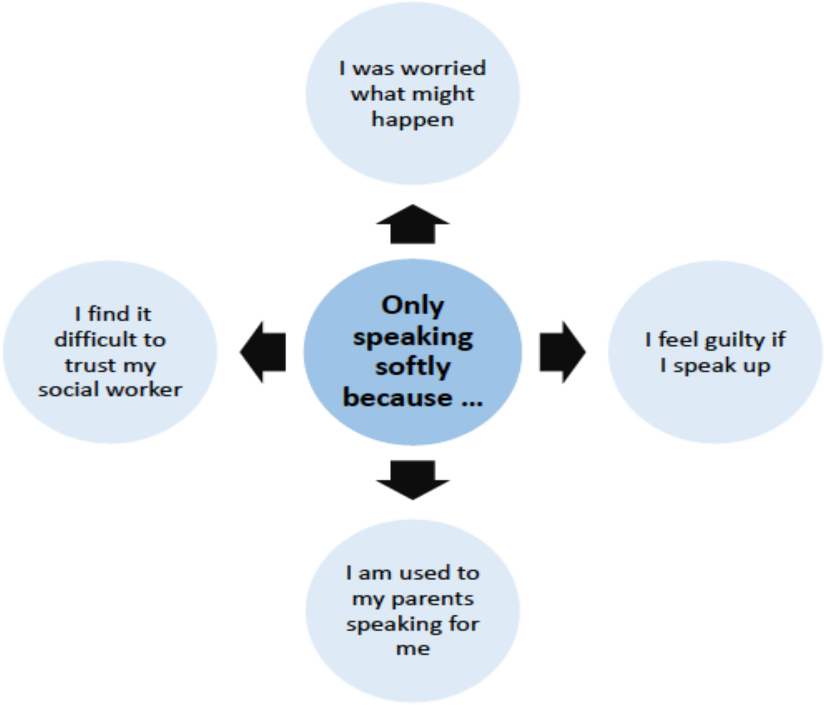

Figure 11: Not confident participating – "Only speaking softly" theme & sub-themes

I was worried what might happen

Disabled young people in this group generally appeared to have a better understanding of child protection processes than those in the ***"it just didn't happen***" group. This was partly perhaps as a result of having fewer learning disabilities and/or difficulties with communication. Nevertheless, all indicated feeling worried by not knowing what might happen to them as a result of child protection enquiries and a child protection conference being held, and these worries appeared to have some influence over how they participated. Chloe, unlike Nicola in the first group, indicates having the choice whether or not to attend her child protection conference. This may have been partly because, being 16 at the time, she was older. However, Chloe decided not to go because she feared what decisions would be made about the concerns, she herself had raised and the impact of this on family relationships:

Did you have anything called a Child Protection Conference?
Chloe: *Yes, they thought Mummy was ill and, I mean I think she is, but I didn't really go to this meeting because I thought that I would be in trouble, I told Mum all the wrong things … but then I regretted it then because I thought I was going to get wrong, and they would do things I didn't want to do"*

Chloe seems especially worried about being in trouble with her mother for sharing her concerns that her mother's mental health difficulties were affecting her ability to adequately care for her, triggering child protection enquiries. However, she also seems to feel in a double bind. On the one hand not wanting to attend, because she recognises it could be difficult and upsetting, but still wanting to feel informed and have a say in decision-making because of what it might mean for her life and relationships. This is particularly as she appears to lack confidence in professionals' ability to make decisions that she herself feels are in her best interests.

Other young people in this group were aware of child protection meetings but had not had a choice whether or not to attend. However, some said they preferred not to attend meetings because like Chloe they thought they might get into trouble:

I don't go into meetings because of my lessons … I don't really mind; it doesn't bother me. If I have to go in fine … probably I am used to getting into trouble and all that … but if I had a choice I would stay in the school.

Ashia

For other young people, their worries about what would happen to them and their families following child protection enquiries made them reluctant to participate in decision-making in other ways. Stevie recalling how she felt about social workers visiting her family said:

"When I was at my uncle's [my social worker] find out how to get there, cos' she went to the Police and asked them … [but] we didn't let her in because we didn't want her to talk to us … she thought to look after us, but we didn't want her to find us, so we didn't let her in"

I feel guilty if I speak up

Another issue that seemed to affect these young people's confidence sharing their views was feeling guilty about speaking to professionals about difficulties within their families. For Stevie this appeared to make her unwilling to speak to her social worker at all during child protection enquiries, because doing so would mean she was being disloyal to her family:

But did [your social worker] come and talk to you?
Stevie: *I would never talk to that person! I didn't listen. I was ignoring her because my Mum told me all the stuff, she was saying about us!*

By contrast for the two other young people in this group (Chloe and Ashia) feeling guilty about having previously raised concerns with professionals about how their parents were caring for them appeared to make them wary of participating further. Although such feelings are a very natural, understandable reaction for any child, for these young people they seemed to be compounded by their heightened dependence on their parents due to their physical impairments, since both are wheelchair users who rely heavily on their parents, including for their personal care needs:

Chloe: *I do moan in the mornings at Mum but that is because I am really sore, I sort of live in my chair and I am very often stiff, and … I didn't like being pulled around especially not in the morning … I know I am going to have to do it tomorrow, get up early again ready to go [to school]. But I don't mind that, I mind that Mum's facing it, I am okay with it"*
So, you were worried about Mum?

Chloe: *Yes, I was worried that she would be a bit upset after the meeting and she was, and it made me a bit upset.*

Chloe eloquently explains how the physical discomfort associated with *'living in her chair*" impacts on her both physically and psychologically, contributing to the struggles she and her Mother experience in the mornings. However, she implies that she feels guilty not only about the demands her impairments needs place on her Mother, but also how much upset sharing her concerns with professionals had caused her.

Ashia similarly says she feels guilty about the allegations of physical abuse she made against her father which led to the police becoming involved during child protection enquiries:

With my house the Police have been involved as well, so [with] my Dad, so yes … I have felt bad that I have said it.

Elsewhere in her interview, like Chloe, Ashia also seems to suggest that this may be partly related to feeling guilty about the impact her impairment needs have on her parents as she downplays the importance of her own feelings and needs:

I know it is a struggle for my parents having me here … I am not complaining, I don't, I don't really care that much of my needs so.

I am used to my parents speaking for me

One way these young people talked about how their dependence on their parents because of their impairments affected their participation was the impact this had their interactions with professionals. Chloe, for example had needed several operations because of her condition but said she found it difficult to understand when medical professionals tried to explain what was happening and sometimes needed her Mother's help:

Chloe: *I find it hard, I do understand some things, yes and I finally get what they are saying if they repeat it twice … Mum does help with certain things …*
Mum: *Well they talk to you, and if you get stuck for an answer, I get that look 'will you say!'*
Chloe: *Mum!*

Mum: *You do though!*

When I asked Chloe, what would help her feel more involved she said: "*if I spoke up more … like when I get my [school] reviews they sort of ask me 'do you want to say something' and I just say, 'no that's fine' and I just go back into my own little world.*" This suggests Chloe blames herself for her lack of participation in decision-making as rather than seeing it as being up to professionals' to better support her to understand and express herself. However, this is arguably what is needed to help Chloe to develop the confidence to persevere with making her own voice heard rather than relying on her Mother.

Ashia expressed a similar preference for her parents to raise concerns about how she is being supported by staff to use the toilet at school. Despite clearly feeling very upset and angry about this issue, she doesn't seem confident, or perhaps feels too ashamed or embarrassed, to talk to them about this issue herself:

"Most of the time I wheel myself, if I need help [support staff] help me, but most of the time I get in trouble because [they say] I am wasting time on the toilet … I have to wait, and it is bad, and I end up having an accident which is no good for me … It is ridiculous! but I don't say nothing because it is rude, I feel bad I don't say nothing … I tell my parents and then they raised it and it doesn't matter"

It is of course often entirely appropriate for parents to be involved in advocating on their child's behalf, particularly given the unequal power relationship young people have with professionals. Disabled young people in particular have indicated in previous research that they welcome parents or other trusted adults to support their participation or take the lead in decision-making (McNeilly *et al*, 2015). While such family-based approaches may help young people to feel more confident contributing to decision-making such issues are often more complex during child protection enquiries. Also, it was clear at several points during Ashia's research interview, for example, that her parents were not supportive of her views and saw her as partly to blame for the issues she was having using the toilet at school.

I find it difficult to trust my social worker

This group of young people's lack of confidence participating in child protection decision-making was also reflected in their interactions with their social worker.

Some, though fairly positive about their social worker, were nevertheless wary of asking for their help and seemed to find it hard to trust them, perhaps fearing what the consequences might be for them or their families. Chloe said:

[My social worker] says if I want anything in the week, will you please give me a call when, have you got any worries, any concerns and other bits as well so … [but] I am still building up to it, I am building up my confidence to ask for help … I am not speaking up well, I am only speaking softly."

Ashia, although she seemed more confident sharing her everyday concerns with her social worker, was similarly cautious sharing information with her social worker about the problems in her family:

Generally, if I have anything, I am worried about I will just say and [my social worker] will deal with it and stuff … but, if, I am not saying it out loud though [pause] if the Police have to get involved!"

Ashia's comments perhaps suggest that she feels that although professionals' responded to her allegations by involving the police, she was not really believed and ended up feeling blamed. This explanation appears supported by the uncomfortable way Ashia tries to change the subject when her Dad refers to these allegations, perhaps fearing what the possible repercussions might be:

Dad: *Ashia said 'my dad hit me', but I am not hitting Ashia, never!' but for about three hours I am at Police Station just with this problem.*
Ashia: *Please don't even, okay – it has happened, Dad it's happened loads of times. Now be quiet please.*

Stevie is even more guarded than either Chloe or Ashia about her social worker, while recognising that at least some of the concerns for her and her sisters that had led to child protection enquiries were valid. She appears to manage this contradiction by expressing her dislike of the social worker and loyalty to her family, perhaps because she feels she has too much to lose by blaming her parents' for the situation:

What did you think about the things social workers were worried about?
Stevie: *Half of the things was true, when I said that [my sister] broke her leg? That one was true she did, and my little sister, she broke her arm … but I was ignoring her because I always listen to my Mum, not to the people we don't like [and] we didn't like that Social Worker at all!*

A tendency for young people to ally themselves with their parents against social workers during child protection enquiries has been noted in previous research with non-disabled children (Bell, 2002; Gallagher *et al*, 2012; Cossar *et al*, 2014). The comments made by young people in this group appear to suggest that this represents an important barrier to disabled young people's participation in child protection enquiries and decision-making too.

Group 3: Participation not meaningful – "Young and dumb"

Why "young and dumb"?

There were four disabled young people in the third group (Ethan, Louise, Jon and Rebecca). Unlike most study participants all had attended either their child protection conference or core group meetings. They nevertheless felt their participation had not been meaningful because they felt unable to contribute their views to decision-making due to a lack of consideration of their needs, or they felt that professional's attitudes towards them owing to their age or impairment affected the weight given to their views. As a result, they felt their voice had not been heard in the meeting, as reflected in the name of the group "***young and dumb***".

Why did these young people feel "young and dumb" and that their participation in child protection was not meaningful?

There were several themes these disabled young people highlighted as contributing to their feeling "young and dumb" and that their participation in child protection enquiries and decision-making had not been meaningful. These are summarised in Figure 12.

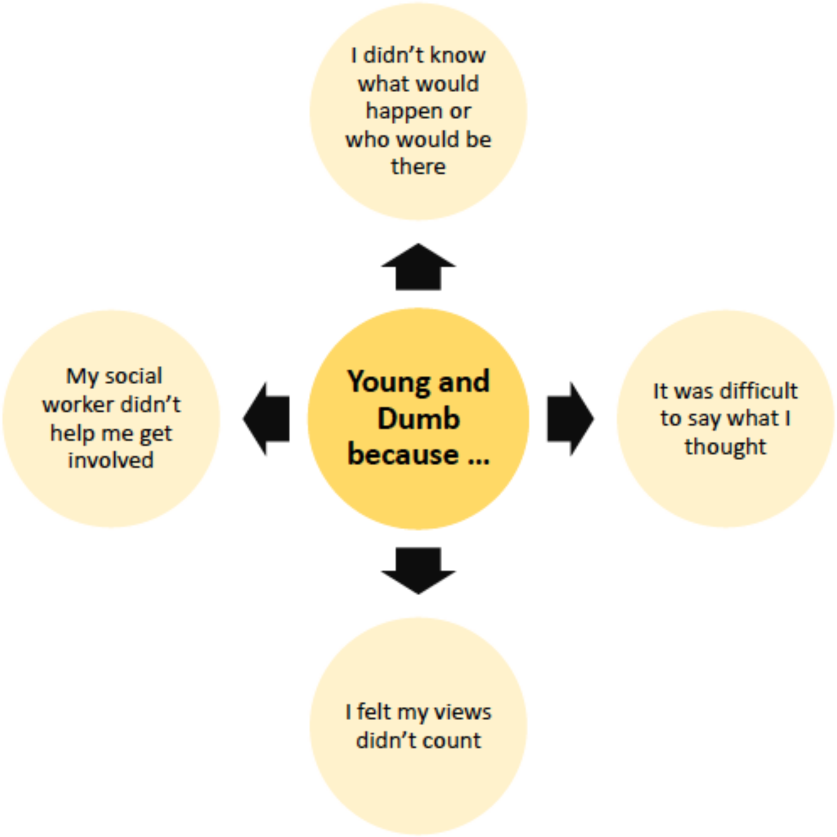

Figure 12 – Participation not meaningful – "Young and dumb" theme and sub-themes

I did not know what would happen or who would be there

A prominent reason this group of young people felt their participation in child protection decision-making had not been meaningful was a lack of preparation for their attendance at meetings. Some felt frustrated at not being given a choice about whether or not to attend, and all described feeling uncertain about what would happen during child protection meetings and who would be there. Ethan, recalling his confusion at being told on the morning of his initial child protection conference that he would not be allowed to attend said:

The Chair spoke to me I think an hour before the meeting and told me and my Nan that we weren't allowed in … [I thought] that's a bit strange because I was invited but I weren't needed … I think it was because there was loads of emotional stuff, which could have been brought up [but] I still wanted to go in … I find the way that they did that was unfair

By contrast Jon and his family felt annoyed by professionals' determination that he attended child protection meetings because they considered this highly inappropriate.

Mum: *Jon had to come to some of these meetings*
Jon: *And listen to it!*
Mum: *They were really inappropriate, they insisted that we bring him … and he would be sitting there at these meetings, about half of which would be people we had never met, and had never met Jon.*
Jon: *And there was that guy that one of the social workers brought, and he was under the impression I needed anger management … oh! if I had punched him it would have kind of proved his point and I really wanted to …*

Though not formally diagnosed with autism at the time, Jon's social anxiety had reportedly led to him missing two years in school, and this formed the basis of the professional concern that had resulted in child protection enquiries. Jon himself also said he found talking to new people very challenging and potentially upsetting and appears agitated recalling this experience, which triggered a strong emotional response. This appears partly due to not having a choice about attending, but also his social worker's apparent lack of thought as to how Jon's anxiety in unfamiliar situations with new people might impact on his experience of or his ability to contribute to meetings.

However, regardless of their impairment, other young people in this group all similarly reported finding it unsettling not knowing who would be at their child protection conference and why, especially as those attending usually included several professionals they had not met before. Louise, for example, said:

I think you should know exactly who is going to be there and why they are there [because] half the people that were there for me I didn't have a clue who they were

It was difficult to say what I thought

These young people also talked about finding it difficult to express their views during child protection meetings. This was either due to a lack of opportunity and/or because they felt the way meetings were set up discouraged them from taking part. Ethan and Rebecca's opportunities to share their views at their child protection conferences had been limited. Ethan said he was "*not too sure*" how his views were represented at his as a result of being excluded from attending, while Rebecca chose to leave her child protection conference part way through.

Although, Rebecca herself says that attending the meeting was '*OK*', her leaving appears to suggest otherwise. Rebecca's Mother said she thought she found it difficult to say what she thought and decided to leave because: "*it was a big meeting with ten or fifteen people, and it got quite heated, discussing all the information, so it was a bit upsetting".* Rebecca has severe learning difficulties and appeared to have very little understanding of child protection processes, therefore finding the meeting quite confusing and perhaps overwhelming may also have contributed to her reluctance to stay.

Although Ethan described later having an opportunity to share his views at core group meetings, he still seemed to feel that professionals' views dominated decision-making, and like others in the group found the large number of people there off-putting:

So, who spoke at the meeting?
Ethan: *All of the [professionals]*
Did you get to speak?
Ethan: *For some of the bits … [but] it was really professionally … the meeting got a bit hot because there was too many people in there and not enough air to be circulating.*

Other young people reported similar difficulties sharing their views at child protection meetings. Louise described having to assert herself in order to have an opportunity to express her views:

I think it was the second meeting that I had, that was when I got my chance to say something, because I had had enough! In the end I was just like 'look it is my turn to speak this is about me basically … and then the Chair lady, she was like 'yes she is right, it is her chance to speak' so I did!

Jon likewise felt professionals, including the person chairing the meeting, did not support his participation in decision-making, and seemed to feel their use of depersonalised language indicated their disinterest in his views resulting in him relying on his family to say what he thought:

Jon: *At meetings [professionals] either called me 'the child', 'the individual'*
Did anyone represent your views?
Jon: *Err, apart from my family no not really.*

I felt my views did not count

A related theme among these young people's accounts was feeling that their views did not count in child protection decision-making. This contributed to their shared sense that their participation had not been meaningful, regardless of whether or not they had managed to express their views at the meeting. Louise, for example, despite eventually getting her chance to speak and say, *"absolutely everything I need to say*", agreed with her sister that:

Sister: *They didn't really ever take Louise's point into consideration, though did they?*
Louise: *No because I was young, they were saying* ***young and dumb*** *basically … [my social worker] said I was extremely vulnerable, … needed like extra looking after, and things like that, so by that I thought she meant, she was basically taking the mick because I am dyslexic and got a few mental problems!*

Louise strongly objected to professionals' view of her as vulnerable because of her age and impairment and felt this also affected the weight given to her views. A particular point of frustration was how her social worker, whom she felt particularly discriminated against her, used her power and authority to influence decision-making:

I stood up in one of the big meetings and said to [Conference Chair] 'you know half of what [my social worker] is going on about is wrong', but apparently, she was perfect! In the end [the Conference Chair] said 'I don't think you need to be on child protection we will bring it down to child in need', but [my social worker] was like 'but there are still more meetings we need to do' and I was like 'no there is not, but [Conference Chair] kept it as child protection.

Other young people were similarly frustrated about their participation in meetings and the weight given their views in decision-making. Jon, talking about attending child protection meetings said he felt it had been: "*time well wasted … No! that was just* *wasted, no 'well'. Wasted just wasted!* Like Louise he also felt that professionals' took little notice of his views and weren't supportive of him:

Did anyone ask you what you thought, like the person that was Chairing the meeting?
Jon: *No, not that they were any good, not that they came and did anything.*

Ethan, though positive about having recently been allocated an independent advocate, seemed similarly disillusioned about attending future meetings himself based on his prior experiences of not being listened to: "*I think because I have got an Advocate I think I'm gonna just let her go to every meeting … she can get my point of view across, like if I am not invited or I am and I don't want to go."*

My social worker did not help me feel involved

It was also noticeable that none of the young people in this group appeared to have a positive relationship with their social worker. Some seemed to see their social worker as a distant figure while others actively disliked them. For all a lack of engagement with their social worker seemed to have contributed to their feeling that their participation in child protection enquiries and decision-making had not been meaningful. Ethan, for example, felt frustrated that his social worker did not speak to him after his child protection conference to explain what had happened, he said: *"I would have liked to have known what everyone else was like saying about me [but] I just went home with Mum*". He also saw his social worker as mainly talking to his mother rather than him directly, and this appeared to contribute to his lack of confidence in her ability to accurately represent his views in reports and meetings:

Ethan: *Well [the social worker] just sort of twists stuff, like she listens to, she asks Mum, and then she sort of forgets what she says and then puts the negative thing down not the one that she, what Mum actually had said.*
And what about what you have said?
Ethan: *I am not too sure what she puts about what I have said.*

Louise, as well as feeling that her social worker was not supportive of her at child protection meetings similarly felt that "*the social worker didn't listen to us or anything*". Like Ethan she welcomed having an independent advocate, but still thought that her social worker should have been able to represent her views "*because it's part of her job.*"

Other young people similarly seemed to feel their social worker did not do enough to promote their engagement and participation **within child protection processes**. Jon strongly disliked his social worker, and said he used to hide from her when she made unplanned home visits. His mother felt this showed a lack of understanding and concern for his social anxiety and how best to try and involve him in these meetings:

Jon: *The first [social worker] sucked … she was horrible! When she turned up, we had this like cupboard under the stairs that I hid in and she is like 'where's Jon?...*
Mum: *She turned up without [arranging it], would never tell Jon in advance what she wanted to talk about, or what she was doing, she would bring people with her unexpectedly*
Jon: *Like the anger management man*
Mum: *And didn't kind of introduce them properly.*

While Rebecca appeared unsure about who her social worker was and what her role was; as when I asked about her social worker Rebecca replied: "*is that the lady with the glasses?*", who her Mother said she was confusing with the continence nurse.

Group 4: Confident participation – "It all gets sorted"

Why "it all gets sorted"?

"***It all gets sorted***" characterises the confidence the four disabled young people in the fourth group (Allison, Hannah, Liam and Jon) felt about their participation in decision-making. All reported feeling supported to express their views, whether or not they attended meetings, and unlike most young people in the other groups appeared to feel they had some say in decision-making. Each also described a trusting relationship with their current social worker, who they saw as crucial in facilitating their participation. It was also striking however, that these experiences of participation each related to these young people's involvement in decision-making after child protection had ended, either as a child in need or a looked after young person.

What was it that helped these young people feel confident about their participation and that "it all gets sorted"?

There were several different aspects of their experiences which these young people reported had helped them feel confident taking part in decision-making. These are summarised in Figure 13.

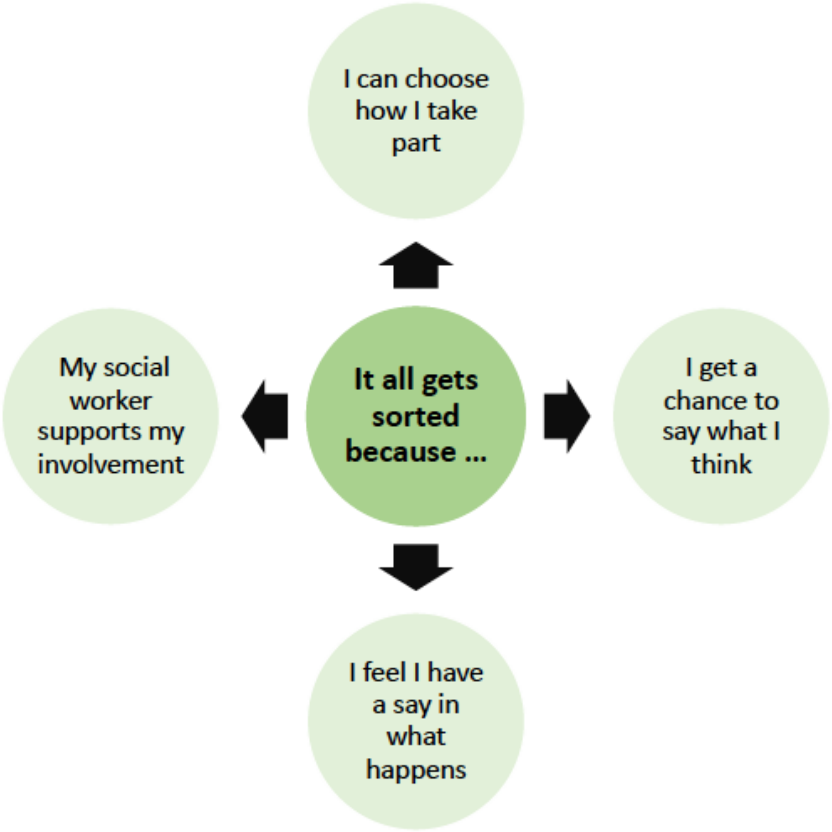

Figure 13: Confident participation – "It all gets sorted" – theme and sub-themes

I get to choose how I take part

One feature of these young people's experience that they said had helped them to feel more confident about being involved in decision-making was having a say in how they participated. For some young people this contrasted with their experiences of contributing to decision-making in the past. Jack, 16, said he had previously attended child protection meetings, but found this experience difficult:

I've tried it once, but it was long, and it really was (laughs), yeah wasn't really my type … [and] I guess saying my stuff in front of family and all that it's just too much

Like disabled young people in the "***young and dumb***" group, Jack seemed to feel child protection meetings were not organised to take account of his needs, and disliked attending because they were '*long*' and not '*his type*'. Like Chloe in the "only speaking softly" group, Jack also worried about the impact his participation in decision-making might have on family relationships, which he said contributed to his decision not to attend his child in need meetings either. What sets Jack's experience apart from Chloe's, however, is his confidence that his social worker will pass on his views, and that these will be taken into account, whether or not he attends meetings: "*It works good cos' [my social worker] passes it on for me. It all gets said, and [my social worker] gets me, gets all the details back".*

The other three young people in this group, who were all in care, by contrast spoke positively about attending their looked after children's reviews and saw being able to take part in these meetings as important. Hannah, for example, seemed to value the opportunity to attend her review meetings:

Do you think it is important that young people go to review meetings or not really, what do you think?
Hannah: Yes, I do because it is about you …

Outside of meetings young people in this group also appreciated their social worker giving them choices about how they spend time together during visits. Allison said: "*[my social worker] is so fun really, she always get me all about everywhere, she lets me pick … we go to the park … oh! you never not know - I have been to McDonalds! She took me to McDonalds"*

I get a chance to say what I think

Young people in this group also felt they had adequate opportunities to express their views, whether this was directly in meetings or with their social worker. Jack despite not attending meetings said: "*well usually I pass [my views] onto to [my social worker], and [he] passes them onto to everyone else, so they know already, so he can put it, and yeah … so, [my social worker]'s like my messenger"*

Liam and Hannah, despite having communication impairments both said they felt similarly comfortable talking to their social workers but unlike Jack also seemed confident to say what they thought at review meetings. Liam said he did not need any additional support to speak up at meetings and agreed with his carer's view that "*anything you need to say, you say it!*" Although Hannah's communication impairments meant it was sometimes difficult for me to understand what she was saying during the research interview, resulting in her using her iPad to help us communicate, she said she did not need her iPad when her social worker visits because she was good at understanding her:

Does [your social worker] bring her iPad when she comes?
Hannah: No
Or do you use yours?
Hannah: We just talk
You just talk? Is she good at understanding you?
Hannah: Yes
Better than me!
Hannah: Yes! {laughs}

Hannah's comments suggest that her social worker had taken the time to get to know her well enough to understand and communicate well with her despite her communication impairments. This relationship also seems to have helped Hannah's confidence participating in general, as she said that during meetings, she felt able to: *"ask people [questions]… and my social worker asks people too*"

Out of this group of young people Allison had the most significant learning and communication impairments. Her carer described how she and Allison's social worker had adapted their approach to help promote her understanding and allow her to express her views:

"Allison's whole learning is very, very visual, she needs very visual prompts. When she came, she wasn't talking so we used PECS [*Picture Exchange Communication System] a lot as routine stuff [and] she has done similar things with [her social worker], like when they done the three islands, drawing the people on the islands and everything"*

Like Hannah, Allison herself also appeared to appreciate her social worker's efforts to encourage her to share her views, as she said: *"[my social worker] is my best one, she always asks me if I am okay or not*"

I feel I have a say in what happens

A further difference between these young people and those in other groups was their confidence that they had some say in decision-making. Jack for example, despite not attending meetings nevertheless felt satisfied that professionals represented his views and took these into consideration:

[my social worker] would always ask me what do you reckon about it? and how did the meeting go and then [my support worker at school] would always [as well] … so that way I've got like my say in it … and yeah, it all gets sorted!

Other young people talked about feeling similarly involved in decision-making. Some described examples of creative practice by their social worker that appeared to help address the inevitable power imbalance between young people and professionals. Hannah talking about her looked after children's review said: "*I normally chair*" and when asked who made the decisions said:

Hannah: *[My social worker], and everyone together*
So, you all make decisions together?
Hannah: *Yes, I said!*

Liam also seemed to view his social worker as supportive of his participation in meetings and helping him feel he has a say in what gets decided:

Who makes the decisions at your review?
Liam: *Me and my social workers*
So, do you feel you have a say in what gets decided?
Liam: *Yeah*

My social worker listens and supports my involvement

For these young people their relationship with their social workers seems to have been the deciding factor in helping them feel confident about participating in decision-making. A crucial element of this relationship was how they viewed their social worker's ability to engage them and enable them to trust him or her. Jack, comparing his relationship with his current social worker to ones he had encountered in the past said:

“The past [social workers] were just not cool … [they] like write everything you say down and then change everything you said and bring that up and it was messed up. Where [my current social worker] don’t do that, anything I pass on to him he’d bring up, and like I pass on he won’t write up unless he needs to. He’d talk to you normally, like a normal person-to-person, sort of talk, so he won’t act like a social worker, he’d be more like mate-to-mate”

The other young people in the group similarly described their social workers as easy to talk to and said that they enjoyed spending time with them. They also seemed confident that they would support them if they had a problem. Hannah said her social worker helped her and she liked her because “*she talks to me*”, while Allison mentioned her social worker as someone she could talk to about her worries. Liam likewise viewed his social worker as someone who was interested in his views, describing her as someone who helps “*look-after me*”.

Conclusion

When taken overall, the experience of disabled young people presented here appears to suggest that their participation during child protection enquiries and decision-making was limited. Although they appear to face many of the same barriers to their involvement in decision-making as non-disabled children, disabled children also face additional barriers because of their impairments. These additional barriers not only relate to their impairments themselves but also their heightened dependency on their parents, their lack of confidence expressing their views and the attitudes of practitioners’ and others towards them regarding their vulnerability and capability to be involved in decisions regarding their lives.

Young people’s relationship with their social worker was central to mediating their experience of expressing their views and taking part in decision-making. This finding is also consistent with the findings of previous research with non-disabled children (Bell, 2002; Luckcock and Lefevre, 2008; Gallagher *et al*, 2012). However, young people also particularly valued practitioners who had a positive, can-do attitude towards communicating with them, who were disability aware but who also saw them as young people first and disabled second. All of which has important implications for practice, given disabled young people's additional support needs arising from their impairments.

A summary of the themes identified in disabled young people's accounts in this chapter is set out in Box 3:

- Disabled young people's experience of participation varied, but often related to their age, impairment and understanding of child protection processes.
- Most disabled young people were unsure or unhappy about how their views had been represented. Many felt anxious as a result of a lack of information and explanation about what might happen to them or their families as a result of the decisions made during child protection.
- Disabled young people identified a range of barriers to their participation. Some related to their impairment and practitioners' and parents' attitudes towards them. Others seemed related to child protection processes more generally.
- A few disabled young people had attended child protection meetings but found this stressful and did not view it as a positive experience.
- Disabled young people's relationship with their social worker strongly mediated their overall experience of contributing to child protection enquires and decision-making . Those with a positive attitude towards their impairments, whose social worker saw them as a child first and disabled second more often felt listened to and involved in decision-making.
- Some disabled young people described creative practice that had helped them participate and took account of their impairments, however the examples they gave were not within child protection processes.
- Disabled young people generally reported fewer opportunities to participate in child protection than during other decision-making processes.

Box 3 – Key findings - Disabled young people's participation in child protection enquiries and decision-making

Chapter 7 – Disabled young people's views and experiences of child protection enquiries and subsequent help

Introduction

This chapter explores disabled young people's overall view of the help and support they and their families had received during child protection enquiries and their aftermath. In interviews participants were asked about the impact the decisions made during child protection had had on their lives, what they thought had been helpful or unhelpful about social workers and other professionals becoming involved.

Firstly, there were some important similarities in participants' overall views of child protection intervention. Almost all described this experience as a stressful and unsettling time for their families, underlining the need for practitioners' to try and help young people understand what is happening during child protection enquiries and reassure them that what is happening is not their fault. Participants' experiences of whether or not they felt their views were listened to during child protection decision-making processes, such as at child protection conferences and other meetings, as outlined in the last chapter, also tended to mediate their overall view of the help subsequently provided.

Some participants, such as Jon, despite a negative experience of initial child protection enquiries and decision-making processes, nevertheless had positive overall view of the support they and their families had received, having been subsequently allocated a different social worker. Other participants, such as Hannah and Liam, despite feeling empowered to take part in decision-making processes, were less positive overall about the support and help they were currently receiving due to the difficult and uncertain nature of their current circumstances. The membership of the groups presented here therefore does not necessarily reflect those in the previous chapter, reflecting the need to take a holistic rather than a one-dimensional view of disabled young people's lives and support needs.

How participants made sense of their experiences of child protection intervention when analysed across the sample seemed to fall into one of three groups. These observations are used to present a three-fold typology of disabled young people's overall views of child protection enquiries, decision-making processes and subsequent help in the remainder of this chapter. The purpose being to try and understand the factors that appeared to influence disabled young people's different views and how practitioners' might better support them in practice at each stage of the child protection process.

A typology of disabled young people's views and experiences of child protection enquiries and subsequent help: "frustrated", "ambivalent" and "reassured"

The three-fold typology proposed in this chapter consists of three groups. The thoughts and emotions of three disabled young people in the first group suggested that they felt "frustrated" that they and their family had become caught up in child protection processes. The five participants in the second group appeared "ambivalent" about the impact that the decisions made as a result of child protection enquiries had had on them and their families. Finally, the six participants in the third group ultimately appeared to feel "reassured", by the help provided as a consequence of initial child protection enquiries, although this had been stressful at the time. In addition, two participants said little about their experiences of child protection intervention, so it was not possible to categorise their views.

As with any typology participants' views do not always exactly "fit" the character of a particular group. For example, participants in the "frustrated" and "reassured" group both identified experiencing aspects of child protection processes. Rather the claim being made is that the overall views each participant expressed can helpfully be categorized as falling into one group rather than another. Each type is also not understood to be static, for example while some participants appeared to firmly represent one type, others' views overlapped more strongly with other types and may have been in the process of evolving from one group or type to another.

"Frustrated", "ambivalent" and "reassured" represent the unifying theme or category felt to best represent the views expressed by participants in each group about their experiences of child protection processes. In qualitative analysis such categories are often not named according to terms used directly by participants themselves (Harding, 2006). Rather they are identified and named by the researcher once they have become sensitised to patterns in the data during the analysis. Their purpose being to give a sense of coherence to different parts of participants' accounts and/or help explain commonalities between participants or groups of participants (Braun and Clarke, 2013). A brief explanation of how each conceptual theme was chosen is given at the start of the section for each group.

Group 1 – "Frustrated"

Why "frustrated"?

"Frustrated" is used to denote this group of three disabled young people's views because it best captures their description of their experiences of initial child protection enquiries and the help subsequently provided. One young person (Ashia) in this group did repeatedly described her experience of getting help as "frustrating" and others described their social worker's actions as "annoying", although most extracts did not reference specific emotions. At some points during interviews these participants, especially Ashia, seemed more "frustrated" by the general stress of being involved in child protection, and the impact this had on their family relationships, rather than with specific events or professionals working within child protection processes.

What was it about child protection interventions that these young people felt frustrated about?

There were several elements of initial child protection enquiries, decision-making processes and the way that support was subsequently provided about which this group of disabled young people described feeling frustrated. These are summarised in Figure 14.

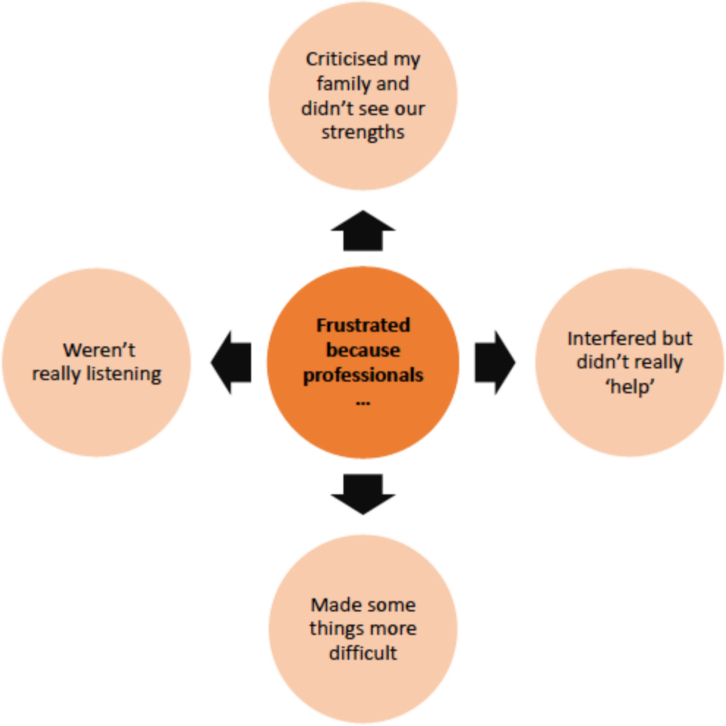

Figure 14: "Frustrated" themes and sub-themes

Criticised my family and did not see our strengths

Disabled young people in this group more strongly disagreed with professionals' concerns for their welfare than did participants in other groups. Most said that they felt that the decision to start initial child protection enquiries had been unnecessary. All were living at home rather than in care and particularly disliked it when professionals' criticised their families, which they described as a major point of conflict with their social worker. Ethan said he understood child protection enquiries as having *"started because I think [social worker] thinks that Mum is mostly neglecting me, but I don't think she is!",* adding that he did not need a social worker because he did not see himself as needing protecting. Louise recalled arguing with her social worker after the initial child protection conference when she told her she had a child protection plan, *"I was like, "well I am not neglected, I am perfectly fine! … there's not a reason I should be on child protection!"*

A common reason these young people gave for disagreeing with the need for child protection enquiries, was their perception that professionals' focused on their family's difficulties within these processes and ignored their strengths. Louise felt irritated by social worker’s inability to see past the fact of her father’s murder and value the good things about her family:

Social workers always say, ‘we never judge a family, never judge a book by a cover but they do! Like, when it came to our Dad passing away, they were horrible … and then they pick on families like us when we have got a safe home, we don’t get beaten by our Mum, where basically we have got the strongest bond going.

A related characteristic of this group was the way they sought to defend their own view of their family by emphasising the ways that their parents, particularly their mothers as their main carer, had advocated and supported them. Ethan, who has cystic fibrosis, challenged the professional concern that had triggered child protection enquiries, namely that his Mother had delayed seeking medical treatment for a chest infection, by contrasting this with his own perception of her as always intuitively taking the initiative to ensure his health needs were met:

Like I was first diagnosed with it because when I came down with my first chest infection she knew something weren’t right, so then I got tested for CF and I had it, and like if any of Mum’s children is sick she always pushes because she knows that there is something wrong, she pushes to get the child seen for a GP appointment or something.

Ashia, who needs support with her personal care due to her cerebral palsy, similarly rejected professional concern that her parents were neglecting her personal hygiene, asserting that “*It is ridiculous to say that, Mum does everything for me!* She backed this view up by giving concrete examples, *“such as when I want to go to the toilet, and with my trousers and all that, it is so frustrating!*”

Previous research has suggested that disabled young people may find it especially risky or threatening to recognise or accept concerns about abuse than other young people as a result of their increased physical or emotional dependency on their carers because of their impairment needs (NSPCC, 2003). This applies in different ways to both Ethan and Ashia, and may help to explain the strength of the views they expressed about their families’ experiences of child protection processes. Both nevertheless also mentioned other issues in their families that they felt professionals’ should have paid more attention to involving other members of their families during initial child protection enquiries. Ethan, for example, implied professionals' should have been more concerned about his Father's care of him, who he stayed with at weekends, because "*Dad knows I have got [cystic fibrosis] but I don't think he wants to believe that I've got it and he hasn't really been looking after my health*"

Interfered but did not really help

Despite disagreeing with the need for child protection enquiries and their frustration about their families' feeling criticised as a result, these young people at least partially accepted there were issues with which they needed support. However, their overall perception was that social workers and other professionals who became involved with their families as a result of child protection enquiries mainly interfered and did not really help. One of the ways they described this as happening was that when support that was meant to be helpful became coercive and controlling. This in turn affected these young people's willingness to engage with the support being offered. Louise disliked the fact that because the counselling she was offered to help her after her father's death was part of her child protection plan this was seen as involuntary. She felt angry about her counsellor threatening her to get her to engage, but which had the opposite effect

My counsellor decided to say to me after my Dad's funeral 'if you don't talk then I am going to get you taken away from your Mum and put you in care' and I just see red, I flipped out and threw the table over and walked out.

These young people also felt the main focus of the support provided to their families via child protection plans involved their being monitored or watched rather than being helped. They described this as contributing to an atmosphere of distrust between their families and professionals in a way that often seemed counter-productive and affected their willingness to engage with professionals. Ashia seemed to welcome having a carer coming in the morning to help her mother shower her but explained that her father had insisted this service be withdrawn because he felt the carer only watched what her mother did and wrote reports about the family for the social worker. Louise similarly described how unannounced social work visits while she was the subject of a child protection plan made her feel like her family were under surveillance:

One time [the social worker] *turned up at half-seven at night when we was all getting ready for bed! I refused to let her in, I was like, go away! but then she was like I have to come in, I have to check everybody!*

The two young people in this group with additional health needs similarly disliked feeling personally monitored whilst on a child protection plan. They described how this had resulted in them feeling that they or their families were being ‘got at’ by professionals, leading to adversarial rather than supportive relationships developing between them, their families and professionals. Ethan strongly objected to what he saw as his social worker’s interference in whether or not he was allowed to work with animals because of the risk to his health: “*like I tell [my social worker] one thing about animals and then she tells the medical staff and then I have been banned from mucking out horses now!*” Ashia described how close monitoring of her health needs had resulted in her feeling caught up in the conflict between her parents and professionals:

When somebody said that I smell it is a very frustrating thing to do. We tried everything, even I have to try deodorant now for my armpits where my Dad doesn’t want me to do this deodorant so, but I have to. I know what the school is like otherwise they start complaining! It is so frustrating I don’t know what else to do.

Ashia seems to feel at a loss to know how to handle this situation. The only person she identified as feeling able to talk to about how she felt was the support worker provided to support her personal care at home, who was now no longer involved because of her family’s conflict with professionals.

Child protection involvement made some things more difficult

These young people’s over-riding impression was that child protection enquiries, decision-making processes and the help subsequently provided had created additional tension and made their lives more stressful. Rather than being the subject of a child protection plan helping to make things better, these young people emphasised how for them social workers getting involved had made some things more difficult. One area they particularly mentioned was how child protection intervention had affected their family relationships. Louise described how their social worker restricting who they could see had led to her family feeling cut off from valued sources of support: “*[the social worker] stopped us from seeing our blood older sister, and other people who have been a massive help to our family and she said every single one of them are threats to us … basically we were isolated in our rooms for about six to seven months …it was horrible!”*

Others saw child protection enquiries and decision-making processes as resulting in increased arguments between family members. Ethan described conflict between his parents as the main reason he had not been allowed to attend his child protection conference. During the research interview Ashia’s parents made it clear that they saw her as partly to blame for her poor hygiene, but that they were unfairly the focus of professional concern, because she sometimes has urinary accidents. Later talking about how feeling blamed for this issue made her feel and affected her sense of self Ashia said:

Sometimes I get so angry, I got to explode … I would like not to get into trouble so much and for [school] not to complain! It is quite upsetting, I don’t mean to be rude, I am just saying some people can’t go to the toilet. Some people can’t talk but I can. Some people can’t walk, I know I can’t but I can do other things!

Other young people similarly described how stress caused by child protection enquiries and their aftermath had affected their physical and emotional well-being. Louise, who has anxiety and depression said:

Since the whole Social Services thing kicked off, I had been back and forth from the Doctors because I physically couldn’t sleep, and I have had major problems with my asthma, which again my Asthma nurse said was down to stress

These young people also felt that the help provided to their families had made things more difficult in other areas of their lives. They disliked their social workers visiting them at school because of the stigma involved. Louise said: “*not being funny but I don’t want to walk around my college with a Social Worker for all my friends to see me there*’. They also described feeling too embarrassed talk to their friends at school about the problems they were having at home, which seemed to make them feel quite isolated. Ashia said “*Most of the time I get into trouble I talk to my friends, but I don’t really talk to my friends about the shower thing because it is a personal thing for me”.*

My social worker weren't really listening

Disabled young people in this group felt their social worker's perceived criticism and close monitoring of their families once they had a child protection plan had made it very hard to trust them. However, a lack of regular and consistent opportunities to meet with their social worker also seemed to contribute to their disinterest in this relationship. Ethan felt his social worker rarely spoke or spent time with him "*most of the time it is just with Mum*". However, when asked if he would like to see her more or less often said "*less, she can talk to Mum*". Ashia said she had 4 or 5 different social workers over the past 3 years, and described a passive easy come, easy go attitude towards social workers "*I don't mind whatever for me, I've got used to it and the change of authority!".*

These young people's main dissatisfaction, however, was feeling that their concerns and priorities, which often differed from their social workers', were not listened to. Louise felt frustrated by renewed child protection enquiries due to concerns about her Mother's new partner, as the family's priority was moving areas which this partner had helped with:

> *The social worker weren't really listening to us me and Mum … she said I was very, very vulnerable, I shouldn't have been near [my Mum's partner], but he is the reason we have got a better life than we did, he got rid of all the bad people because like there were people who used to like start fights and that in this horrible place [where we used to live] and he got rid of all of that and got us a fresh start.*

Louise's social worker's concerns about her mother's partner may or may not have been valid. Regardless of the truth of the matter what was more important to Louise and other young people in this group was feeling that their voice and perspective on how they were trying to cope with their difficulties had been heard rather than their social worker simply imposing their view on the situation, which usually only focused on the potential risks involved. Other young people similarly felt that their social worker's response was mainly focused on their health-related needs, rather than the ways they were trying to cope with the psychological or social consequences of being a disabled teenager. Ethan, for example objected to his social worker's insistence that he wear masks when working with animals. Though he understood the risks to his health, not standing out from his peers was more important to Ethan, who had been bullied about his condition in the past:

Social workers seem to listen to one thing, it's like she pushed Mum to get masks for when I am cleaning out the animals, because then it will look like I am different to everyone else and when I go to [college] if it can't be seen I want to try and keep it like that from strangers … it is a bit of a gamble with animals but I have been fine around them for ages.

For these young people not feeling listened to by their social worker contributed to their disillusionment with child protection processes. Ethan concluded that: *"I just dislike social workers in my life because they are just really annoying"*. Ashia felt similarly let down by what she saw as her social worker and other professionals' over-focus on her health needs during child protection enquiries while failing to adequately address wider concern she had raised that her Father had hit her: *"[My Dad] does the same things even they spoke to him,* PICKS UP CARDS *[teacher] speaks to [social worker], [social worker] speaks to [police], [police] speaks to Dad, no work, no it doesn't work at all!"*

Despite these young people's shared frustration with their social worker and disenchantment with child protection enquiries and decision-making processes, they also agreed that some of the support their families had received had been helpful. Ethan and Louise were both very positive about having an independent advocate and saw this as potentially enabling them to have a voice during child protection enquiries and decision-making processes. Ethan said: *"I think [having an advocate] is going to be helpful, she can step in and be my voice."* Louise was also positive about her social worker having arranged for her to have ongoing counselling for her brother Ben to attend residential short breaks (also a study participant). However, she also felt strongly that both of these supports could have been provided without the need for child protection enquiries and Ben and herself each having a child protection plan.

Group 2 - "Ambivalent"

Why "ambivalent"?

The second group of five disabled young people had mixed views about child protection intervention and the changes this had meant for their lives. Although not a word used by any of the five young people themselves, "ambivalent' was felt to best convey the mixed feelings and sometimes contradictory opinions these young people expressed about the help they and their families had received from professionals as a result of child protection enquiries and their aftermath. For example, all had spent time in care and saw this as having been necessary for their protection, however had mixed feelings about it because they missed their family and friends. Most got on well with their social worker but felt they did not listen properly to their views.

What was it about the impact of child protection intervention that these young people indicated feeling ambivalent about?

There were a number of inter-related aspects of these young people's experiences of child protection enquiries and receiving help from professionals about which they described feeling ambivalent. These are represented in Figure 15.

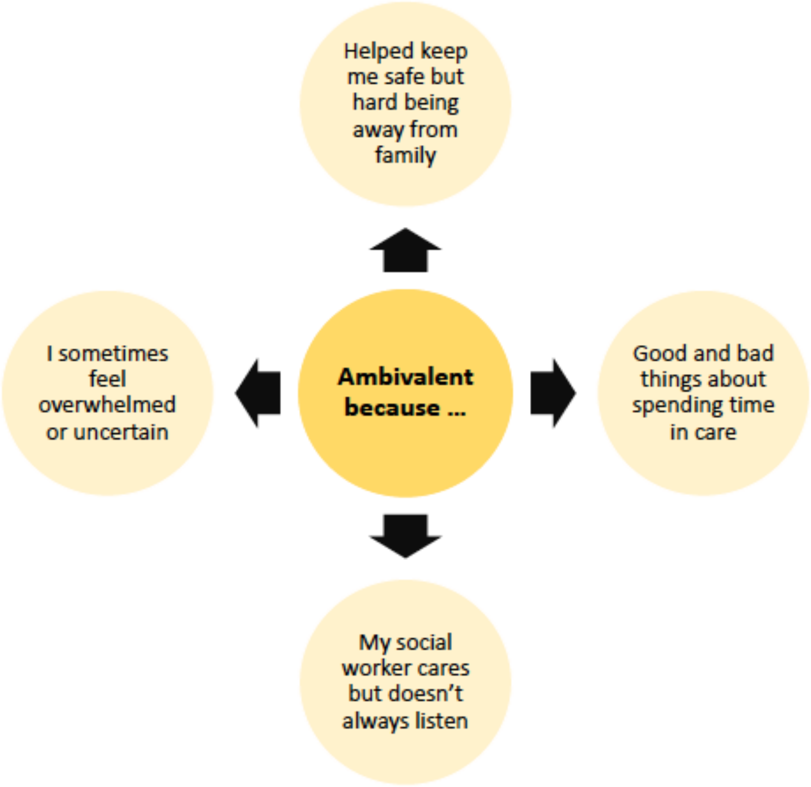

Figure 15: "Ambivalent" themes and sub-themes

Child protection helped keep me safe, but hard being away from family

In contrast to participants in the 'frustrated' group, the five disabled young people in the second group were mainly positive about receiving help from social workers. Despite the fact that for all of them the decisions made as a result of initial child protection enquiries had resulted in them spending time in care, all described feeling relieved that professionals' had noticed that their families were having problems and had intervened to try and help keep them safe. Liam, for example, talked about how the police had helped him:

They've helped me (points to police card), the Police brought me here … they took me into my Nan's in … I sat in the back of a police car, the police helped me, and I was happy that they were there, help-ed get me away from the situation at home.

Mathilde was likewise pleased her social worker had listened to her wish to stay in foster care after an incident where she said her Mother had hit her: "[Social workers] *helped me when I went to the foster care when I was fifteen years old and I didn't want to go back to Mum's, so I had to stay in foster-care".*

Nevertheless, young people in this group commonly expressed apparently contradictory views about whether or not child protection intervention had been helpful, and all had very mixed feelings about the impact that the decisions made as a result of child protection enquiries had had on their family relationships. Nataly, on the one hand agrees social workers had needed to be involved with her family: *"If I don't have a social worker I'd be lonely, I'd be afraid, and I'd be upset, I was alone in my house, no one looked after me, I was eating sweets, chocolates like that, but now I feel happy*". But later she downplays the situation: "*me and Mum was just having fun together",* and says social workers being involved was "*not a good thing"*.

Nataly's mixed feelings towards her mother help to explain her conflicting views about child protection intervention, particularly given previous research highlighting children's continuing emotional ties to their parents despite the presence of maltreatment (Schofield, 2005). Other young people in this group, seemed more able to separate out their views about child protection intervention from their feelings about their families, however they still emphasised how hard it was living away from their families and wished that things could be different. Nicola for example, in contrast to young people in the "frustrated' group rather than defending her parents, saw them as responsible for professionals' needing to get involved in their lives:

I just knows that my Mum did wrong, now I don't want to go back there, being in foster care is a good thing for me and my sisters". However, she then goes onto say *"but* *it's really hard when you live with someone, and you're not staying with them anymore and they give birth to you … I wish I could live with my Mum again.*

Good and bad things about spending time in care

Spending time in care was the main, though not only, form of support and help this group of young people described having received as a result of child protection enquiries and subsequent decision-making processes. Four were still living in care when I interviewed them, and one (Mathilde), had returned to her family. Despite their difficult feelings about being separated from their families, all described good things and bad things about their experiences of spending time in care.

All described good relationships with their carers and other people they lived with, although those in residential care generally described more transient relationships than those in foster care, and this was a source of uncertainty for some. Liam, said he liked all the staff in the unit and got on well with the two other young people he lived with, but seemed unsettled by the recent high turnover of staff and mentioned several times that he did not have a key worker because his old one had left. Hannah talked enthusiastically about going on various trips and attending a music festival at the residential unit where she had been staying during the summer holidays and when asked if she liked living there said: *"I do, I really do!",* but was understandably anxious about moving on to a residential school in a few weeks.

By contrast, young people who had spent time in foster-care generally described more established relationships with their carers and talked about how spending time in care had benefitted them. Nataly said "*I feel happy here now in this home, and I am not alone anymore … I like playing with all my sisters"* and seemed to enjoy being part of a large busy household. Nicola talked about how her foster-carer encouraged her to try new things, like getting her dyed and going on roller-coaster rides. She also saw her carer as someone she could confide in about her problems, including her relationship with her boyfriend but also her difficult feelings about seeing her birth family. Mathilde, despite having returned to live with her family was similarly positive about her time in care. She said: "*I like being in foster care and they have to look after me … it was a good time".* She seemed to appreciate being placed with a carer from a similar cultural background to hers (her family are Black African), describing her as "*an Ethiopian person*" and particularly appreciated her foster-carer helping her save up to buy a new mobile phone.

The disruption caused to these young people's birth families represented the main downside of spending time in care as a consequence of child protection enquiries and decision-making. Young people described feeling upset about being placed separately from their siblings or having infrequent contact with their birth families. Nicola, although she got on well with her foster carer, really missed living with her sisters:

I want that to happen though, I want to live with them, with my sisters because like a sister, you can do anything with them, and I want someone like be around me all the time, like someone who cares about me and makes friends.

Nataly similarly alluded to the enduring emotional significance of birth family relationships when describing her deep sense of loss about her birth mother, whom she had not seen for two years:

All this time I haven't seen my Mum. {pause, long sigh} Oh! You should never have to live without your Mum {pause} you have to keep saying it over and over but like your Mum, Mum, Mum, Mum.

Feeling upset and unsure about their ongoing relationships with birth families was understandably also source of ambivalence and confusion for these young people. Nataly, despite her strong feelings about seeing her Mother, at another point during the interview said: "*maybe I don't want to see them anymore*".

Living in placements a long way from where their birth families lived caused disruption to their other relationships and was a source of frustration for some young people. Liam, Nicola and Hannah had all had to change schools as a result of moving to a placement in a different area. Nicola in particular missed her friends from her old school and felt quite ambivalent about moving to a rural placement in a neighbouring county, away from her family and friends:

I do miss my old school, so like I wish my Mum would change and I'd have my old friends back … I used to have loads of friends; I was the one that was popular in that school then.

Mathilde, the only young person in this group not still living in care felt ambivalent about her current circumstances for quite different reasons. She starkly contrasted her positive experiences of living in care with the pressures she felt from living in a household with two younger disabled siblings, who, like her, have autism. She became distressed talking about her situation at home, describing frequent arguments with her Mother, and poor relationships with her siblings who she said bullied her, and implied she felt ambivalent about having returned home: *"At home my children keep calling me a name and I don't like it, I don't want to see my children anymore"*

Social worker cares about me, but doesn't always listen

In contrast to young people in the "frustrated" group, young people in this group were more positive about their social worker and saw them as an important source of support. Most said they felt their social worker cared about them, that they enjoyed spending time with them and found them easy to talk to. Nicola said she liked her current social worker: "*because like her worries about me, and we do and we talk about stuff, and I can tell her like anything I want, and if me not happy I can tell her why and lots of stuff we're allowed to tell her"* Liam, similarly described his social worker as someone who helped look after him, and said he liked her coming to see him and just having a chance to have a chat.

Some young people said they saw their social worker as someone they could turn to if they had a problem. Nataly said: *"If you feel nervous or something is worrying you [can] just tell your Social Worker what's happened"*. Others identified specific things that their social worker had done to help them. Mathilde said: "*my social worker did sort me out, it was about Facebook … she said something about strangers, [not] adding those to my Facebook account".* Nicola and Nataly said they had enjoyed making a life story book with their social worker and appreciated having an opportunity to talk about the past and how they felt about the things that had happened in their birth families.

However, some young people said their social worker did not visit them often enough or weren't always available when they needed to talk to them. Nicola commented that it seemed like a long time between visits, and thought she visited her "*only like every eight or nine weeks*", Nataly said her social worker only visited sometimes and wanted to see her more. Liam had been trying to get hold of his social worker the day I saw him, and seemed frustrated that, "*I've rang [my social worker] twice today before five; cos they go home at five o'clock"*

Others described mixed feelings towards their social worker because they felt they disregarded their views. Mathilde for example, despite feeling that her social worker had helped her with Facebook, was upset because she felt her social worker had not believed her and had told her off:

My social worker did help me out, though she wouldn't listen to me … because it was only a Facebook chat, because it is about a relationship me and [a boy] … because I wasn't lying to her because I was telling the truth … Mum said no, but she has lied before, Mum she lied and [my social worker] told me off!

Mathilde's social worker may have been right to be concerned about her use of Facebook, and Mathilde herself admitted she needed help with this. However, Mathilde appears more upset about her social worker not believing her and siding with Mother on this issue, and elsewhere in her interview became quite distressed and described feel unsupported by professionals in relation to ongoing conflict between her and Mother since returning home from foster-care.

Nicola, similarly, felt frustrated that her social worker disregarded her views about attending sessions with the Child and Adolescent Mental Health Service, because she preferred to confide in her carer and felt the sessions weren't suited to her needs:

Sometimes, I don't know if [social workers] listen … what's it called, CAMHS, I go do that but I'm trying to sort it out cos I really don't want to go do that, cos I know who I can speak to cos I've got [social worker], and [carer] and teachers I can always talk to so, I don't need anyone else, and it's boring there's nothing to do over there … and I try to tell them and tell them but they don't listen to that.

I sometimes feel overwhelmed or uncertain

Most of the young people in this group appeared to feel that social workers becoming involved in their lives had helped keep them safe. However, they generally they seemed less confident about how well they were coping with their feelings about the difficulties in their families that had led to child protection intervention and involvement, and/or coming to terms with being separated from them as a result of living in care. Some described or appeared to feel overwhelmed by ambivalent feelings even where they had received support with their mental health from CAMHS. Mathilde talking about the support she had received from social workers and other professionals said:

It is better social workers helping me, it has helped me feel better [and] Dr R and Dr B help me, it is about my life and my feelings… but sometimes I have got hurt feelings and I don't know what to do.

Although Mathilde's distressing feelings seemed likely related to the ongoing difficulties in her family, other young people in this group living in care described feeling similarly overwhelmed by their difficult feelings towards their birth families. Nataly explained how missing seeing her Mother affected her:

I wish for my Mum to be here with me right now … sometimes I get so angry sometimes even my sisters can't help me to calm down, because of how I feel like this {points to sad feeling face} and I tend to do something really annoyed and do something really naughty to myself.

She also described being aware of how feeling overwhelmed sometimes affected her behaviour. Nataly's ambivalence about her mother in turn appeared to be having a knock-on effect on the stability of her foster placement, as her foster carers mentioned that a recent outburst from Nataly had led them to question whether they could continue to care for her:

[Nataly's] a lovely girl, but I mean we are more concerned about the resurfacing of all the problems she's had … because I am not sure if we would be able to cope with them as some of them are so extreme … but you know we'll see how we go"

Nataly's Foster-Father

By contrast Liam and Hannah, who like Nataly currently had no contact with some members of their birth families barely spoke about their families at all. However, this by no means can be interpreted as indicating that their families were no longer important to them. This may simply represent a different way of coping with the intensely conflicting feelings young people commonly experience towards their parents in the context of separation and/or maltreatment (Howe, 2005). This may help to explain why Hannah, who had recently entered care because her relationship with her father and step-mother had broken down, specifically requesting not to be asked about her family at the start of her interview. Later when talking about moving to a residential school some distance away said she hoped her family would visit her there.

Group 3 – "Reassured"

Why "reassured"?

The third group of disabled young people included those who were the most positive about social workers becoming involved in their lives as a result of child protection intervention. It did not appear that these young people had faced fewer difficulties or that their circumstances differed from other study participants, however. Indeed, two of these six young people were or had recently been the subject of a child protection conference or plan (Chloe and Mark), and two were living in care (Stevie and Allison, Nicola's younger sisters). Rather, the unifying theme among this group of participants was their shared sense of feeling "reassured" by the way their social worker and other professionals had listened to their views during child protection enquiries and decision-making processes and responded in ways that took into account their impairments and existing ways of coping when providing subsequent support and help.

What was it about their experiences of child protection involvement that helped disabled young people feel reassured?

There were distinct features of these young people's experiences of receiving help as a result of child protection enquiries and subsequent decision-making that appeared to help them feel "reassured". These features or sub-themes are summarised in Figure 16.

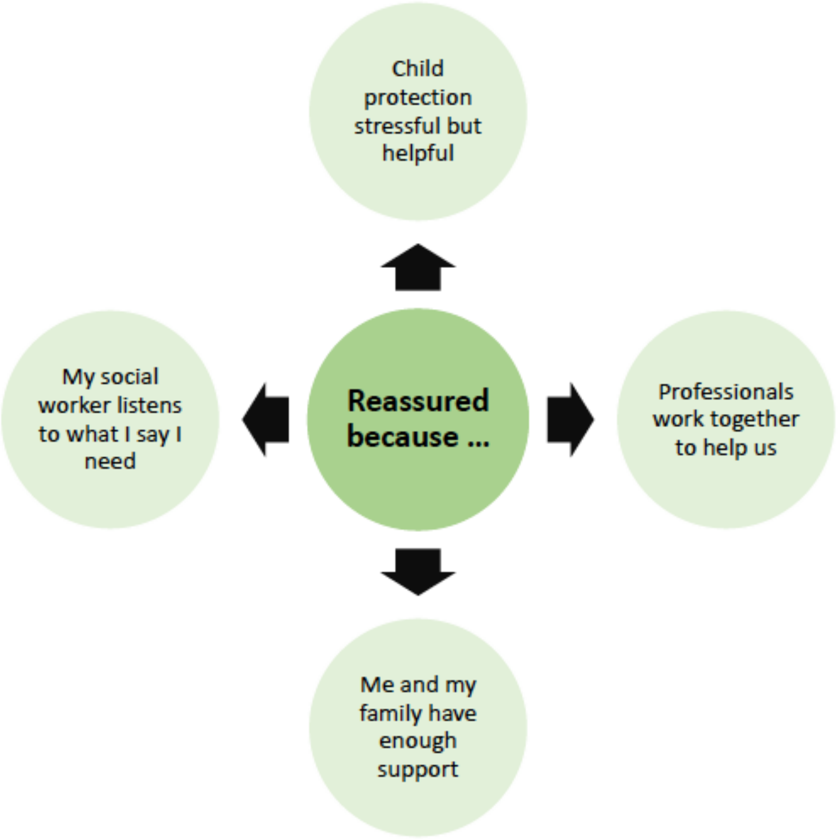

Figure 16: "Reassured" theme and sub-themes

Child protection was stressful but ok in the end

Although generally positive about social work involvement, these young people described initial child protection enquiries and subsequent decision-making processes as an anxious and unsettling time for their families. Several described feeling frightened about what might happen to them or their families and feeling that they had little or no say in decision-making. Chloe said*: "I thought they would put me in care and I really just wanted to stay with Mum"*

Some commented on the intrusive and sometimes coercive nature of child protection enquiries and intervention in a similar way to disabled young people in the "frustrated" group. Jon, who was the subject of a child protection conference due to concerns that emotional abuse was contributing to his school refusal, described how: *"[My social worker] basically was just breathing down everyone's neck to get me to go to* *school all day every day!"* and Stevie described how her social worker: "*made me cry because she was forcing us to go into foster-care and we couldn't stop her.*"

However, despite finding initial child protection enquiries and subsequent decision-making processes stressful many disabled young people in this group also described how the support and reassurance they had received from their social worker and others had helped them cope with the impact of these experiences on their lives and relationships with their families. Chloe seemed relieved that her social worker had listened and acted on the concerns she had raised about her Mother's care of her, but understandably felt upset about how this would affect her relationship with her Mother: *"Now that I have got it out in the open, I feel better for that. It can be quite difficult to get it out in the open. … me and my Mum are really close."* She also described how her social worker talking to her after her child protection conference had made her feel a bit less worried, despite still finding this a very emotionally draining experience: [My social worker] *talked to me after [the meeting] and said: 'don't worry everything will be alright,' and I felt I was just dead tired then."*

Stevie, although she also expressed mixed feelings about child protection enquiries having resulted in her living away from her family, in care, seemed similarly reassured by knowing her social worker had talked to her Mother about the reasons she was in care, and seems to see this an important part of helping her adjust to this experience: "*but now we are in foster-care, and just everything is fine now, my social worker talked to my Mum all about it*". Her sister Allison, who lived in the same placement described how the care and support she had received from her foster-carer had helped her cope with her difficult feelings she had about living away from her family:

Because my home is a dump so yes. That is why I am not living with my Mum, but it's alright really because I love this home, I do … I always cry in the night sometimes, but I am good I am alright with these [carers].

Social worker made sure I was OK

Disabled young people in this group saw their social worker's role as helping to keep them safe. A key feature of their accounts was their feeling that their social worker had responded appropriately to risky situations they faced, as well as helping them, often in very practical ways, to cope with their ongoing difficulties. Jack talked about how his social worker had helped him and his Mother manage ongoing risk and conflict from other family members:

My social worker is always there, like, um, family problems what happened, is that half of them showed up at the door, what wasn't expected. We went on the line to [social worker]*, he completely had a word with us, chatted with us, calmed us all down, and the situation that we was in …*

What seemed to help give Jack confidence in his social worker was not only how he helped to reassure and calm down the immediate situation, but also how he worked together with other professionals to make sure he was supported in the days that followed: *and* [my social worker*] talked to the school straight away so they knew, if they felt I was depressed or anything so, yeah helped as much as he could, it was pretty sorted. It was quick!"*

Other young people gave specific examples of how their social worker had supported their families to address the concerns that had led to initial child protection enquiries. Chloe said:

My social worker tried protecting me, like getting the carers in like morning and night and we recently made a chart, my bubble like, and if I need Mum at night, she will help me get there, so that is a big step forward, yes!

Chloe, who uses a wheelchair, felt her social worker arranging additional support to help her Mother meet her personal care needs had helped improve things at home, but also appreciated how she worked alongside her and her Mother and felt that this had helped improve their relationship.

Several young people in this group also mentioned valuing support from their social worker with their impairment related needs, not just those that had been the focus of the initial child protection enquiry. Chloe had been worried that her Mother would not be able to afford to fund her short breaks activities during the summer holidays. She knew her parents' were having financial problems and was very relieved that her social worker had agreed to fund these, so she did not miss out: *"I really was a bit concerned, but [social worker] said she would pay for all my activities so Mum didn't have to, and I will be able to thank her next time."*

Jon felt his current social worker was understanding and responsive to how his autism affected him. He appreciated when she had sent through photos of the building and room where his child in need review meeting would be taking place to help allay his social anxiety and talking to him on home visits while he was using the computer, because he said: "*I am lot better verbally than writing it down".* For Jon, more support around his impairments had coincided with a reduced focus on risk following the decision made at his initial child protection conference that he should have a child in need rather than a child protection plan. This also seemed to affect his view of his current social worker compared to his social worker who had overseen the initial child protection enquiry:

Well I don't hide when [current social worker] turns up, that is kind of a difference. She doesn't try to arrest everyone [and] she has helped me so much more than [previous social worker] did at all.

However, other young people in this group such as Chloe and Mark were similarly positive about their relationship with their social worker despite being currently or recently the subject of a child protection plan. Mark, for example, simply described his social worker as "*friend"*

Social worker listened to what we said we needed

A prominent theme in these disabled young people's accounts, was feeling that their social worker listened and responded to issues they themselves considered important. Feeling that their social worker had listened to what they said they needed helped them build a sense of confidence in themselves as well as in the help they received. Stevie said how she had been unhappy in her previous foster placement but felt happy that her social worker had listened when she said she wanted to move:

If we are not happy, we can tell [our social worker] then if you wanted to do a move, they will let you move … so that's why I am here now, I asked [current social worker] that, can I move to [sister's foster-carers]? And guess what I'm here now! She listened first time to me!

Jon felt similarly pleased with his social worker's response to the problems he was having with bullying at school involving another child with autism:

There is teachers, their job has to defend and make excuses for the other child but [my social worker] doesn't do that, she just sits and listens to my bit then doesn't say 'oh well, I am sure they didn't mean it' when they definitely do … I didn't think there was much there she could do, and I didn't make her, I just said it was a thing and she said she would look into it.

What was crucial to Jon was his social worker's willingness to listen and see things from his perspective, without minimising or judging how his difficulties were affecting him. For him knowing that she was using willing to use her authority to try and help seemed almost as reassuring as achieving the outcome he wanted:

It is kind of nice to know that there is someone who is actually, that it is not just me who is trying and sort out everything, that [my social worker] is kind of higher up doing it as well, so it is kind of not doing it by yourself sort of thing.

Several young people in this group also mentioned feeling grateful to their social worker for encouraging their families to use their own strengths and resources. Jack, whose grandparents had stepped in to provide a kinship placement during initial child protection enquiries, felt this arrangement had helped keep him safe and appeared to value the role they continued to play in his life since returning to live with his mother:

Child protection? I've had that, obviously they're only trying to protect the people, but family, all that stuff, I've got all that, no I feel safe, like quite a lot, um like Grandad's coming round tonight cos he takes me to [youth club].

Mark, whose grandmother was helping care for him and his siblings after his mother had left the household because of abuse concerns, seemed similarly positive about these changes: "*Yeah, grandma's in the family, yeah good choice, I don't want Mum, just Grandma"* Mark's family are Chinese his father explained, via an interpreter how his social worker was trying to help secure her immigration status because "*because they are aware how important Grandma is here, she's a very important member in our family, I hope that they can make sure Grandma can stay here so um Mark wouldn't lose his Grandma".*

We have got the help that we need

The overriding theme in this group of young people's accounts was their confidence that they had enough support to move forward with their lives, whether or not they and their families were still receiving support within child protection processes. Although this set them apart from participants in other groups, it was not that they weren't experiencing ongoing difficulties, rather it was the confidence they expressed in the people supporting them. Their relationship with their social worker was crucial to this, however, young people also emphasised the importance of good communication within their wider network of support. Jack saw this as essential to him feeling well supported by his support worker at school and his social worker:

Cos' the school's gotta always know anyway [if there's a problem] my social worker talks to the support person there, so it's basically like feed-to-feed … it's all good communication. They work together to get the job done I guess.

Stevie similarly seemed to appreciate her psychiatrist and foster-carer working together to support her with her behaviour and mental health needs, she said: *"when people talk to me about my behaviour then it works, [foster-carer] and Dr. A., the one who gives me medicine, if I don't take my medicine I don't concentrate"*

For Chloe it was just as important that her Mother had her own support with her mental health as well as her receiving support herself. This seemed to help her feel more confident that things would continue to improve at home:

"Mum has got a lady as well who helps her, so Mummy got the help that she needs, and I have got the help that I need so we are both alright."

However, young people in this group particularly appreciated the help to develop their social networks, which many described as having helped them feel more confident. Like many disabled young people, they had fewer opportunities to socialise because of attending special schools or found making friends more difficult in other ways because of their impairments. Jon has autism and struggled with social anxiety, especially at school, but described how receiving support from a personal assistant had helped him to progress from hiding under pillows and refusing to leave the house, to feeling confident enough to meet up with his own small group of friends on his own:

Making friends is the challenge, meeting new people as well … but [now] I have a lot of friends, I have three, and it is nice to know that you have people who are there when you go out and adults aren't there who can sort you out.

Chloe also said she did not yet feel confident to leave the house on her own in her wheelchair. However, she said she had "*made a big group of new friends, so I am quite happy*" as a result of attending residential short breaks unit and other activities set up as part of her child protection plan to help reduce her social isolation. She was grateful to her social worker for how these supports had helped her improve her confidence and reassure her about her family's future:

I like [my social worker] *because she got me into thinking about leaving [home] and keeping in touch with my friends and now I have got my confidence back I see a happy future for me and my Mum and Dad and sisters and brother, but we all have to move forward we can't go back.*

Conclusion

This study provides support for strengths based and person-centred approaches when supporting disabled young people in need of protection and their families, which take account of their impairments. It highlights that disabled young people experience many of the same issues identified by non-disabled young people during child protection enquiries and decision-making processes, but also how professionals' responses can either heighten or address the additional impairment related barriers disabled young people face to their social inclusion.

Disabled young people have the same need for therapeutic support to help them recover from trauma and abuse as part of the help following on from initial child protection enquiries and their aftermath, nevertheless informal sources of support are equally valued by them. In particular, the majority of disabled young people, whether they were living in home or out-of-home care, highlighted the importance of professionals' valuing and supporting their family relationships and other people who are important to them, including their foster-carers, teachers and personal assistants and their friends.

Disabled young people living apart from their siblings and where their birth families lived appeared to find this especially difficult, having also lost contact with their school friends and other social networks as a result of coming into care, even where they felt this decision had been in their best interests. Having a positive and supportive relationship with their social worker, alongside their own ways of managing these difficulties (e.g. Hannah's use of social media) was especially valued and appeared to be empowering, despite these otherwise challenging circumstances.

Disabled young people's overall views about their experiences of child protection processes are summarised in Box 4:

- Disabled young people felt frustrated when practitioners' criticised their parents during child protection enquiries and decision-making processes or support was provided in a way that made them feel bullied, particularly where they felt their strengths and priorities were not valued.
- Many disabled young people recognised that difficult judgements are sometimes necessary as a result of child protection enquiries and decision-making. However, despite their mixed feelings about this, wanted practitioners' to remain mindful of how their use of power impacted on them.
- When conflicts arose during child protection decision-making processes, disabled young people said that having an independent advocate helped them to feel that they still had a say in what happened next.
- Disabled young people wanted help to feel safe, but also wanted help to be able to thrive. They wanted help to maintain and build their social networks and relationships, to maintain connections with their birth families when in care, and to overcome barriers to social inclusion.
- Therapeutic support was valued by some young people but being able to talk informally about their worries to parents, carers and their social worker was just as important.
- Disabled young people valued support that took account of their priorities, and when practitioners worked together with parents, caregivers and other people they considered important, particularly teachers, support workers, other family members and friends.

Box 4 – Summary of disabled young people's views of their experiences of child protection

Part 4

Discussion and conclusions

Chapter 8 – Discussion and conclusions

Introduction

This study has explored disabled young people's social worlds and their views of their experiences of child protection enquiries and their aftermath. It was driven by a desire to understand their identities, families and wider social relationships, not just as subjects of professional concern but in terms of their lives overall.

It sought to answer the following research questions, as reflected in the findings presented in each of the three preceding chapters:

- How do disabled young people see themselves within their families and wider social worlds?
- What are disabled young people's experiences of child protection enquiries and taking part in decision-making?
- What are disabled young people's experiences of receiving help and support following initial child protection enquiries?

Participatory methods were used with the aim of allowing young people some opportunities to raise issues of importance to them, reflecting my intention to involve them as active agents in the research process. This approach also allowed me to adapt the methods used to take account of young people's individual preferences and needs.

The study aims have been met in so far as an in-depth description and analysis of disabled young people's views of child protection processes and the sense they made of their experiences has been produced. In view of the lack of previous research regarding disabled children's experiences of child protection enquiries and decision-making, noted in the literature review (Stalker and McArthur, 2012), this study represents an important contribution to knowledge and our understanding of the particular needs of disabled young people following alleged maltreatment. It also provides valuable insights into the family and caregiving contexts of disabled young people who become involved with the child protection system.

This chapter brings together this study's findings and discusses them in relation to existing theory and research. The study's main findings in relation to the three research questions are explored in turn in relation to the themes from the corresponding literature review chapter. The cross-cutting themes from across the study's findings are then integrated, a model for improving our understanding of child protection practice with disabled young people is presented and the implications for policy and social work practice discussed. The study's limitations and suggested directions for future research are then outlined, before concluding with disabled young people's messages for social workers about how they want to be supported during child protection enquiries and decision-making.

How do disabled young people see themselves within their families and wider social worlds?

What young people had to say about themselves, their everyday lives and relationships was explored in chapter 5. Most of what they shared revealed similar interests and concerns to other disabled and non-disabled young people (Stalker, 2012; Amplify *et al*, 2013). Understandably, participants talked more enthusiastically about who or what was important to them than about their impairments or the problems in their families. Nevertheless, these two aspects of their lives strongly mediated their experiences (Connors and Stalker, 2007; Cossar *et al*, 2013), providing an important basis for understanding their views about their experiences of child protection processes discussed in Chapters 6 and 7.

Young people's sense of themselves

Study participants, for the most part, appeared to have a positive view of themselves and their lives, regardless of their impairments. This is in line with several studies with disabled young people (Dickinson *et al* 2007; Singh and Ghai 2009), including those living in care (Kelly, 2016). They likewise tended to emphasise how their interests and aspirations were similar to those of other young people (Stalker, 2012). Most also identified with and wanted to be part of mainstream youth culture (Wickenden, 2011), although older young people were more aware of and interested in social media and those with more significant learning disabilities often had interests associated with much younger children.

In the latter case it was difficult to know whether this reflected an active choice by these young people, or possibly a culture of low developmental expectations in special schools and/or among their caregivers as commented on in previous studies (Davis *et al*, 2003: Kelly, 2005). Some of these same young people were also interested in romantic relationships and becoming more independent, illustrating the varied, often uneven nature of disabled young people's social, emotional and behaviour development, which Smeaton *et al* (2015) identify as one factor that may contribute to learning disabled young people's increased vulnerability to being sexually exploited.

Most participants saw themselves as having diverse aspects to their identities, reflecting the complex and intersectional nature of social relational identity (McCall, 2005). Some participants seemed relatively unaware of their impairments, perhaps reflecting the observation of previous studies that disabled young people often have few opportunities to talk about their impairments (Connors and Stalker, 2003; Kelly, 2005). Most participants did describe some sense of themselves as different, but likewise did not view their impairments as an important part of who they were, even where these significantly impacted on their daily lives, as reported by earlier studies (Abbott and Carpenter, 2010; Wickenden, 2011). Very few described themselves as disabled and many disliked others foregrounding this aspect of their identity (Davis *et al*, 2003; Connors and Stalker, 2007; Wickenden, 2011), particularly where they felt practitioners' used their disability as evidence of their vulnerability and need for child protection enquiries and intervention.

Awareness of the stigma associated with their impairments but also their experiences of maltreatment appeared to adversely impact some young people's self-esteem and self-confidence. This was particularly an issue among participants with more visible physical impairments, as noted by previous studies (McLaughlin, 2014; Wickenden, 2011). This perhaps lends support to Thomas' (1999) suggestion that barriers to being, that is other's negative attitudes to impairment, which she also refers to as "psycho-emotional disablism", may be more damaging to disabled people's sense of self than barriers to doing, i.e. how their impairments or factors in the environment influence what they can and can't do.

There was evidence of some participants having internalised medical model ideas of disability in relation to their behaviour. Interestingly these young people's carers' viewed these difficulties as related to their experiences of maltreatment, rather than their disabilities. This is in contrast to previous studies reporting that behavioural signs of possible maltreatment are often wrongly attributed to children's impairments (Brandon *et al*, 2011). This highlights the complexities involved for practitioners' in disentangling the consequences of each factor for individual children's welfare and development (Spencer *et al*, 2005; Taylor *et al*, 2014), but also the arbitrary nature of focusing on one aspect of children's experience to the exclusion of others.

Young people also expressed a range of different views about having a disability. This appears to confirm the findings of earlier studies that disabled children's understanding and experience of disability is more complex and varied than is accounted for by either the medical or social model of disability (Davis *et al*, 2003; Kelly, 2005). Jon saw being recognised as disabled as a disadvantage in social settings, but an advantage to accessing appropriate support, suggesting he saw his disability as both a label and a badge (Shakespeare, 2014).

Some young people's interests appeared to be partly a way of coping with their impairments providing additional evidence that young people were active agents in mediating the impact of impairment on their experience (Davis *et al*, 2003). This finding highlights the relevance of childhood studies as well as disability theory to helping promote practitioners' understanding of disabled young people's life-worlds (Tisdall, 2012; Curran and Runswick-Cole, 2013).

It was also striking that young people in this study with more positive and/or reflexive views towards their impairments tended to be older with less visible impairments and fewer learning disabilities. This illustrates that disabled young people are not a homogenous group in terms of experience or identity (Watson, 2012). It also suggests a role for developmental psychology in making sense of disabled young people's understanding and experiences of childhood and impairment (Carpenter, 2010), particularly as longitudinal research with disabled young people has demonstrated how their perceptions change as they mature (Kelly, 2013).

The ambivalence some young people expressed about their relationships with their parents likewise confirms the usefulness of attachment theory to understanding disabled as well as non-disabled young people's responses to maltreatment (Cossar *et al*, 2014) and practitioners' helping disabled young people in care make sense of their histories and identities (Schofield and Beek, 2009), while also needing to tailor these activities to their impairment needs (Franklin *et al*, 2015).

Young people's views of their relationships with families and caregivers

Disabled young people in this study identified their relationships with their caregivers and families as important to their well-being and helping them achieve their goals, echoing the findings of previous research with both disabled and non-disabled young people (Foley, 2012; Amplify, 2013). Birth families also remained an important source of identity for disabled young people in care though they no longer played a significant part in their everyday lives (Schofield and Beek, 2009; Kelly, 2016).

Young people's impairments, experiences of maltreatment and burgeoning adolescence mediated their relationships with parents, caregivers and siblings in varied and complex ways. Many participants had experienced considerable disruption within family relationships and a few found it very upsetting to talk about their conflicting feeling towards their families and/or said little about them. This indicates these disabled young people's need for ongoing support from practitioners and carers to manage their difficult emotions and behaviour associated with their experiences of maltreatment, which for a few participants was threatening to undermine their current placement (Kelly *et al*, 2016) .

By contrast, disabled young people's desire for greater autonomy and independence seemed to cause the usual ups and downs associated with adolescence. Despite several encouraging examples of young people asserting their agency, however, some described their parents' and carers' as unduly over-protective as a result of their impairments, as reported by earlier studies (Kelly, 2005; McNeilly *et al*, 2015). Although, most participants nevertheless said they felt close to their family's young people who were physically and/or emotionally dependent on their carers due to their impairments tended to describe especially strong bond with their parents, particularly their mothers, as reported by earlier studies (Abbott and Carpenter, 2010; Mitchell and Sloper, 2011).

Mothers and female carers

The gendered nature of caregiving, with mothers and female carers described as the main source of practical and emotional support was similarly reflected in most participants' accounts. This situation is frequently reported as especially pronounced among disabled young people because of their additional care needs (Green, 2007). This may also help explain why so few of the mothers in this study worked (Blackburn, Read and Spencer, 2010), particularly given the number who were also single carers.

As highlighted by previous studies, several young people described mothers and female carers as their main advocate, including in their relationships with professionals (Wickenden, 2011; Mitchell and Sloper, 2011). However, these same relationships were also described by young people as a source of conflict and tension, highlighting the complex and multi-faceted nature of familial relationships. Some young people with physical impairments expressed guilt regarding the demands their personal care needs placed on their mothers (Abbott and Carpenter, 2010). Though, one young person (Chloe), in turn expressed a sense of concern and responsibility for her mother's mental health needs, which while itself in some ways was concerning, particularly as this was part of the child protection concern for her, also highlights that caregiving relationships are not straightforwardly dependent, but interdependent and reciprocal in the same way as other relationships (Shakespeare, 2014).

Fathers and male carers

Young people expressed a similar range of views about their fathers and male carers, suggesting their experiences of these relationships are equally complex and varied. Some described being very close to their fathers, especially one young person whose father was his main caregiver, while a few, whose fathers appeared to be largely absent from their lives, did not mention them. The remaining participants appeared to view their fathers or male carers as playing a slightly different role in their lives than female caregivers, being more involved in boundary setting but providing less practical and emotional support. Three young people also felt their fathers had less understanding of their impairments partly due to only seeing them at weekends or working long hours and described this as a point of conflict in their relationship. One young person also saw his father's lack of understanding of his condition as having contributed to the child protection concerns for him.

These reflect important findings since disabled young people's perspectives of their relationships with male as distinct from female caregivers is largely unknown. They may also have implications for practice, given that father's role in promoting family resilience within families with disabled children is under-researched (McDonald and

Hastings, 2010), and evidence suggests that fathers involvement during child protection is often overlooked by practitioners' (Scourfield, 2003; Brandon, Philip and Clifton, 2017).

Siblings

Young people presented a similarly varied and complex picture of their sibling relationships. Most identified their siblings as important to them, even where they were not currently living with them, and the intimacy and irritation they described as characterising these relationships supports the findings of previous studies that disabled children's sibling relationships mirror those of typically developing children (Connors and Stalker, 2003; Foley *et al*, 2012).

Young people who described feeling especially close to their siblings tended to be those who also emphasised closeness in other family relationships. These participants highlighted similar benefits to these relationships as those identified by earlier studies, such as feeling accepted by their siblings regardless of their impairment or being able to spend time with siblings when other social opportunities were limited (Connors and Stalker, 2003). Several young people whose siblings no longer lived with them said they missed them and valued having regular contact, as reported by disabled young people in care in Kelly *et al's* (2016) study.

A minority of participants had difficult sibling relationships that included sibling on sibling abuse, reflecting the findings of previous research with disabled children (Connors and Stalker, 2003). Though, except for one young person who had two younger siblings with autism, these young people's caregivers or social worker considered these difficulties to be related to other problems in their families, including previous maltreatment rather than their disabilities. This further highlights the difficulties practitioners sometimes face differentiating between the impact of maltreatment and impairment on disabled children's relationships and development (Taylor *et al*, 2014).

Grandparents

Of further interest was the four disabled young people in this study, including three from BAME backgrounds, whose grandparents played a significant role in caring for them. Each mentioned their grandparent or grandparent(s) as an important source of practical and emotional support, and in all but one case these arrangements were reported by their caregivers as having been supported by the young person's social worker to help avoid these young people going into care.

These examples, though inevitably limited by the small numbers involved, are at odds with previous studies reporting difficulties identifying family members as kinship or short breaks carers for disabled children (Connors and Stalker, 2003; Kelly, 2016). What can be learnt from these examples of positive practice represents an important area for future research, given that disabled children are more likely to be looked after away from home, often in residential care at a distance from where their birth families live (Baker, 2007; Kelly, 2016) due to lack of suitable foster placements.

Young people's views about their friendships and social lives

Young people reported their impairments and experiences of maltreatment as similarly impacting other areas of their lives, including their friendships and social lives. This often had to do the ways in which they were socialised and/or perceived differently because of their impairments, and in some cases their family difficulties or experiences of abuse too. Some reported feeling frustrated or socially isolated or lacking the confidence to extend their social networks as a result, reflecting the findings of previous studies (Kelly, 2005; Wickenden, 2011).

A few young people by contrast appeared to have an active social life and/or were less aware of these issues, interestingly these young people were also more confident taking part in decision-making during child protection enquiries. This reflects the findings of previous studies that disabled young people's opportunities or lack thereof to develop their relationships with peers can have a cumulative effect on other areas of their lives (Raghavendra *et al*, 2012). While Smeaton *et al* (2015) suggest disabled young people's lack of opportunity to develop their social skills may also increase their vulnerability to being sexually exploited.

Friendships

Most young people valued their friends and saw them as an important part of their lives, reflecting previous research with both disabled and non-disabled young people (Foley, 2012; Amplify, 2013). Some said more about their friends than they did about their families, perhaps reflecting the growing importance of peers during adolescence (Coleman, 2011), while others mentioned their friends only in passing.

As for most young people their friendship group consisted mainly of their peers at school. However, although many viewed their friends as a source of emotional support they also felt their opportunities for friendship were limited by their attendance at special schools because of smaller class sizes, fewer female friends (due to a higher prevalence of disability among boys), and spending time with adult support assistants as reported by previous studies (Davis *et al*, 2003; Ytterus, 2012; Kelly, 2016). Though some also seemed to regard these adult helpers as their friends (Watson *et al*, 2000; Wickenden, 2011).

Young people both at special and mainstream schools mentioned changing school, both as a result of coming into care or their impairment needs as disrupting their friendships (Munro and Hardy, 2006; Watson *et al*, 2000). Others saw the effects of their impairments themselves as a barrier to developing friendships, such as missing a lot of school due to illness or lacking the confidence and social skills to make friends (Ytterus, 2012). The latter was reported as a particular difficulty by young people with autism (Beresford *et al*, 2007).

Bullying

A lack of confidence and poor social skills also appeared to contribute to some disabled young people in this study's experiences of bullying, as observed by other studies (Raghavendra *et al*, 2012). Several young people also described instances of being bullied by other disabled young people (Watson, *et al*, 2000). Bullying was more often mentioned by young people attending mainstream schools, however, suggesting that negative attitudes towards disability and difference were also a factor (Ytterus, 2012).

Participants themselves likewise attributed their experiences of bullying to being seen differently because of their impairments. However, a few also mentioned their awareness or experience of being bullied due to the stigma associated with their family difficulties, in common with the experience of other maltreated children (Cossar *et al*, 2011). For some participants being bullied represented a long-term problem that had significantly affected their self-confidence and mental health, and in some cases their behaviour at home. Young people's views about the professional response to these issues were mixed, as reported by previous studies (McLaughlin *et al*, 2012; Kelly, 2016). A few also described feeling bullied by school staff, who they felt lacked an understanding of their impairments.

Life outside school

Most participants reported restricted social lives outside of school, with social segregation, the impact of disablist attitudes on their self-confidence and their impairments themselves all contributing to this experience (Connors and Stalker, 2003; Kelly, 2005). Several described being bored at home because they lacked access to other social opportunities in their local area (Kelly, 2013). Most rarely saw their school friends because their special schools were at a distance from where they each lived, and some did not feel confident or were unable to leave the house without adult assistance because of their impairments (Abbott and Carpenter, 2010).

Interestingly, although poverty appeared to be a prominent feature of many participants' lives this was only mentioned by one young person as potentially limiting her social opportunities. Although this contrasts with some research focusing on this topic (Larkins *et al*, 2013), others have suggested that some disabled young people may lack awareness of such issues, partly due to having fewer opportunities to compare their lives with other young people because of their relative social isolation (Beresford *et al* 2012).

A suggestion supported by the findings of this, and previous studies (Kelly, 2005; Wickenden, 2011) was that disabled young people's opportunities to socialise almost always consisted of activities organised and supervised by adults with other disabled young people or family members. Young people also described their parents' and carer's attitudes as influencing their friendships and opportunities for social interaction to a large extent (Connors and Stalker, 2003; Kelly, 2005). There were some exceptions to this pattern, however, in that a few older young people reported socialising with non-disabled young people with minimal adult surveillance. Though, these young people had less visible impairments and, aware of the stigma associated with their disability, were keen to "pass as normal", as reported by earlier studies (Davis *et al*, 2003).

Managing risk and risk-taking behaviour

The participants, who by contrast, appeared to experience the highest levels of adult surveillance included not only those with personal care needs but also two young people whose behaviour was sexually challenging, seen by their carers as likely linked to their own prior experiences of abuse. This finding highlights the potential for maltreatment experiences to restrict disabled young people's opportunities for social interaction in addition to their impairments.

A particular source of tension between some older participants and their caregivers was in relation to their desire to engage in sexual relationships or other behaviour viewed as potentially risky, such as using social media. Caregivers, concerned about young people's vulnerability not only in terms of their impairments and negative social attitudes towards disabled people, but in some cases the young person's prior experiences of maltreatment, were keen to restrict risk taking behaviour. Young people, in contrast, tended to view these behaviours as a usual part of growing up, or, in the case of social media an opportunity to maintain or extend their limited social networks (Asbjornslett *et al*, 2012).

Such tensions are complex and not easy to resolve, and many parents and carers of disabled young people report struggling to calculate which risks are appropriate for their individual child as they negotiate their way towards independence and is an area where both may require additional support from professionals (Almack *et al*, 2009). However, some examples in this study, such as one young woman reportedly being denied access to contraception, seem to support Franklin *et al's* (2015) view that overprotection and the infantilization of disabled young people, through denying them access to sex education and opportunities to learn about healthy sexual relationships is prevalent in practice and can potentially be just as damaging for young people's wellbeing and development as a lack of protection.

What are disabled young people's experiences of child protection enquiries and taking part in decision-making?

Disabled young people's views and experiences of taking part in child protection enquiries and decision-making were explored in Chapter 6. Although there were some encouraging examples of creative practice, the majority of participants appeared to feel their participation in decision-making, especially within child protection processes, had been limited. Young people highlighted feeling particularly frustrated by not being able to understand what was happening (Woolfson, *et al*, 2010) or not having a choice over how and whether they were allowed to be involved by practitioners or their parents (Bell, 2002).

Recognising child protection decision-making is different and difficult

One of the most striking and consistent features of young people's accounts was the differences and contrasts they often drew between their experiences of taking part in child protection and other decision-making processes. Young people were often very positive about contributing to decisions about their needs as a looked after young person or child in need (Kelly *et al*, 2016), although they were largely indifferent about attending school review meetings, which several said they found boring (Wilson *et al*, 2016). Whereas child protection decision-making was almost universally associated with strong negative emotions for participants, such as anxiety and distress or anger and frustration (Wooflson, *et al*, 2010; Winter, 2006) even where their family's contact with the child protection system had concluded several years previously.

Young people especially feared what child protection enquiries and decision-making might mean for them and/or their families. Many described feeling worried that they would go into care, felt distressed by seeing their parents upset as reported by earlier studies (Cossar *et al*, 2011). Many previous studies have identified similar themes, leading some to see this as a reason for not encouraging children and young people's involvement in child protection decision-making (Healey and Darlington, 2009). Others, while acknowledging that exposing children unnecessarily to conflict is unhelpful, argue that restricting their opportunity to take part is disempowering (Cossar *et al*, 2014) and can reinforce feelings of powerless associated with maltreatment (Bell, 2002) as well as representing a denial of their rights (Reading *et al*, 2009).

Evidence from this study suggests this may be a particular issue for disabled young people, since it was striking that young people in this study who were the most emotionally and/or physically dependent on others due to their impairments also tended to be the most tentative about taking part in decision-making (Kelly, 2005; McNeilly *et al*, 2015). This underlines the need for practitioners' to be sensitively attuned to young people's particular needs and experiences as a result of their impairment needs when seeking to involve them in child protection enquiries and decision-making (Schofield and Thoburn, 1996). This is particularly so given that the responses of young people with complex cognitive or communication impairments, despite having limited cognitive understanding, indicated they were just as emotionally aware of the stressful nature of child protection enquiries and their potential to disrupt family relationships as were other young people.

Different ways of taking part

Young people themselves also had differing views about whether and how they wished to be involved in child protection decision-making (Cashmore, 2002), and this often appeared more a matter of personal preference than anything else. This chimes with Bell's (2007) assertion that "different children want different things with regard to participation [*in child protection*] age is not the main criterion in determining attitude" (page 295-6) and further suggests that the same applies to young people's impairments as well.

Access to clear and consistent information

Being able to understand what was happening and why was a high priority for young people in this study in helping alleviate the worry caused by child protection enquiries (Woolfson *et al*, 2010). Although most young people were aware of having a social worker, the majority seemed to have very little information about or overall understanding of child protection processes. This was a source of distress for many young people, especially those who also apparently lacked an understanding of the concerns for their welfare.

Other young people had a partial understanding of child protection processes, but often receiving conflicting information from professionals and family members had left them feeling confused or caused them to mis-interpret what was happening. A few also said they felt discouraged from getting involved in decision-making by receiving too much, often upsetting information about their families or by professionals' unhelpful use of jargon (Creegan *et al*, 2006; Whitehead, 2009). This seemed especially to be an issue among participants with learning disabilities underlining these young people's need for particular clarity and additional time to process complex information, such as is likely to be involved in child protection processes (Kelly, 2005; Taylor *et al*, 2014).

Study participants' overall experience suggests that practitioners' need to make providing clear and understandable information a higher priority in child protection practice with disabled young people (Taylor *et al*, 2014; National Working Group on Safeguarding Disabled Children, 2016). This is especially given disabled young people's often, different ways of communicating (UNCRPD, 2006; Franklin and Sloper, 2009). The high levels of distress expressed by many participants in this study, underlines that practitioners' need to be additionally mindful that the emotionally charged context of child protection enquiries and decision-making processes can impact on young people's receptiveness to information, even when this is tailored to their impairment needs (Gallagher *et al*, 2012).

Expressing views

The majority of young people wanted to express their views and feel listened to during child protection enquiries, even those who did not wish to be actively involved in decision-making. Although, most participants described having some opportunity to speak to their social worker, some said they found it hard to say what they thought, and many felt uncertain about how their views had been represented during child protection meetings. This highlights that practitioners' need to be aware that taking part in formal decision-making represents an unusual and unfamiliar situation for most young people (Bell, 2002), who may therefore need additional support to express their views and to receive feedback. This study suggests that this may be especially the case for disabled young people as several participants had communication needs and/or appeared to have internalised a negative view of themselves because of their impairments.

Several young people described social workers as mainly talking to their parents and there was little evidence from their accounts of practitioners' adapting their practice to take account of their impairment needs in their interactions with them. Where creative methods were used this tended not to be during child protection enquiries. Visual prompts, technology and other communication supports were mainly described as being used with young people in care to help them make sense of what had happened in their families, or to seek young people's views about child in need services.

This suggests more needs to be done to improve practitioners' knowledge, confidence and skills in undertaking direct work with disabled young people to ensure they have an opportunity to express their views during child protection enquiries in line with other areas of practice (Franklin and Sloper, 2009). This is especially given the serious implications decisions made during child protection enquiries will often have on their lives. As well as improved training, greater sharing of knowledge and skills between social workers in disabled children's and child protection teams as well as practitioners from other disciplines may be one way of achieving this (Taylor, *et al*, 2014).

Attending child protection meetings

Attending child protection conferences or core group meetings is sometimes seen as the most direct way of involving young people in decision-making (Vis and Thomas, 2009). However, the majority of participants in this study had not attended these. How they felt about this varied. Younger participants and those with more significant learning disabilities appeared relatively unaware of child protection meetings. Others knew about them but had not been given the option of attending, which some found frustrating, particularly if the reasons were not clearly explained (Thomas *et al*, 2002), or because they saw going as an important way of gaining information and expressing their views (Bell, 2002; Cossar *et al*, 2011). A few young people, by contrast had made a choice not to go to child protection meetings because they thought it would be too upsetting or would be boring.

Young people in this study who had attended child protection meetings were all aged over 16 and only one had learning disabilities. This reflects the findings of other studies that younger children and those with more significant impairments generally have fewer opportunities to participate in decision-making in meetings (Shemmings, 2000; Franklin and Sloper, 2006). However, these young people reported finding child protection meetings stressful where it was difficult to express their views due to feeling intimidated by the large number of professionals present. Some described their participation as a waste of time, while for others it appeared that processes not being adapted to take account of their needs had resulted in them merely "being present" rather than taking part (Leeson, 2007).

Other young people, by contrast, felt confident that their views had been represented and listened to even though they had not attended meetings. Some also described very positive experiences of taking part in their looked after or children in need review meetings. In both cases young people emphasised adequate preparation and support both before, during and after meetings by their social worker as crucial to helping them to feel that their contribution was valued. This highlights that participation is not a one-off process, and that practitioners' need to be actively involved in facilitating and supporting young people's participation in order for this to be meaningful (Kirby, 2003; Sinclair, 2004).

The experiences of participants in this study therefore suggest that, although going to meetings is often seen as maximising young people's involvement in decision making (Vis and Thomas, 2009), that this is not always necessary or perhaps desirable, particularly given the highly multi-disciplinary and often tense nature of child protection enquiries and decision-making. This likewise challenges hierarchical typologies of children's participation since it seems to suggest that the 'highest' level of involvement (i.e. going to meetings) is not always the best or most appropriate option for all young people (Mitchell and Sloper, 2011). Rather, it was more important to young people that they were able to take part and express themselves in a way that felt comfortable and fitting for them.

Someone speaking on the young person's behalf

A related and important theme was that most young people in this study, regardless of their impairments were happy for adults to take the lead in decision-making (McNeilly *et al*, 2015). This often included a preference for an adult speaking on their behalf (Thomas, 2002; Coyne *et al*, 2011). This, in itself, further challenges hierarchical typologies of participation by signalling that not all children want or are perhaps able to be the main decider (Mitchell and Sloper, 2011). However, it also raises important questions about who is best placed to promote their involvement, particularly in child protection processes.

Parental involvement

Many participants in this study wished for their parents to represent their views or support them to express themselves (Coyne *et al*, 2011; McNeilly *et al*, 2015). This approach did appear to have some value in promoting the participation of young people in decision-making, whose views might otherwise not be included (Franklin and Sloper, 2009). For example, in this study establishing the views of young people with complex impairments and/or limited verbal communication often relied on practitioners' triangulating the views of those who know them well, which naturally included their parents.

However, the experience of some other study participants suggests that a "family-based approach" (McNeilly *et al*, 2015) to involving young people in decision-making may be particularly problematic where there are child protection concerns. Although young people's views often differ from those of their parents' (Dickinson, *et al*, 2007; Welch *et al*, 2014), some were reluctant to speak up independently due to not wanting to upset them. This was especially true of young people who had disclosed abuse, or who physically depended on their carers, which in some cases resulted in these young people's voices becoming muted or lost in decision-making (Morris, 2003). This highlights the dangers of practitioners' relying on parents' as proxies, both in terms of losing sight of disabled young people's safety and welfare (Brandon *et al*, 2011; Kelly and Dowling, 2015) and reinforcing their view of themselves as passive and dependent (Watson, 2012).

Relationships with social workers

Some other participants did view their parents as effectively advocating on their behalf during child protection processes. However, for the majority of young people the availability of professional support crucially determined their overall experience of taking part in decision-making. Where young people felt confident expressing their views and that their contribution to decision-making was valued this was almost always underpinned by a trusting and supportive relationship with their social worker, as consistently highlighted by previous research (Bell, 2002; Cossar *et al*, 2014; van Bijleveld *et al*, 2015).

The aspects of this relationship young people particularly emphasised as promoting their participation in decision-making included: good communication and support to express their views; feeling that their social worker took time to get to know them; listened to what they had to say and explained decisions in a way they could understand (Whitehead, 2009; Tregeagle and Mason, 2008). Two young people especially valued their social worker's efforts to understand their communication well enough not to rely on other support, for example. Another young person with severe learning disabilities appreciated her social worker allowing her to choose where they met during visits, demonstrating that practitioners' can still empower young people by allowing them to make choices, even when their participation in child protection processes is limited in other ways (Shemmings, 2000).

By contrast young people disliked practitioners' who they felt did not bother to get to know them and mainly spoke to their parents, who they felt often misrepresented their views as a result, as found in other studies (Cossar *et al*, 2011). Similarly, young people who had experienced several changes of social worker or lacked a regular opportunity to meet with them also tended to be those who were least confident about how their views had been represented in decision-making processes (Cashmore, 2002; McLeod, 2007). All of this highlights the need for social workers to consult disabled young people directly and develop their skills communicating with them in order to uphold their right to be included in child protection decision-making (Taylor *et al*, 2014).

Independent advocacy

For a few participants in this study a high level of conflict between parents and professionals appeared to have affected the young person's willingness to engage with their social worker during child protection enquiries. Some of these young people had received support from an independent advocate and seemed to view this as helping them to promote their participation, even though they strongly disagreed with the reasons for professional involvement.

Previous authors have similarly observed that the frequently adversarial nature of child protection enquiries and the strength of children's emotional ties to their parents despite maltreatment sometimes results in children aligning themselves against their social worker (Schofield and Thoburn, 1996). The findings of this study would appear to support the use of independent advocacy as one way of helping to address this issue (LaValle and Jellic, 2012). The experience of one study participant further indicates that specialist advocacy may be especially effective in allowing the views of young people with complex communication impairments views to be included in child protection enquiries and decision-making. This suggests practitioners' and organisations need to do more to promote the availability of advocacy for disabled young people, especially as other studies indicate that such services are rarely used (Franklin and Knight, 2011).

Recognition and respect for young people's participation

Challenging negative attitudes and assumptions

Overall, the extent to which participants in this study felt practitioners and other adults were able to see past their impairments and respect their agency largely determined their experiences of taking part in decision-making. Several young people reported feeling that practitioners' seeing them as vulnerable and in need of protection, including on the basis of their impairments, had affected their involvement and the weight given to their views during child protection enquiries. While other young people said they felt confident expressing their views and taking part in decision-making, despite having significant communication or learning difficulties.

This appears to suggest that severity of impairment was not necessarily the main factor determining whether young people in this study's views were included in child protection decision-making. That other studies report similar findings (Ofsted, 2012; Taylor *et al*, 2014) implies that the barriers to disabled children's participation in decision-making are at least partly socially constructed (McNeilly *et al*, 2015). This in turn highlights the need for disability awareness training for practitioners and challenging of disablist attitudes within organisations in order to encourage practitioners' to actively respond to young people's impairment needs and uphold their right for their views to be included in decision-making (Franklin and Sloper, 2009).

Addressing power differentials

How practitioners' balanced working in partnership with young people and their families and exercising their power to protect them also impacted on young people's experiences of participation (Cossar *et al*, 2014). Where young people described feeling positive about their participation in child protection decision-making these examples were characterised not only by their social worker's apparent recognition of their agency (van Bijleveld *et al*, 2015) but also some attempt to redress unavoidable power imbalances between the young person, professionals and other adults (De Boer and Coady, 2007). This included involving young people in running meetings by encouraging them to ask questions of adults, passing a ball around to give everyone an opportunity to speak or, as mentioned above, through using of an independent advocate.

Such examples are consistent with a child-centred approach to upholding children's rights to participate in decisions made about them (Reading *et al*, 2009) and a childhood studies understanding of young people as competent social actors (Christensen and James, 1990). Young people in this study whose participation had been supported in this way appeared to feel empowered and were confident that their views had been taken into account. It is impossible to know what the longer-term benefits might be for young people in this study based on one interview. However, other studies have reported that participation in decision-making can be protective for vulnerable young people by increasing their self-efficacy and confidence (Schofield, 2005; McNeilly, *et al* 2015).

Young people who, by contrast, felt that their social worker had used their power to restrict their participation or the weight given to their views, expressed feeling disillusioned and frustrated. For some participants their sense of disempowerment appeared to have reinforced their already negative view of themselves, associated with their impairments and possibly also their experiences of abuse (Bell, 2002). This suggests that practitioners' should view disabled young people's participation in decision-making as an opportunity to challenge dominant views of disabled people as helpless and dependent (Franklin and Sloper, 2009). Moreover, from a social justice perspective, organisations should arguably give greater priority to disabled young people's participation in recognition of their social marginalisation (Fraser, 2000), which in itself also justifies the redistribution of resources required to achieve it (McNeilly *et al*, 2015).

What are disabled young people's experiences of child protection enquires and subsequent help?

Similar themes were reflected in what disabled young people had to say about their experiences of child protection enquiries and subsequently receiving help, which was explored in chapter 7. The range and types of support participants' described receiving as a result of child protection enquiries and decision-making processes was very diverse: ten young people were living at home and either had a child protection plan or were receiving support as a child in need and six were living in foster or residential care. Most were also receiving help focused around their impairments as well as to address the perceived causes or consequences of maltreatment. Regardless of how and why young people were being supported, their view of the help provided was mainly determined by the respect afforded to their own view of their support needs alongside their need for protection; the availability of understanding and supportive relationships; and the account taken of the strengths and complexities of their family relationships.

Recognising the impact of child protection, maltreatment and disability

Young people's views about having received help via child protection processes varied but all indicated finding this more stressful and difficult than other ways of being supported. Most feared what the consequences might be for them or their families, and many described the 'help' provided as intrusive, particularly the increased monitoring of their daily lives. Some said child protection enquiries and had made things worse at home or resulted in them feeling stigmatised or isolated from their friends at school. Although this reflects the findings of previous research (Bell, 2002; Cossar *et al*, 2011), this study further suggests this is also the experience of young people with complex learning and communication impairments who, despite apparently having less understanding of the reasons for professional involvement, showed behavioural changes that seemed attributable to the tension child protection enquiries and intervention had caused in their families.

This underlines the need for practitioners' to be sensitively attuned to the impact child protection involvement has on young people, regardless of their impairments, and attempt as far as possible to reassure them; while at the same time also keeping an open mind as to what changes in young people's behaviour might mean. This is especially given disabled young people's greater difficulties understanding others' behaviour as abusive (Allnock and Miller, 2013) and that young people's ability to recognise maltreatment commonly begins with an emotional awareness something is not right often reflected by their behaviour rather than what they say (Cossar *et al*, 2013). All of which places a particular onus on practitioners' to develop the skills and awareness to spot signs of maltreatment rather than relying on disabled children to recognise and report it (Brandon *et al*, 2011; Taylor *et al*, 2014).

Other disabled young people, despite being more able to understand, had difficulty acknowledging the validity of professionals' concerns and/or blamed themselves for their family's problems. Although previous studies with maltreated young people report similar findings (Palmer *et al*, 1999; Cossar *et al*, 2011), these issues seemed exacerbated for young people in this study by their heightened physical or emotional dependence on their parents due to their impairments. This contributed to participants either reacting strongly to professionals' criticism of their families or feeling guilty for raising concerns for their welfare because of how their additional care needs impacted their parents. This highlights the need for practitioners' to be aware that disabled young people's impairment needs can undermine their self-esteem increasing the likelihood they will blame themselves for maltreatment (Herschowitz, *et al* 2007), or result in them feeling they have more to lose by engaging with practitioners and accepting help (Abbott and Carpenter, 2010; Shah *et al*, 2016).

Despite the additional complexities and barriers created by young people's impairments, over half of study participants said they felt relieved that professionals' had noticed their families were having problems and had tried to help. Although there was some evidence that these young people's view of their circumstances had developed over time (Cossar *et al*, 2013), a number also mentioned having raised concern for their own welfare triggering child protection enquiries. This seems to support Taylor *et al*'s (2014) assertion that the barriers to disabled children recognising and disclosing abuse are sometimes overstated, again pointing to the need for practitioners' to improve their confidence and skills communicating with them (Miller and Brown, 2014; Jones *et al*, 2017).

Young people reported receiving a mixed response to reporting maltreatment, however. Although some felt listened to and were reassured by how professionals' had responded, others were frustrated by more weight being given to their parents' views or upset that their concerns remained unresolved. There was also some evidence of parents' and carers' questioning young people's competence to disclose abuse. This suggests disabled young people may be less likely to be believed when they do report abuse (Kvam, 2004). Some participants in this study experienced this as disempowering, which may discourage them from reporting future concerns (Cossar *et al*, 2013). This underlines the need for practitioners' to actively challenge disablist attitudes and advocate on disabled young people's behalf to ensure their equal right to protection from abuse is upheld during child protection enquiries (Jones *et al*, 2017; Franklin and Smeaton, 2018).

Prioritising supportive relationships

It is perhaps not surprising that the quality and availability of supportive relationships was fundamental to determining both young people's experience of reporting maltreatment and their overall view of the help subsequently received as a result of child protection enquiries. Most especially valued the day-to-day emotional and practical support they received from carers' and personal assistants, as well as friends and family members. For example, those who had raised concerns about abuse or neglect, had usually initially spoken to their personal assistant, teacher or member of school support staff. This reflects the findings of earlier studies (Orelove, *et al*, 2000; Taylor *et al*, 2014), and highlights the need for all those coming into regular contact with disabled young people to receive awareness training regarding their increased risk of maltreatment and how to encourage young people to share their concerns (Jones *et al*, 2017; Franklin and Smeaton, 2018).

Many young people also viewed their relationship with their social worker as an important source of support and help with several mentioning them among those they would turn to if they had a problem. The qualities young people particularly appreciated were feeling that their social worker cared about them, took time getting to know them, and could be relied upon to listen and respond to the issues that were important to them. Although this reflects the findings of similar research (Cossar *et al*, 2013; Sanders *et al*, 2017), it was additionally important to young people in this study that practitioners' understood their impairments and how these affected them, their families and daily lives. For example, one young person (Jon) particularly valued his social worker's help to address bullying at school that was related to his autism.

By contrast young people disliked practitioners' who they felt were narrowly focused on addressing the risks to their welfare identified during child protection enquiries and showed little interest in what life might be like for them as a disabled teenager. Participants' differing experiences demonstrating both the value of practitioners' taking time to build supportive relationships with disabled young people and the missed opportunities for engagement, not to mention the denial of rights and agency, associated with practitioners' all too commonly reported failure to consult disabled young people directly regarding their support needs (Ofsted, 2012; Taylor *et al*, 2015).

The importance of supportive relationships was especially highlighted where professional concern during child protection enquiries focused on how young people's impairment needs were being met. This was a difficult situation for young people, which without appropriate support they often experienced as stigmatising, particularly where professionals' adopted a medicalised or deficit approach to their impairments (McLaughlin, 2014). For example, one young person found her parents' and professionals' preoccupation with her personal hygiene especially invasive in a way that would likely have been seen as unacceptable had she not been disabled (Shah and Priestley, 2011).

Another young person, by contrast, despite experiencing similar issues, described feeling empowered by her social worker helping her and her Mother renegotiate her care routine using a written agreement, based on what the young person herself felt she needed. This highlights the need for social workers to address sensitive issues relating to young people's impairments in a way that helps them feel less responsible for their family's problems and develop a sense of confidence that they have the same rights to self-determination and to have their needs met as other young people (Curran and Runswick-Cole, 2014).

Where young people spoke positively about their social worker this was underpinned by a trusting supportive relationship that had built up over time based on regular contact. This was crucial to enabling young people to develop a sense of practitioners' "being there", albeit sometimes in the background, but able to respond when required. Whereas, participants whose contact with practitioners was inconsistent or who had experienced several changes of social worker tended to have little trust in their ability to understand or respond to their needs.

Young people's need for consistent relationships reflects the findings of many other studies with vulnerable populations (Sanders *et al*, 2017; Franklin and Smeaton, 2018). It also has important implications for resources and the way services are organised, since practitioners' report high caseloads and pressure of time as preventing them from forming meaningful relationships with young people (Taylor *et al*, 2014; Kelly and Dowling 2015). Disabled young people's longer-term support needs and the additional time and skills required to get to know them would also appear to be an argument in favour of specialised disabled children's workers or teams (Taylor *et al*, 2014). This is particularly so given that most participants in this study's positive relationships with social workers had been established or had continued after child protection enquiries had ended.

Working in partnership with families

Practitioners' being able to work collaboratively and in partnership with their parents, caregivers and families was also an integral part of providing effective help for young people following child protection enquiries. This meant being able to recognise and support their family's strengths and the ways they were trying to cope as well as addressing the risks to their welfare. Many participants were experiencing a high level of need and/or complexity in relation to their impairments, and it was important to them that practitioners' acknowledged the ways their parents' supported them and advocated for services on their behalf.

This underlines that practitioners' need to take into account the additional stress associated with bringing up a disabled child (Cousino and Hazen, 2013), the disablism families experience trying to access services and social support (Jarrett *et al*, 2014) as well as the factors associated with resilience (Patterson, 2005; Grant *et al*, 2007). It also points to the value of family-based approaches in child protection practice with disabled young people (Truesdale *et al*, 2006), one "that honours and respects their values and choices and which includes the provision of supports necessary to strengthen family functioning" (Dunst *et al*, 2007, page 370). For example, several participants were receiving support from a grandparent or another family member to help meet their needs or provide substitute care, which in some cases had prevented a need for the young person to come into care.

The need for an ecological, whole family approach to maltreatment involving disabled young people is further indicated by the complex difficulties many participants' families were facing, of which young people's impairments were often only a part (Morris, 2012). Many appeared to be experiencing particularly high levels of economic and social disadvantage and a few young people mentioned their families receiving practical or financial as well as social support as having helped them to cope. Some participants with disabled family members likewise described feeling reassured by their parent or sibling receiving support in their own right. Almost all young people and their families welcomed support aimed at promoting their social inclusion, even where they strongly disagreed with the reasons for the initial child protection enquiry.

Balancing support around impairments with protection from maltreatment

The complex challenges for practitioners involved in balancing support for young people's impairments with ensuring their protection also needs to be acknowledged, however (Kelly and Dowling, 2015). For example, though many young people in this study valued the support they and their families had received, a few appeared overwhelmed by their family's problems and/or did not feel adequately protected despite their families receiving a range of support and help following child protection enquiries, including with their impairments. This highlights the need for practitioners' not to lose sight of the child by allowing their empathy with parental stress to mask or excuse the maltreatment of disabled children, which in itself is arguably a subtle form of disablism, an issue repeatedly highlighted by previous studies (Brandon *et al*, 2011; Taylor *et al*, 2014)

For other young people, their caregivers reported a lack of support for their emotional or behavioural needs related to their impairments or prior maltreatment had contributed to their coming into care or was creating a risk of placement breakdown. In a few cases, an escalation of the young person's behaviour or a lack of suitable foster placements had apparently contributed to their being placed in residential care and/or in a different area from where their birth families lived, echoing the findings of similar studies (Kelly *et al*, 2016). These young people reported finding the resulting loss of connection to their family, friends and other social networks especially hard, highlighting the need to prioritise the provision of early help for caregivers' concerning disabled children's behaviour as well as the recruitment and training of specialist foster carers to limit disruption when they do require out-of-home care (Taylor *et al*, 2014; Kelly *et al*, 2016).

Young people's own view of the support they had received with their behaviour or to recover from maltreatment after child protection intervention had ended varied. Over half had received support from Child and Adolescent Services (CAMHS), and some had found this helpful. However, most saw this support as to do with monitoring their impairment-related behaviour or medication rather than helping them cope with difficult family relationships or abuse. This points to the need for a social not just purely medical model approach to therapeutic support for disabled young people following maltreatment, one that takes into account rather than focuses on young people's impairments (Cooke and Standen, 2002). This is particularly pertinent given that some participants seemed to blame themselves for their behaviour. Several young people also said they preferred to talk to their carers or support worker at school about personal issues, and valued therapeutic support being provided in a way that gelled with these other relationships and aspects of their lives, further demonstrating the need for an integrated and child-centred approach to supporting disabled young people following abuse (Franklin and Smeaton, 2018).

This study also indicates that disabled young people's support needs following abuse or neglect are largely the same as other maltreated children (Jessiman *et al*, 2017). For example, participants who were in care, despite most feeling that this had been necessary for their protection, struggled with a deep sense of ambivalence about living apart from their birth families (Schofield and Thoburn, 1996) and emphasised their need to maintain a connection with them. This underlines the need for practitioners' to promote appropriate contact between disabled children and members of their birth families, and complete life-story work with them, tailored to their impairment needs, to help them understand the reasons why they are in care and reduce the likelihood of them blaming themselves (Fahlberg, 2012).

Encouragingly, most young people who were living in care in this study reported very positive relationships with their caregivers, though, in some cases there was evidence that their sometimes very challenging behaviour was threatening to undermine their current placement. This suggests that therapeutic practice approaches based on attachment theory, such as the secure base model (Schofield and Beek, 2009), may be beneficial in helping to improve placement outcomes for disabled children in care. This is particularly given evidence that disabled children are at increased risk of attachment difficulties (Howe, 2006) and also more likely to experience multiple placement moves than those without impairments (Kelly *et al*, 2016). Greater use of therapeutic approaches to care may also help to mitigate, or even eventually reduce the need for, the sometimes oppressively high levels of surveillance reportedly experienced by participants in this study who displayed sexually harmful behaviour, most likely resulting from abuse they themselves had experienced.

Despite their sometimes, complex needs related to their maltreatment experiences, young people in this study wanted the same things as other young people their age (Wickenden, 2011; Foley *et al*, 2012). As a result, they tended to view support provided by social workers and other professionals following child protection enquiries in terms of its ability to help or hinder their achieving their goals and overcome barriers created by their impairments (Hultman *et al*, 2015). Support to access social and leisure activities, particularly those that provided opportunities to learn new skills, build their social networks and reduce their isolation, were especially valued and helped young people develop a sense of confidence and agency often otherwise denied them (Welch, *et al*, 2014). For a few young people this included receiving residential short breaks, but their view of this support depended on whether they felt it helped meet their need for social inclusion not just their parents' need for respite (Every Disabled Child Matters, 2011).

Conversely young people were frustrated when they felt that their experiences of maltreatment and/or vulnerability associated with impairments were being used to restrict or deny their choices and opportunities due to the perceived risks to their welfare. While, as acknowledged earlier, these are not easy or straightforward issues to resolve, practitioners' have an important role in supporting disabled young people to navigate an appropriate course towards adulthood and build their confidence and resilience (Hughes and Lackenby, 2015). Training for practitioners in the use of mental capacity assessments with young people aged 16-17 may be one way of supporting them to make specific decisions about their welfare (Gratton, 2013). For disabled young people of all ages access to sex and relationships education is also crucial to improving their understanding of risk and helping them to learn the skills required to keep themselves safe (Franklin and Smeaton, 2018).

Implications for theory, research, policy and practice

This section brings together and integrates the study's main findings from the three research questions. It explores the repeated themes highlighted by participants' views of their experiences of child protection processes. This includes the application of these themes to the theoretical perspectives on childhood disability outlined in chapter 1. The discussion also draws on the findings of previous research with disabled children, as well as non-disabled children's views of child protection processes, re-affirmed by the experiences of participants in this study. Suggestions are made about how the insights gained can be usefully applied to child protection practice with disabled young people and their families.

Same, same but different

This study has made an important contribution by highlighting how the needs of disabled young people who experience child protection processes are in many ways similar to those of their non-disabled peers. This is in terms of the difficult and intrusive nature of child protection enquiries and the fears young people commonly experience for themselves and their families as a result (Woolfson, *et al*, 2011). Participants spoke of their struggles and frustrations contributing to adult oriented decision-making processes and their difficulties coping with the consequences of maltreatment (Bell, 2002; Cossar *et al*, 2014). These findings highlight that, despite childhood studies' emphasis on agency and rights, the focus in child protection remains on evidencing children's vulnerability as a justification (albeit sometimes necessary) for intruding into the usually private sphere of family life (Fox-Harding, 1991). Likewise, practitioners' frequent failure to adapt child protection processes to children's needs reinforces their subordinate status in relation to adults, and privileges their right to protection over their other human rights (Hammarberg, 1990; Holland and Scourfield, 2004). All of this underlines practitioners' need to be sensitively attuned to the emotional, and often disempowering, impact of child protection enquiries and their aftermath on all children, regardless of impairment (Schofield and Thoburn, 1996).

Despite these similarities, a recurrent theme in study participants' accounts was the added complexity created by the presence of impairment alongside suspected maltreatment, and the impact this complexity had on their experience of child protection enquiries. This complexity operated at multiple different levels in participants' lives. This ranged from the impact their experiences of impairment and maltreatment each had on their everyday lives and sense of self, their experiences of family and caregiving (Howe, 2006), as well as how both were mediated by the availability or otherwise of social support (Welch *et al*, 2014).

It was also apparent how impairment and maltreatment each required practitioners to have different but complementary knowledge and skills in order to respond effectively to disabled young people's needs and those of their families during child protection enquiries (Taylor *et al*, 2014; Kelly *et al*, 2016). What was also clear, however, were the different ways in which the social constructions of disability as well as childhood influenced participants' experiences of safeguarding practice (Kelly and Dowling, 2015). The experience of being perceived by professionals as lacking competence and agency, a result of being both a child and having an impairment, was seen by some participants as a double disadvantage with respect to the weight given to their views in decision-making (Murray and Osbourne, 2009).

Taking an ecological approach

The effect of this complexity on different aspects of participants' lives reaffirms the value of a transactional ecological approach to understanding and responding to maltreatment involving disabled children (Howe, 2006). Such models are already well embedded in child protection policy and practice (Department of Health, 2000; Working Together, HM Government 2018). Concern has been raised, however, about how such models have been applied within an increasingly techno-rational practice environment in childrens social care (Horwath, 2007; Munro, 2011). This specifically includes practice with disabled children, where a deficit approach to impairment reportedly remains prevalent (Sloper *et al*, 2009). This finding is also reflected by the experiences of participants in this study.

This confirms the need to incorporate theoretical perspectives from disability and childhood studies within an ecological systems theory approach. The social model of disability, which has dominated thinking within disability studies, challenges the view that disability resides in the individual, and instead sees the ways society is structured and organised as resulting in the discrimination that disables people (UPIAS, 1976). This is evidenced by the findings of this study, for example, by the restricted opportunities for friendship many participants experienced as a result of attending segregated special schools located at a distance from their homes. It also helps to explain the high levels of social and economic disadvantage among participants' families, which reflect wider trends among families with disabled children (Blackburn, Read and Spencer, 2010).

Policy initiatives which draw on an ecological approach to child development, such as the "Every Child Matters" outcomes (HM Treasury, 2003), have been critiqued within disabled children's childhood studies for promoting ableist notions of a "good childhood" (Runswick-Cole and Goodley, 2011). This dominant cultural view of childhood is also reflected by evidence that some study participants had internalised a negative view of themselves and their capabilities due to their impairments. Thus the findings of this study highlight the need to retain a critical perspective on childhood disability and to celebrate the diversity represented by disabled children's experiences (Curran and Runswick-Cole, 2013), when using an ecological framework to understand disabled young people's experiences.

Notwithstanding the need to carefully consider the contribution of both disability and childhood studies, critically appraising this study's findings within an ecological theoretical framework has several advantages (Bronfenbrenner, 1979). One being that ecological systems theory is sufficiently broad to overcome criticism that neither childhood studies' focus on personal agency, nor disability studies' focus on the structural causes of disability is able to adequately capture the complexity of childhood disability (Watson, 2012). Another advantage is the ability of ecological systems theory to incorporate other more micro-level theoretical developments, without privileging these over other approaches and perspectives. These theoretical developments include the use of Thomas' (1999) concept of 'psycho-emotional disablism' to help explain disabled young people's view of themselves, and the use of attachment theory to help make sense of participants' experiences of maltreatment and loss of connection with their birth families as a result of being placed in care.

The main advantage of ecological systems theory, however, is its compatibility with a critical realist relational approach to disability (Ytterhus, *et al*, 2015). Within this approach, disability is viewed as arising from complex interactions between the individual child with an impairment and their physical, human built, social, attitudinal and cultural environment (Bhaskar and Danermark, 2006). This person-in-environment approach allows connections to be observed and understood between the individual, familial, relational and structural factors that combined to influence study participants' lives and experiences. How ecological systems theory was applied to the study's overall findings is summarised in the sections that follow.

A model for understanding child protection practice with disabled young people

Bronfenbrenner's (1979) four inter-related systems of social influence (micro, meso, exo and macros-systems) are used to capture the study's main findings, as set out in Figure 17. These nested systems represent the context within which child development, impairment and maltreatment take place. Children's experiences within each context are recognised as being mediated by social support, professional intervention and wider structural and cultural factors. These factors include the socio-economic disadvantage and disablist attitudes that interact to influence young people's experiences of child protection practice. To show how these different systems mutually influence one another, each is represented in the model by a dotted line, with two-way arrows between each level.

Each system radiates out from the individual young person in the centre, initially to different micro-systems, which together form the meso-system, the different contexts where young people spend their time and within which most socialisation and identity development takes place. As study participants' primary microsystem contained their caregivers' and family these are prioritised and referred to as 'the care-giving environment' in the figure. Though, for most participants the meso-system also included their school, peer group and other contexts that formed part of their daily lives and influenced their experiences of disability and maltreatment (e.g. grand-parents' home, youth centre, or short breaks unit).

The exo-system, whose influence while less direct being external to the young person, can also significantly influence individual young people's development and life trajectory. For some participants in this study, for example, the social support their families were able to access from wider family, community and professional networks had affected whether or not they came into care. Finally, although participants themselves rarely directly referred to the wider social and policy context of the macrosystem, how the needs of disabled young people and their caregivers are responded to politically and culturally had clearly influenced their experiences and the supports and services they had received both within child protection processes and more generally. In the remainder of this section the study's main findings at each of these different levels is examined in more detail.

Impairment and maltreatment "effects" (Individual ↔ Micro/mesosystem)

It was clear from young people's accounts how their impairments and experiences of maltreatment inter-acted to affect their daily lives and development in complex ways at an individual level. Some of these, what Thomas (1999) calls "impairment effects", were a direct consequence of their impairments. Some participants needed to rely on others for even the simplest and most intimate of everyday tasks, for example, while others had physical or psychological limitations that made it difficult to go out unaided.

Other effects' related to the negative impact their impairments had on how others saw and responded to them, so called "barriers to being" (Thomas, 1999) which in turn affected how young people viewed themselves. Most participants were interested in and wanted the same things as other young people, for example, but described their impairments as variously influencing their family relationships, experiences and opportunities at school, social lives and prospects for friendship.

Social models of disability have tended to emphasise these socially constructed effects of disablism, while downplaying the limitations caused by impairment. However, this study's findings confirm how each of these factors can significantly affect young people's confidence and self-esteem (Connors and Stalker, 2007), as well as their social skills and behaviour (Raghavendra *et al*, 2012). This highlights the need for practitioners' to view disability as an interaction (Shakespeare and Watson,

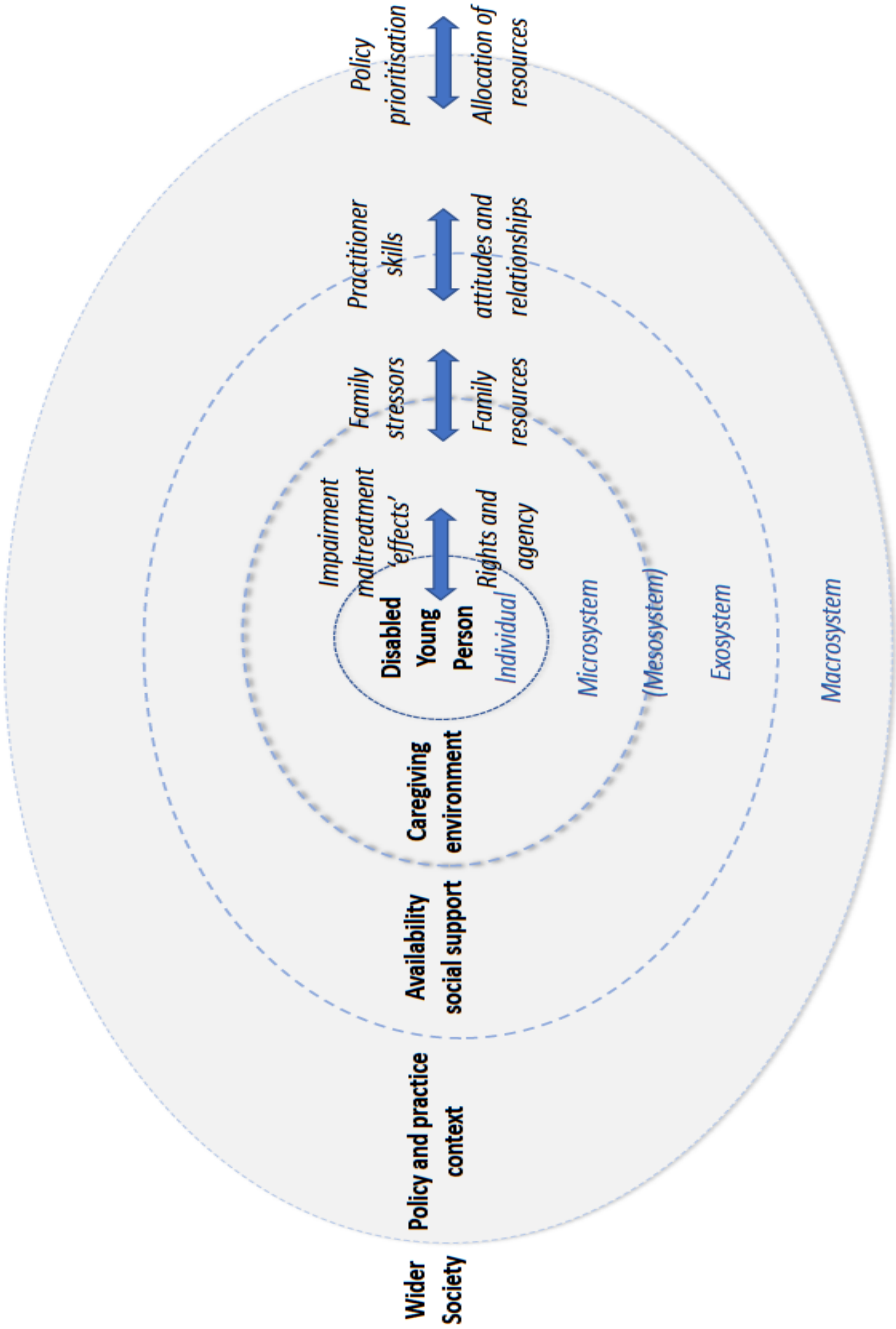

Figure 17: A model for understanding child protection with disabled young people (adapted from Bronfenbrenner, 1979)

2010). Taking this approach to disability requires practitioners' to have both a sound knowledge of child development, as well as building up an understanding of the, often subtle, ways young people's impairments affect them, while not losing sight of the impact disablism and disablist attitudes each have on their lives and experiences.

Participants' experiences of maltreatment similarly appeared to have had a number of 'effects' on their relationships, opportunities and identity; though some were more tangible, while others appeared intertwined with their impairments, at least in how they were interpreted by professionals and sometimes young people themselves. Young people living in care understandably felt ambivalent about being separated from their birth families, an experience that inevitably affected their identity development (Schofield and Beek, 2009). A few participants also seemed to blame themselves for maltreatment, especially where this was seen as related to their impairments. While others spoke of difficulties with managing their emotions and behaviour, which, although possibly related to maltreatment, they themselves and sometimes their caregivers attributed to the effects of their impairments.

This situation seemed partly a consequence of what often appeared to be a deficit or treatment-based approach to young people's behaviour and impairments in general. This highlights the need for more holistic-person centred approaches to assessment and intervention. These findings also affirm practitioners' need to carefully consider attachment theory as a way of making sense of the combined impact of maltreatment and impairment on young people's emotions and behaviour (Howe, 2006). There is a related need, however, for practitioners' to remain mindful of the tendency of psychologically-based theories to individualise explanations of maltreatment and disability. Thus, obscuring the role played by sociological factors, as highlighted by disability studies, in accounting for the difficulties and disadvantage disabled young people often experience.

These findings also indicate that differentiating between signs of maltreatment and impairment related needs is often challenging and perhaps best responded to by practitioners' with knowledge and skills in both child protection and working with disabled young people (Brandon, *et al* 2011). This points to the need for specialist training and close collaboration between child protection, disabled children's teams and others working directly with the young person when maltreatment is suspected (Taylor *et al*, 2014).

Respect for agency and rights (Individual ↔ Micro/meso/exo-system)

It was very important to young people in this study that neither their impairments nor experiences of maltreatment were viewed as a "master status". In essence they wanted to be treated as "subjects, [with rights and agency], rather than objects of concern", to paraphrase Dame Butler-Sloss's seminal statement. This was evidenced by participants' keenness to emphasise their achievements and sense of self-efficacy, often combined with a resilient and resourceful determination to find ways of coping with their impairments and family difficulties. This emphasises the need for practitioners' to view disabled children as competent social actors and challenge disablism, (Curran and Runswick-Cole, 2014) by developing the confidence and skills to work alongside them to establish young people's own view of their support needs during and following child protection enquiries (Taylor *et al*, 2014)

Many participants described feeling especially frustrated by the lack of opportunity to express their views or be supported to take part in decision-making, echoing the findings of previous studies (Franklin and Sloper, 2009). This was particularly where they felt more weight was given to adults' views. This underlines the importance of practitioners' adopting a children's rights approach by adapting their practice to take account of young people's impairments and address the power balances inherent within child protection processes (Cossar *et al*, 2014), by providing access to independent advocacy especially as study participants who had advocates viewed them very positively.

Young people were likewise frustrated by the restrictions to their right to self-determination in other areas of their lives created by their perceived vulnerability or risk due to their impairments or prior experiences of maltreatment. This highlights the complex tensions involved for practitioners and caregivers achieving an appropriate balance between promoting young people's autonomy and independence and trying to promote their wellbeing. While this includes protecting them from further abuse or exploitation, the findings of this study suggest that disabled young people need to be allowed opportunities to develop the confidence and skills to keep themselves safe through appropriate sex and relationships education (Franklin and Smeaton, 2018) and learning to take risks within safe boundaries. For older young people this might include sensitive use of mental capacity assessments, rather than denying young people the right to make decisions themselves.

Family ‘stressors’ and Family ‘resources’ (Individual ↔ Micro/meso/exo-system)

Similar themes of complexity and attempting to cope under difficult circumstances were echoed in young people’s experiences of family and caregiving relationships. Many young people described feeling especially close to their caregivers, partly as a result of their impairment needs. Relationships with caregivers were equally a source of stress, however. Though this is partly to be expected during adolescence (Coleman, 2011), for some participants these tensions, usually related to the young person’s behavioural difficulties, threatened to destabilise their current living arrangements.

It was often hard to be sure whether these young people’s emotional and behavioural difficulties related to their impairments, experiences of maltreatment or both (Howe, 2006). This study’s findings nevertheless reiterate the need for early help, including therapeutic approaches to care based on attachment theory to be provided to caregivers of disabled children to enable them to help disabled young people manage their emotions and behaviour (Schofield and Beek, 2009). This is particularly needed to help prevent the need for young people coming into care, or for their attachment difficulties to be further heightened by instability within the care system, itself partly related to structural disadvantage, reflected by the lack of priority given to recruiting foster carers able to meet disabled children’s needs (Kelly *et al*, 2016).

Many participants’ families were also experiencing a range of other difficulties aside from their impairments, which had also contributed to stress and complexity in family and caregiving relationships. A high proportion of participants were living with single parent caregivers and/or in households where none of the adults worked. Many participants had disabled parents and/or siblings, creating an overall picture of very high levels of need among participants often within a poorly resourced environment. This reaffirms the relevance of the social model to understanding the social and economic marginalisation that families of disabled children frequently face (Howe, 2006; Watson, 2012).

Nevertheless, it was also very important to young people that practitioners’ acknowledged their family’s strengths as well as their needs. A notable number of families had, for example, managed to mobilise support from extended family and other social networks to help them to cope. This study’s findings therefore confirm the value of strengths-based and whole family approaches to child protection practice with disabled young people (Truesdale, *et al*, 2006; Morris, 2012). It also suggests a role for family systems theory in helping practitioners' to understand how families develop resilience in response to childhood impairment and other challenges and the support needed to help them achieve this (Carpenter, 2010). Such approaches may perhaps, help practitioners' to address the central question in assessing disabled children's needs, namely: "Does the family (or caregiver) have, or can they acquire, the needed resources and coping behaviours for managing their ongoing demands" (Patterson, 2005, p. 1019) and care for the child or young person safely? Not an easy or straightforward question to answer, but one that may at least help practitioners' remain focused on the young person's welfare and avoid over-empathising with caregivers in the context of impairment related family stress, as appeared to be the experience of some participants in this study and as highlighted by previous research (Brandon *et al*, 2011; Taylor *et al*, 2014).

Practitioner skills, attitudes and relationships (Micro/mesosystem ↔ Exo-system)

This study's findings confirm social workers' pivotal role in recognising and responding to the needs of disabled children and young people at risk of or who have experienced maltreatment. This is both by cultivating the diverse knowledge and skills required to understand their needs and communicate well with disabled young people directly during child protection enquiries, and where possible supporting their caregivers to address risk and continue caring for them (Ofsted, 2012; Taylor *et al*, 2014).

Young people in this study especially appreciated practitioners who, as well as addressing maltreatment concerns, adopted an enabling approach to their disability, by adapting their practice to support their participation during child protection enquiries and decision-making and securing access to short breaks and other supports aimed at promoting their social inclusion (meso-system) and reducing family stress (micro-system). Conversely young people disliked practitioners who they felt had little understanding of their lives as disabled teenagers. This highlights the need for social workers involved in child protection enquiries to undertake disability awareness training (Jones *et al*, 2017).

Underpinning the examples of good practice mentioned by study participants was a trusting and supportive relationship with their social worker. This reiterates the findings of previous research that regularly spending time listening to young people was crucial to practitioners' developing an appreciation of the complexity of their family relationships (Cossar *et al*, 2014) as well as how their impairments impacted their lives. This underlines the time and skills needed to successfully undertake comprehensive ecologically based assessments (Department of Health, 2000) and the importance of relationship-based practice when undertaking child protection enquiries (Lonne *et al*, 2016). Young people also valued practitioners working alongside other people who were important to them in their meso-system, including their caregivers as well as other professionals and family members. This reaffirms the benefit to young people of multi-agency partnership working (Working Together, HM Government 2018).

Practice and policy context (Exo-system ↔ Macrosystem)

As well as the knowledge, skills and attitudes of individual practitioners', as Horwath (2007) has pointed out, undertaking effective assessments and building relationships with young people depends on a range of other professionals and organisational factors. This is reflected by the less frequent contact and numerous changes of social worker some participants in this study reported experiencing. All of this seems likely to be related to the pressure of time on individual practitioners caused by high-caseloads, related to the way social work teams are organised and resourced, as mentioned by some participants' caregivers and by previous studies (Taylor *et al*, 2016).

Supportive relationships and practitioners' having a detailed understanding of disabled young people and their family's needs, however, do not guarantee the availability of the range of resources required to meet them (exo-system ↔ macro-system). This is evidenced by some study participants in care living in residential and/or placements at a distance from where their birth families lived (Kelly *et al*, 2016). Neither is disability awareness for practitioners enough on its own to tackle the structural factors underlying both disabled young people's higher risk of abuse and neglect or the social and economic exclusion experienced by many families in this study that contributes to their difficulties coping with their child's impairment needs.

This underlines the need for greater policy prioritisation and commitment of resources at national and local level both to safeguarding disabled young people and supporting their caregivers to continue caring for them whenever possible (National Working Group on Safeguarding Disabled Children, 2016). This is particularly so given the adverse long-term consequences that maltreatment can have on disabled young people's lives and family relationships, as evidenced by the experiences of several participants in this study.

Some ways of achieving this might be through greater participation of disabled young people living in care or who have experienced child protection processes in the planning of service provision (Franklin and Sloper, 2009), political lobbying via disabled people's organisations or through the promotion of social justice perspectives such as recognition theory within disability studies research (McNeilly *et al*, 2015).

Recommendations for policy-makers, service managers, practitioners and researchers

Recommendations for policy-makers

- Prioritise early help services and services aimed at preventing disabled children's maltreatment.

- Further development of policies aimed at addressing disabled children's social isolation and exclusion, including that arising from continuing educational segregation.

- Ensure that any sex and relationships education provided in all schools is accessible and inclusive of all children's needs, regardless of disability or impairment.

Recommendations for managers and service providers

- Recognise the additional time social workers require to establish relationships with disabled children. Arrange workloads to allow practitioners to get to know disabled children and find ways of communicating with them.

- Provide training regarding signs of possible maltreatment for staff coming into contact with disabled children, particularly school-based staff and personal assistants

- Give priority to providing formal support and supporting informal family support to help prevent disabled children from coming into care.

- Prioritise the recruitment and training of local foster-carers able to meet disabled children's needs, to reduce the impact on disabled young people of being placed at a distance from their birth families and communities.

- Build an inclusive approach to participation. This includes providing resources and flexibility within organisations to support the development of creative practice with disabled children and young people.

- Find funding for independent advocates for disabled children, particularly where there is a high level of conflict between parents and professionals, or the young person has complex communication or learning needs.

Recommendations for practitioners

- Be open to discovering disabled young people's view of themselves, their family circumstances and relationships and retain a focus on what's important to the young person. This includes being mindful of the strategies young people may have developed in order to cope with their impairments and their family's problems.

- Ensure disabled young people are provided with clear and understandable information about child protection processes in a manner and format appropriate to their needs. Take into account the dynamics within the family and the emotional impact of child protection as well as the young person's age and understanding.

- Spend time building relationships with disabled young people in order to better understand their needs. This includes providing a range of opportunities for them to express their views and supporting their participation in decision-making.

- Listen to disabled young people's aspirations and priorities. This includes trying to mitigate how their disabilities restrict their opportunities for friendship, to socialise and develop independence.

- Build positive working relationships with disabled young people's birth families and carers, acknowledging their strengths and the need to work in partnership, while not losing sight of young people's needs in the presence of safeguarding concerns.

- Work with both disabled young people and their caregivers

Recommendations for researchers

- Apply theoretical insights from disability and childhood studies in seeking to understand disabled children's lives and perspectives. This includes using participatory methods to enable disabled children's concerns to be placed at the heart of the research enquiry.

- Further exploratory research is needed about disabled young people from black and ethnic minority backgrounds

- The role of fathers and extended family in promoting resilience of families with disabled children and the needs of families with multiple disabled members represent interesting and important areas for future research.

- This study's focus on disabled young people during adolescence means younger disabled children's perspectives of child protection processes remain largely unknown.

Study limitations

This study has given voice to disabled young people who were considered at risk of maltreatment and who had received support via the child protection system, an area that remains largely under-researched (Taylor *et al*, 2016). However, this study's limitations must also be acknowledged. Firstly, the findings of this study reflect the experiences of disabled young people where maltreatment had been recognised and services provided and not those whose maltreatment had remained hidden throughout childhood. This is an important area for future research since disabled young people are under-represented among children who have child protection plans (Ofsted, 2012) but at greater risk of experiencing significant harm leading to a serious case review during adolescence than earlier in childhood (Sidebotham *et al*, 2016). This study's diverse sample had some strengths in that it included disabled young people with a wide range of impairments, some participants from ethnic minority backgrounds and those who had remained at home following child protection enquiries, as well as those living in care. However, the relatively small number of participants with specific characteristics and experiences inevitably limited the inferences that could be drawn from their accounts. Due to its cross-sectional design, this study had limited scope to address the interesting questions participants' experiences raised concerning the longer-term needs of maltreated disabled young people as they move towards adulthood.

Undertaking only one interview with most participants made exploring more sensitive aspects of their lives and experiences more difficult as this provided limited opportunities for establishing rapport and a relationship with them. For example, although the focus was on participant's experiences of services and not of maltreatment, most were understandably reluctant to discuss their views about their sexual identity and relationships, an area of particular discrimination and vulnerability for disabled young people (Franklin and Smeaton, 2018; Berelowitz, *et al*, 2013). However, ethical considerations, given the sensitivity of the topic and the vulnerability of study participants, some of whom still had child protection plans, limited the possibilities of undertaking additional interviews with individual participants.

The use of participatory methods appeared relatively successful in helping to engage young people and allowed them some direction over the topics discussed. Interview materials and activities could perhaps have been improved, however, if the group of disabled young people involved in their design had experience of child protection processes. These materials were also harder to adapt for use with young people with significant communication impairments, despite efforts being made to involve parents and carers to tailor these to these participant's individual needs. Longer term involvement with these young people and the use of participant observation may have helped gain better understanding of their experiences (Wickenden, 2011; Beresford, 2007). However, this was not possible within the limited time and scope of my PhD research.

Undertaking and using interviews with young people's caregivers to supplement and help contextualise young people's accounts was used to help mitigate some of the limitations of their data. Though a similar approach has been employed in much previous research with disabled young people (Connors and Stalker, 2003; Beresford *et al*, 2007; Franklin, Raws and Smeaton, 2015) given the high proportion of participants in this study living with single parent carers on low incomes it would have been helpful to formally gather data information on participants' social demographic circumstances as well. It was also not possible to eliminate risk of bias, or the limitations and ethical issues associated with using adults as proxies (Watson, 2012). Parents and carers' being present or nearby during interviews with young people also inevitably affected the views and experiences they were willing to share. However, many young people valued the supportive proximity of their parent or carer and some would likely otherwise not have taken part in the research.

Relying on the interest and motivation of individual practitioners to recruit participants further limits the scope and general applicability of this study's findings, since these practitioners were arguably more likely to have a positive relationship with young people and be committed to good practice. Though interested participants were sent a summary of the study's main findings, the validity of the study's findings could have further been improved by involving them more directly in the analysis. However, this was again restricted by the sensitive nature of the topic and limited scope of the research.

Despite these inevitable limitations this study represents a hugely important step for me in my own journey from practitioner to researcher. I have learnt a great deal both about myself, as well as about the exhilarating questions and inevitable challenges and steep learning curve involved in developing a plethora of new skills. I feel incredibly humbled by the willingness and enthusiasm of these young people and their families, to share their lives and experiences with me. They have truly guided this study, as well inspired and challenged my development as a researcher. I still have much to learn. However, these disabled young people's messages for practitioners about how they want to be supported during child protection enquiries and their aftermath form the crux of this study, and it is with these that we conclude.

Disabled young people’s messages for social workers about child protection

In a study that set out to prioritise disabled young people’s views it seems fitting to give them the last word. Figure 18 therefore summarises disabled young people’s key messages about how they want social workers and other professionals to support them during child protection enquiries.

Figure 18: Disabled young people’s messages about child protection

Each circle represents a key area where disabled young people felt social workers could help make their experiences within child protection processes potentially less stressful.

We want to be kept informed and involved

Disabled young people want social workers to help them understand what is happening and might happen during child protection enquiries, as not knowing is stressful.

[Young people] *wanna know what's happening, if they're going in foster-care or not going!* Nicola

Disabled young people want social workers to explain things to them in a way they can understand and that takes into account their age and impairments, as too little or unclear information is confusing and upsetting.

I was too little to understand … I feel I worry about her my Mum Nataly

Disabled young people want a chance to say what they think. They want support from social workers and other adults when they find it difficult to express themselves or to get involved due to their impairments, a lack of confidence or their feelings about their families. However, they also don't want social workers to make assumptions about their ability to take part in decision-making because of their impairments.

I find it hard; I do understand some things … I am building up my confidence to ask for help … I am not speaking up well, I am only speaking softly Chloe

My social worker said I was extremely vulnerable … she was basically taking the mick because I am dyslexic and got a few mental problems! Louise

Disabled young people want social workers to make an effort to understand their views and involve them in decision-making in ways that feel comfortable for them. Most find attending child protection meetings upsetting and intimidating and want their social worker to make taking part in meetings easier or find other ways of helping them to feel involved, such as providing an independent advocate or sharing their views on their behalf.

Saying my stuff in front of family and all that it's just too much … so, [my social worker]'s like my messenger … so that way I've got like my say in it Jack

My advocate can get my point of view across, like if I am not invited [to meetings], or I am, and I don't want to go Ethan

Social workers need to:

- Go on training and spend time getting to know me so we can understand each other better
- Be sensitive to how upsetting child protection enquiries are for me and my family
- Help make it easier for us to say what we think and be involved

Box 5 – Informed and Involved

We want to be safe and supported

Disabled young people want social workers and other professionals to notice when they or their family are having problems. Most want social workers to provide help and support, including with their impairments, so they can carry on living with their families. However, they also want social workers and other professionals to take them seriously if they say someone is abusing them and keep them safe if their families cannot.

My social worker tried protecting me, like getting carers in the morning and night
Chloe

I was just happy that [the police] were there [they] helped me get away from the situation at home Liam

Whether or not they can remain living with their families disabled young people want support from social workers to help them achieve their goals. This includes having friends and interests, becoming more independent and staying safe online and in the community, things that they sometimes find more difficult because of their impairments.

Making friends is the challenge, meeting new people as well Jon

I like [my social worker] because she got me into thinking about leaving home and keeping in touch with my friends Chloe

My social worker did sort me out, it was about Facebook Mathilde

As well as help to feel safe disabled young people want support, including from social workers to help them manage their difficult feelings and behaviour related to their impairments, experiences of maltreatment or the trauma of being separated from their families

Its better social workers helping me, it has helped me feel better … but sometimes I have got hurt feelings and I don't know what to do Mathilde

Social workers need to:

- Talk to us about our worries and take us seriously when we say someone is hurting us or not looking after us properly
- Help our families to carry on looking after us whilst also working with other professionals to keep us safe
- Provide opportunities for us to spend time with our friends and get the help we need with our feelings and behaviour

Box 6 – Safe and Supported

We want to have our families included

Disabled young people want social workers to recognise how important their families are to them, even when they have problems, or they are unable to look after them. Young people in out-of-home care want social workers to help them stay in touch with their parents, siblings and other family members.

I wish for my Mum to be here with me right now … I get so angry sometimes even my sisters can't help to calm me down Nataly

Disabled young people want social workers to recognise their family's strengths and the ways they are trying to cope, rather than just focusing on their problems.

[Social worker's] *pick on families like us, when we have got a safe home, we don't get beaten by our Mum, where basically we have got the strongest bond going* Louise

Disabled young people want social workers to support their family's own ways of trying to solve their problems, such as grandparents stepping in to help.

Grandma's in the family, yeah good choice! Mark

Social workers need to:

- Help us keep in touch with our families
- Support our families to solve their problems and acknowledge our strengths

Box 7 – Our families included

We want to be listened to and looked after

Disabled young people want their social worker to listen to their worries and help them feel that their views matter. They appreciate social workers making the effort to get to know them, finding out what is important to them and how their impairments affect them rather than just talking to their parents. It is really important to young people that they feel their social worker is listening, even when they may not agree or be able to give them what they want.

[My social worker] *just sits and listens to my bit and then doesn't say 'oh well I am sure [the bully] didn't mean it' when they definitely do … I didn't think there was much there she could do, and I didn't make her, I just said it was a thing and she said she would look into it"* Jon

It is also important for disabled young people to feel that their social worker cares about them, sees them regularly and does fun things with them as well as asking them how they feel and working with other professionals to make sure they are OK.

"My social worker is always there, like, um, family problems … [he] *talked to the school straight away so they knew, if they felt I was depressed or anything so, yeah helped as much as he could* Jack

[My social worker] is so fun really … she always gets me all about everywhere … she always asks me if I am OK or not Allison

Social workers need to:

- Spend time getting to know us
- Listen to what is important for us and help us with what we say we need
- Work with others to make sure we are OK and have the support we need

Box 8 – Listened to and looked after

We want to be recognised and respected

Disabled young people want their social worker to recognise their impairment needs but also respect their rights and needs as a young person. They want social workers to think about what life might be like for them as a disabled teenager, wanting to fit in and do the same things as other young people but often frustrated and/or hurt by other people's negative reactions to them or their disability.

People always stare [and] I always think "have you never seen a chair before" [and] it makes me really upset when people don't actually see like I am here, so sometimes with strangers they make me feel really invisible Chloe

Disabled young people want social workers to understand their ways of managing their impairments alongside their family's difficulties. They want social workers to respect their rights to make decisions about their own lives as they get older, as long as they have capacity, and support them to develop the skills needed to understand and weigh up the risks involved.

[My social worker] *pushed mum to get masks for when I am cleaning out the animals, because then it will look like I am different to everyone else and when I go to* [college] *if* [my condition] *can't be seen I want to try and keep it like that from strangers … it is a bit of a gamble with animals but I have been fine around them for ages"* Ethan

Social workers need to:

- Recognise how our impairments and our difficult experiences in our families affect us but see us as young people first and foremost
- Respect and support our right to make decisions for ourselves where appropriate as we get older

Box 9 – Recognised and respected

Conclusion

This thesis has attempted to shed light on disabled young people's thoughts and feelings about their experiences within child protection processes. The study confirms that what disabled young people want from social workers during child protection enquiries and their aftermath, as outlined above, is not dramatically different from the needs and concerns identified by non-disabled children in previous studies (Cossar *et al*, 2011). Disabled young people want themselves and their families to be treated with respect and their interactions with professionals, despite inevitably being fraught with tension and emotion, to be grounded in honest, yet sensitive information and communication. They want practitioners to seek to build a relationship with them, to reassure them that what is happening is not their fault, and that all will be done to try and enable their families to continue caring for them, whilst prioritising their safety and welfare.

Participants' accounts, however, also highlighted specific ways in which their impairments impacted on their experiences within child protection processes, their need for information and explanations to be tailored to their impairment needs, but also for practitioners' not to make disablist assumptions about their ability to express themselves and take part in decision-making. Disabled young people frequently expressed a heightened sense of guilt and responsibility towards their families during child protection enquiries because of the way their impairments impacted family life. Many also appeared to lack confidence in contributing to child protection decision-making due to restricted opportunities to be included in decision-making in other areas of their lives. Nevertheless, it was of upmost importance to these young people that social workers and others supported them so that their voices and own view of their support needs could be heard and considered within child protection processes, rather than remaining hidden. Ways that this might be achieved more effectively for disabled children and young people in practice have been highlighted and discussed.

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Appendices