A MIXED METHODS STUDY OF CHILDREN'S SOCIAL WORKERS' DECISION-MAKING RELATING TO FAMILIES HEADED BY PARENTS WITH INTELLECTUAL DISABILITIES

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A mixed methods study of Children's Social Workers' decision-making relating to families headed by parents with Intellectual Disabilities

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People with intellectual disabilities (ID) have faced prejudice throughout history. The evolution of human and civil rights particularly pertaining to individuals with disabilities led to dramatic revision of governmental policy. People with ID are better supported in many areas of their lives. However, as parents, they experience disproportionately high rates of child removal compared to other groups. A three-stage mixed methods approach was used to investigate decision-making by children's social workers (CSWs) in England relating to cases concerning the children of parents with ID (PWID). The aim was to identify the components of decision-making and formulate an empirically-based theory of how safeguarding concerning the children of PWID is considered and addressed. Data was collected from 33 serious case reviews involving children of PWID, a modified factorial survey with 191 participating CSWs, and a series of focus group discussions with CSWs. Qualitative data was analysed using the Framework Method and the Constant Comparison Method, and the quantitative data was fitted into a generalised ordinal logistic regression model. The findings indicate that a range of factors contribute to decision-making. Families often presented with multiple vulnerabilities rather than ID alone and had complex support needs. Factors featuring to various degrees in decision making include availability of time, specialist resources, and professional expertise; parental engagement and their wider social and familial relationships; and children's resilience and the presence and readiness of their own support and safeguarding structures. The pertinence of parental ID (PID) to CSW assessment appeared to be relative to the other characteristics of a child safeguarding case. In safeguarding scenarios where PID was accompanied by less risky factors, PID increased the likelihood of CSWs making an assessment of higher risk. Where PID presented alongside more overtly risky factors, it did not contribute significantly to a higher assessment of risk. The study concludes that discriminatory practice by CSWs towards PWID does not appear to be a direct factor in the removal of children.

A mixed methods study of Children's Social Workers' decision-making relating to families headed by parents with Intellectual Disabilities

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CHAPTER 1

Introduction

1.1 Chapter overview

People with intellectual disabilities (ID) have a complicated history in England, characterised by discriminatory practices and limited understanding that have been subject to relatively recent formal revision. In this thesis the contemporary circumstances of people with ID and their parenthood is explored in the context of the professionals working in the best interests of their children, children's social workers (CSWs).

This chapter serves as a means of introduction, tracing the evolution in policy towards people with ID, the nascent provisions made specifically for their position as parents, their history, and legal protections. Parents' experiences of parenting are briefly reviewed, outlining indications that prejudicial treatment by professionals working with parents with ID (PWID) remains, jeopardising the fulfilment of their family lives. An overview of parenting training and support programmes is given, showing that challenges persist despite considerable efforts to find ways of ensuring children are parented safely.

However, the interactions between parents and professionals do not exist without a climate encapsulating the professionals themselves. In addition to the difficult societal history of people with ID to which professionals are also party, their working environment and its impact must be considered. An introduction to children's services in England is given, including an overview of literature relating to risk assessment by CSWs. Risk assessment appears to be fraught with obstacles inherent to the work itself, and shaped by the systems in which CSWs are accommodated.

Having located yet unanswered questions through a series of focused reviews, this thesis aims to fill the gaps identified by providing insight into the decision-making processes of CSWs working with these families. The "Dual Process Model" with its

emphasis on the use of heuristics in uncertain decision-making, as CSWs do on a regular basis, is used as a framework upon which the components of decision-making can be placed. These components are found and explored using a range of mixed methods. In the following chapters, the use of qualitative and quantitative inquiry and their subsequent findings form the basis of an empirically-based theory of CSWs' decision-making relating to families headed by PWID. In doing so, the question of "how CSWs assess cases concerning the children of PWID" is answered.

1.2 People with intellectual disabilities

ID, also referred to as "learning disability" and "learning difficulty" (Holland, 2011), is used in this study to indicate "the presence of a significantly reduced ability to understand new or complex information, in learning new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development." (Emerson and Heslop, 2010, 1).

ID may originate from a range of antenatal, perinatal, and postnatal causes, such as Down's Syndrome or Fragile X Syndrome; oxygen deprivation causing cerebral palsy; or meningitis, or accidental and non-accidental brain injury, respectively. The International Classification of Diseases states that "detailed clinical diagnostic criteria … cannot be specified for mental retardation … because the two main components … namely low cognitive ability and diminished social competence are both profoundly affected by social and cultural influences" (WHO, 1993). Determining the cognitive ability of a person with ID is guided by Intelligence Quotient (IQ) and its corresponding estimation of mental age (WHO, 1993):

IQ range	Severity of ID	Mental age (years)
50-69	Mild	9 – under 12
35-49	Moderate	6 – under 9
20-34	Severe	3 – under 6
Under 20	Profound	Below 3

IQ can give an indication of the degree of ID but does not reflect the specific needs or abilities of individual people. As such, the labels guide decisions about support and as a framework for service planning and delivery. The divisions between the groupings are blurred and there is “no clear cut-off point between people with mild learning disabilities and the general population” (Holland, 2011, p. 1). Often people with mild ID are undiagnosed and the term, ID, covers a wide range of individuals.

1.2.1 *History of people with ID in England*

The eugenics movement was founded in the 19th century by Sir Francis Galton. The term ‘eugenics’ was used to describe the “science for the biological improvement of the human race” (Garver and Garver, 1991, p. 1109). This was based upon the belief that physical, mental, and moral traits were inherited and that human progress depended upon “improving the selective transmission of the population’s hereditary endowment to future generations (Garver and Garver, 1991, p. 1109). This could be accomplished through positive eugenics, whereby those with desirable characteristics are encouraged to “breed early and frequently”, or negative eugenics which “discouraged those manifestly unfit from breeding to prevent dysgenic effects upon society” (Antonak et al., 1995, p. 316). People with what is now known as “intellectual disability” were then considered to be “mental defectives”. Through the prism of eugenics, the perceived link between mental defectiveness and criminality led to these people being seen as “genetically tainted … [and] should be both separated from society, and prevented from reproducing” (Hall, 2008, p. 1006). This was accomplished through policies of sterilisation, institutionalisation and segregation, and protection and prevention of harm to people with ID.

The 1950s and 1960s marked a significant change in how ID was understood, leading to a transformation in services for people with ID. It marked the end of blanket institutional care and the dawn of care in the community (Bouras and Holt, 2004, p.

291). This was due to research leading to greater understanding of the extent to which people with ID could learn, challenging traditional assumptions about the limited capacity of people with ID to acquire new skills (Hall, 2008). This coincided with the development of the normalisation principles, beginning as a Scandinavian concept whereby normalisation was a "relatively simple pragmatic alternative to institutional care" (Alaszewski and Roughton, 1990, p. 22). Within this, normalisation meant "making available to mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life in society" (Nirje, 1980, p. 33). These concepts gained proponents in the US and found salience in England in the 1970s when scandals regarding the treatment of people in institutional hospitals emerged, prompting dramatic changes in policy (Chappell, 1992). In the wider context of civil and human rights movements, great improvements in integration, participation, inclusion, and choice for people with ID have taken place (Bouras and Holt, 2004).

1.2.2 *People with ID experiencing parenthood*

Evolution in the understanding of ID has meant that in England, people with ID became more likely to experience the "normal" patterns of life experienced by everyone else. They are more likely to live in ordinary places, do ordinary things, and be around "ordinary" people. Support options include community-based services, supported living, and remaining to be cared for at home. In sum, their autonomy is promoted. People with ID are now more likely to experience relationships, intimacy, pregnancy, and parenthood. Despite this, enduring ideas about people with ID and society's difficulty accepting their wanting to experience these dimensions present a significant challenge to their fulfilment (Brown, 1994; Williams and Nind, 1999; Malacrida, 2009).

1.2.3 *Legal entitlements to parents with ID*

The changes in how people with ID are understood by society and the state have been fed by and have contributed to the development of human rights. These are the

inalienable rights held by every person on the basis of their being human. There are several human rights instruments but those of particular relevance to PWID in England are:

1) The Universal Declaration on Human Rights (1948)
2) The Convention on the Rights of Persons with Disabilities (2006)
3) European Convention on Human Rights (1950)
4) Human Rights Act (1998)

These establish a range of entitlements applicable to PWID, outlining the responsibilities and obligations that are owed to them. The Universal Declaration on Human Rights places obligations on the state and society to support the integrity of the family unit, to refrain from arbitrary interference, and to provide support in the event of disability (Art.12, 16, 25).

The Convention on the Rights of Persons with Disabilities outlines rights specific to the family lives of persons with disabilities. Article 22 (1) states that “no person with disabilities … shall be subjected to arbitrary or unlawful interference with his … privacy, family …”, while article 23 (1) states that “States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children … and the means necessary to enable them to exercise these rights are provided;
(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.”

Article 23 (2) further cements the parenting rights of persons with disabilities, protecting their parenthood, stating that “States Parties shall render appropriate

assistance to persons with disabilities in the performance of their child-rearing responsibilities". Further to this, Article 23 (4) states that "States shall ensure that a child shall not be separated from his or her parents against their will, except when … such separation is necessary for the best interests of the child … In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents".

1.3 Parents with ID

Government policy in England also reflects how understanding of ID has evolved. There are now policies intended to uphold the rights and support for people with ID in everyday life as well as in parenthood.

1.3.1 *White papers, policy, and good practice guidelines*

Significant changes in legislation relating to people with ID began in 1970 with the Education Act (1970), ensuring that education was provided to all children regardless of disability. In 1971 the White Paper, *Better Services for the Mentally Handicapped*, set an agenda for change for the following two decades. This meant increasing services in the community, reducing the number of places in hospital, and emphasising the close collaboration between health, social services, and other local agencies. Since 1971, there are now fewer large institutions, expanded community care, more people with ID in work, and self-advocacy and citizen advocacy movements have gained prominence (DH, 2001). In 2001 the *Valuing People* strategy was introduced and revised in 2009 with *Valuing People Now*, setting out priorities in health, housing, and employment. The *Fulfilling Potential* (2012) initiative also aimed to promote independence for people with ID and people with disability in general.

The Winterbourne View hospital abuse cases in 2012 brought the treatment of people with ID in institutionalised care and the general treatment of people with ID back into the forefront. It prompted a further drive towards reduced institutional care, increased

care in the community, and lead to the establishment of the Learning Disability Programme Board (LDPB). The LDPB works to improve health and wellbeing outcomes for people with ID and their families in conjunction with *Transforming Care*, a revised health and care delivery programme intended to re-haul care for people with ID and/or autism who have a mental illness or whose behaviour challenges services (HM Government, 2015).

Alongside the movement towards better care and treatment of people with ID in general, their experiences of parenthood and the quality of the support they receive has been subject to greater scrutiny. The Department of Health and the Department for Education and Skills published good practice guidance for working with PWID (DH and DfES, 2007). This provides instruction on how adult and children' services should work together to improve support to PWID and their children. In the same year the House of Lords and House of Commons Joint Committee on Human Rights published a report on the human rights of adults with ID. The report, based on concerns that children of PWID were more likely to be removed from their parents' care than children of parents without ID, considered the inherent human rights violations if this were the case. It raised concerns about the lack of measurable targets for improving support for parents; limited dissemination of the good practice guidance; limited planning for improved advocacy for parents; and the weakness of monitoring mechanisms for tracking progress of initiatives (HoL and HoC, 2007). The Social Care Institute for Excellence also published guidelines on supporting parents with disabilities (Morris and Wates, 2007) that included provisions for PWID.

1.3.2 *Parents' experiences*

PWID have been reported to experience a disproportionate level of child removal. This pattern has been observed in several countries and (Booth and Booth, 2004, p.5) the percentage of children of PWID found to be placed outside of their parents' care ranges from 30-50%. A study of 437 care applications initiated by local authorities in a

sample of courts in England found that one in six children subject to care proceedings had at least one parent with “learning difficulties … or … borderline learning difficulties” (Booth, Booth and McConnell, 2005, p.9). These children were significantly more likely to be subject to freeing orders than those of other parental groups and were significantly more likely to be placed out-of-home and outside of their kinship network.

PWID have been the subject of significant academic interest in relation to their experiences of parenthood, elucidating on themes of pressure, discouragement, interference, removal of children, and limited supports. Parents reported their general isolation, sense of victimisation, low socio-economic status, but also their validation and happiness upon becoming parents (Booth and Booth, 1995; Ehlers-Flint, 2002; Baum and Burns, 2007; Mayes, Llewellyn and McConnell, 2008; Mayes, Llewellyn and McConnell, 2011; Shewan et al., 2012).

Parents reported being pushed to abort pregnancies and felt professionals pressured them into putting controls on their fertility (Booth and Booth, 1995). They received limited support following the removal of their children and upon the removal of subsequent children, would experience cycles of grief and powerlessness (Mayes and Llewellyn, 2012). Parents felt challenged in their parenting roles and further undermined by their general circumstances, usually characterised by social isolation and limited support (MacIntyre and Stewart, 2011). Negative responses from relatives and professionals upon the disclosure of pregnancies and fear of losing their children impacted on parents’ behaviours during service provision, limiting support assessments and overall effectiveness (Hoglund, Lindgren and Larsson, 2012).

Many of these accounts have been framed within the context of the parents’ victimisation, described as “uncelebrated parent[s] … caught in the child protection net” (Booth and Booth, 2006, p. 94). It is frequently explained that ID is the basis for parents’ negative experiences due to “prejudicial assumptions held by many practitioners” (Booth and Booth, 1995, p. 30) or that systems were incompatible with

their needs (Booth and Booth, 2005). The result is that parents receive “rough justice” due to the “expectation of [their] parental inadequacy” (Booth and Booth, 1995, p. 81) and the presumption of their “high risk of parenting breakdown” (Booth and Booth, 1996, p. 81). Parents also felt they were unfairly scrutinised due to their ID (Baum and Burns, 2007; Gould and Dodd, 2014).

The “history” of people with ID is still relatively recent and there remains to be reason for ongoing concern over the treatment of people with ID in general. However, the literature appears dominated by particular academic figures and the use of widely accepted but apparently not wholly substantiated accusations of discriminative practices, often used to explain high child removal rates among these families. Whether practitioners involved with child protection decision-making do so based on negative views of PWID, consciously or otherwise, is yet to be established.

1.3.3 *Support and training programmes*

For PWID, support networks have a positive impact - “risks can be reduced when parents have access to … family and social support … and professional support” (James, 2004, p. 31). Mothers with ID who have limited support have been found to be more likely to have their children removed than those who have had greater support (Aunos, Goupil and Feldman, 2005). Providing support early in parenthood lessens child protection concerns, boosts parents’ confidence, and enhances parenting ability (Ward and Tarleton, 2007; DPPI, 2012). Despite this, absence of appropriate support in addition to child wellbeing concerns is cited as cause for child removal in cases concerning PWID (Tarleton, Ward and Howarth, 2006). A review of support provision for parents with disabilities in England found that services were inflexible, inaccessible, and did not comprehensively assess families’ needs (Goodinge, 2000).

Support can be sorted into two types – those designed to strengthen supportive social relationships and those that teach parenting skills (Wilson et al., 2014). Work in this area has produced diverse studies into the effectiveness of various approaches, such

as parenting groups (Heinz and Grant, 2003) and informal learning (Llewellyn, 1997), at-home interventions (Feldman, Sparks, Case, 1993; Llewellyn et al., 2002; Mildon, Wade and Matthews, 2008), tools to assess parents' emergency responses (Tymchuk, 1990), home-safety awareness (Tymchuk et al., 1992), and capacity to report child illness (Tymchuk, 1992), child interactional training (Tymchuk and Andron, 1992), training for mothers with ID to care for children with developmental delay (Tymchuk and Andron, 1988), self-instructional materials (Feldman and Case, 1997, Feldman, 2003); and affection and responsivity training (Feldman et al., 1998; Glazemakers and Deboutte, 2012).

These studies have been subject to periodic review and the findings do not indicate conclusive evidence of intervention efficacy. Feldman (1994) found that the most common instructional approach was behavioural and while initial training, follow-up, and social validity were encouraging, generalisation and child outcome data were weak. This is a recurring theme; a later review found parent training programmes to be in their "infancy" and requiring further research (Hur, 1997, p. 147). A Cochrane review of randomised control trials (RCTs) of parent training interventions where the outcomes of interest were intervention-specific parenting skills, safe home practices, and understanding of child health, found that the three studies that met inclusion criteria indicated improved parenting post-training. However, the evidence quality was moderate to low with limited information to assess bias. They concluded that while evidence seemed promising, larger RCTs would be needed before conclusions could be drawn about effectiveness of training for PWID (Coren et al., 2011). A further systematic review included interventions to strengthen social relationships as well as taught-parenting skills (Wilson et a.l, 2014). Evidence from relationship-centric interventions was inconclusive due to limited generalisability despite positive changes. Evidence for parental training suggested behavioural interventions were more effective

than less intensive measures, such as lesson booklets and provision of normal services, though these were also subject to limitations.

1.4 Children's services and child protection in England

The role of children's services is to support and protect vulnerable children, young people, and their families. They offer a range of services including family support, services for children with special educational needs and disabilities, looked-after children (those who are "looked after" by their local authority [LA], living in residential care or with foster carers on a short-term or long term basis), and child protection services. Child protection is available when children and young people are at risk of significant harm and need protecting due to issues including physical, emotional, or sexual abuse, and neglect. In these cases, children's services investigate and take action to ensure children's safety and welfare (NHS, 2015). These duties have a legislative basis in the Children Act (1989). Specifically, Section 17 places a duty on LAs to promote the welfare of "children within their area who are in need", and Section 47 whereby LAs must investigate cases where they have cause to suspect a child "is suffering, or is likely to suffer, significant harm" (SCIE, 2012). LAs play a lead role in child safeguarding but every agency that has contact with children and families shares in this responsibility (DfE, 2013), as stipulated by Sections 10 and 11 of the Children Act.

1.4.1 *Assessment and decision-making in child protection*

The subject of assessment and the wider issue of protecting children from maltreatment has been one that has long attracted attention (Parton and Otway, 1995). Interest has come from many sources, prompting "call[s] to action" (Aynsley-Green and Hall, 2008) and review of how children's rights and wellbeing are conceptualised and handled (Jack, 1997; Aynsley-Green, 2004; Reading et al., 2009; Komonis and Dudau, 2012).

A heightened emphasis on a preventative approach to child protection has placed greater interest upon early information sharing and communication between agencies, assessments, and decision-making processes (Parton, 2006). Series of inquiries into child protection practices such as those that take place after child fatalities have been observed to have created a culture of blame where practitioners and policy-makers are forced to act defensively and reactively (Lachman and Bernard, 2006; Mansell et al., 2011). The systems that have resulted from these investigations have been found to be incompatible with the realities of child protection and risk assessment (Munro, 1999). In theory, assessing whether a child is in need and understanding the nature of these needs requires a systematic approach to gather and analyse information about children and their families (SCIE, 2012). However, the process of risk assessment has been likened to assembling the pieces of a jigsaw puzzle (Munro, 1996), whereby social workers must "fit … pieces together to arrive at a picture of a family", starting at a point where the final picture and the pieces themselves are unknown (Munro, 1996, p. 795). Further complicating this is that the verity of each piece is unclear.

Working in inherently uncertain conditions such as these, errors and mistakes in judgements are more likely (Rzepnicki and Johnson, 2005). CSW decisions have been found to be made by balancing the interests of children and wider family members (Bell, 1999; Holland, 2000); managing risk in the interest of maintaining families (Keddell, 2011); working with the views of other professionals (Kelly and Milner, 1996); and estimating parental compliance (McConnell, Llewellyn and Ferronato, 2006). Challenges to accurate decision-making include the use of heuristics (Munro, 1999), and limited access to settings where positive discussion, challenge, and review of assessments can take place between CSWs and their colleagues (Munro, 1996; Munro, 2010).

Means of regulating and ordering assessment through the development of tools designed to capture relevant information have been suggested (Harnett, 2007).

However, these have been found to be used inappropriately in practice, have limited applicability, undermine the development of expertise, and divert attention to implementation of processes and bureaucratisation (Wald and Woolverton, 1990; Holland, 1999; Gillingham and Humphreys, 2010; Gillingham, 2011).

1.5 Conceptual framework

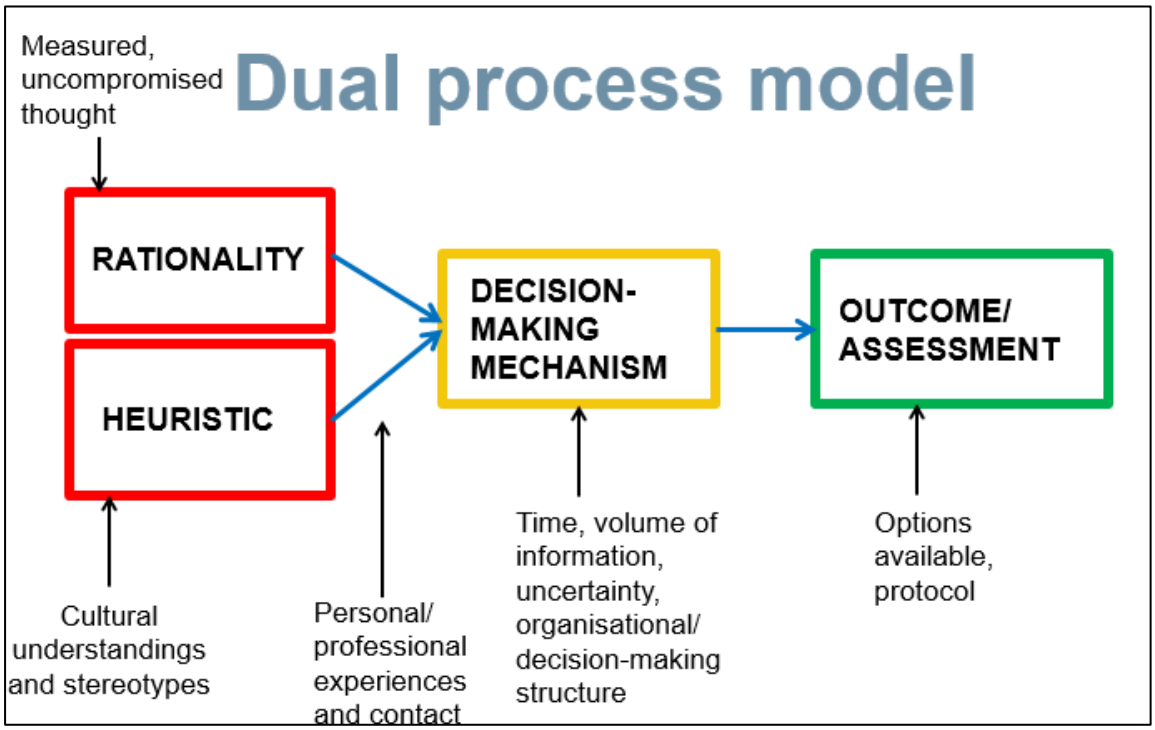
This thesis uses Dual Process theory as a conceptual framework to form the basis for investigation into how CSWs assess cases concerning the children of PWID. The components of CSWs' decision-making are examined using parental intellectual disability (PID) as the key unit of interest within a child safeguarding setting. The findings are used to inform and develop a theory of CSWs' decision-making in these cases.

The dual process theory model stipulates that there are two distinct processes involved in social evaluation. These two processes are characterised by their use of explicit or implicit attitudes. Attitudes that are explicit are "evaluative judgements that are deliberately reported" (Ratliff and Nosek, 2010, p. 721). Implicit attitudes are "introspectively unidentified or inaccurately identified traces of past experience that mediate favourable or unfavourable feeling, thought, or action towards social objects" (Greenwald and Banaji, 1995, p. 5). Implicit attitudes "reflect associative processes that are activated automatically, without intention, upon encountering a relevant stimulus" (Ratliff and Nosek, 2010, p. 721). In the case of this study, PID is the stimulus of interest. The interplay between these two systems are believed to be related (Jones and Jacoby, 2001; De Neys, 2006; Barouillet, 2011) and whether either of the systems is over-ridden by the other results in particular types of decisions.

The implicit system is "fast, automatic, highly contextualised, and largely independent from working memory and general intelligence" (Barrouillet, 2011, p. 80). These default responses and rapidly recalled intuitions are related to heuristic processing, and

"simplify perception, judgment, and action … As energy saving devices" (Macrae, Milne and Bodenhausen, 1994, p. 37). The explicit system is "inherently deliberative … slow, and demanding" (Barrouillet, 2011, p. 80). While this system does not necessitate ignoring heuristic information, "it does imply going beyond such factors to look at the broader constellation of characteristics" (Bodenhausen, 2005, p. 112).

In terms of assessing cases concerning PWID, the extent to which CSWs are able to inform their decision-making by "deliberate", explicit processes first depends on the extent of their training and experience in the area of PWID, and the available information. This is particularly important given the likelihood of falling back on heuristic principles in cases of uncertainty such as in the field of child protection. Unmediated reliance on heuristic processes can lead to severe and systematic errors (Tversky and Kahneman, 1974, p. 1124).



For the purposes of this research, the dual process model is used as a guide with which the components of CSWs' decision-making in cases concerning PWID can be investigated. The study uses a mixed methods design composed of three stages:

1. Secondary analysis of serious case reviews (SCRs) using the Framework Method, of cases where one or both of the parents involved were known or suspected to have ID;
2. A questionnaire-based experiment (QBE) using a modified factorial survey design to examine the effect of a PID disclosure upon assessments made by CSWs;
3. A series of focus group discussions (FGDs) with CSWs to discuss fictional case vignettes where a hypothetical child was involved in a range of safeguarding scenarios under the care of his parents who are suspected to have ID.

1.6 Overview of remaining thesis

This thesis contains 7 chapters and the following section outlines the remaining 6 chapters. Chapter 2 - *Children's social services and parents with Intellectual Disabilities: Secondary analysis of Serious Case Reviews* – presents the SCR analysis and findings. The rationale, aims, methodology are critically discussed and the subsequent themes form the basis of the wider investigation.

In Chapter 3 – *Questionnaire-based experiment: Methodology and findings* - the questionnaire, its methods and results are described. The theoretical framework used in designing this instrument, the study population, and sampling are detailed. The analytical considerations and strategy are discussed and justified. The findings illustrate how the participants would assess cases concerning the children of PWID compared to cases where PID is not disclosed, and how the specific safeguarding scenario affects this decision-making.

Chapters 4, 5, and 6 discuss the focus group discussions carried out with children's social workers. Chapter 4 – *Focus group discussions: Methodology* is used to discuss the methods used for the design and execution of the FGDs. The strengths and weaknesses of the methodology are discussed at length. Chapter 5 – *Focus Group*

Findings: Parental capacity assessment: Information gathering, assessment, and decision-making – presents the first part of the FGD findings. How participants gather information and assess parenting capacity are described. The factors that contribute to their decision-making are also discussed. In Chapter 6 – *FGD Findings: Support, time and resource pressures* – the findings relating to support and services for PWID are discussed. There are two parts – Part A outlines procurement and delivery of services by children's social workers, and Part B outlines the resource and system constraints that affect their practice.

In the final chapter, Chapter 7 – *Discussion* – methods and findings from the study are summarised and set within the existing literature. The conclusion and implications of the study are discussed. Possible considerations for future policy are described, as are potential avenues for further research. The strengths and weaknesses of the study and its use of mixed methods are discussed.

1.6.1 *Ethical and organisational permissions for research*

This study received ethical clearance from the Medical Sciences Inter Divisional Research Ethics Committee at University of Oxford (Ref: MSD-IDREC-C1-2014-024). The QBE component of the study received permission from the Association of Directors of Children's Services (Ref: RGE140128). [For letters of approval, see Appendix 1.]

CHAPTER 2

Children's social services and parents with Intellectual Disabilities: Secondary analysis of serious case reviews

2.1 Chapter overview

In this chapter the aims, objectives, methods and rationale for the serious case review (SCR) analysis phase of this research are described. The findings, and methodological strengths and weaknesses are discussed.

This research stage, the first of three, involved the use of the framework method to perform qualitative content analysis on a selection of SCRs involving the children of parents with intellectual disability (PWID). In doing so, the circumstances in which children's social workers (CSWs) make decisions about PWID and the impact of adding parental intellectual disability (PID) into the sphere of child safeguarding can be better understood. This stage also served as a scoping exercise to inform on how to proceed with the stages of research that followed – the questionnaire-based experiment (QBE) and the focus group discussions (FGD). It provided insight into the working environment of participants and the climate in which they make decisions. Also, the QBE and FGDs both placed participants in hypothetical scenarios, whereas this phase is entrenched in a real-life context. It provides a genuine backdrop against which the rest of the study can be considered.

2.2 Background, rationale, and outline

The practice of children's social care professionals and those involved with the safeguarding of children has been of considerable interest in the UK. This has particularly been the case following series of prominent cases of serious abuse against children resulting in government sanctioned inquiries into the circumstances and the lessons to be learned from these events. Following the death of Victoria Climbié in

2000 and the commissioning and publication of Lord Laming's inquiry in January 2003, a major overhaul of children's services in England took place. This resulted in the publication of a white paper, *Every Child Matters*, in 2003 and the implementation of the Children Act (2004). The white paper outlined a set of aims that children's services were to work to help children achieve, underpinned by a range of structural and organisational, legislative, and administrative changes. One of these was the establishment of Local Safeguarding Children Boards (LSCBs) to oversee the safeguarding duties of councils. A function of LSCBs is that they must publish a serious case review (SCR) following the death of a child when abuse or neglect is known or suspected to be a factor. LSCBs must also consider publishing a SCR when a child is seriously harmed and the case gives rise to concerns about how local professionals and services worked together to safeguard and promote the welfare of children (Department for Children, Schools and Families, 2010). This provides a means for the agencies and individuals concerned to learn lessons and improve how they work individually and collectively to best safeguard and promote the welfare of children (HM Government, 2003). The findings of these reviews are to be disseminated quickly and effectively to ensure that wherever possible, the recommended changes are installed with the aim of protecting children from suffering or being likely to suffer harm in the future.

There is no shortage of review and inspection of child welfare mechanisms. The culture of reflection, introspection, and monitoring of safeguarding practices continues to be driven by high profile reporting of child deaths, the ensuing public and governmental scrutiny, and the constant motivation within child safeguarding agencies to improve practice. The death of Peter Connelly in 2007 led to the publication of *The Protection of Children in England: A Progress Report* by Lord Laming. Recommendations from this report led to the bolstering of the government's official child protection guidance, *Working Together to Safeguard Children*, the establishment

of the Social Work Taskforce, and the Social Work Reform Board. In 2010, the Munro reports, a series of reviews of all child protection procedures in England were commissioned. These reviews set out proposals for social work reform to facilitate the best professional judgements made by social workers to help children and young people suffering from abuse and neglect.

The intention of this research phase was not to replicate the reports and reviews that have already been conducted. Frameworks have already been developed with which the findings from SCRs can be consolidated and built upon to improve services (Brandon et al., 2012; Fish, Munro and Bairstow, 2012). Instead, this phase examines child safeguarding practices through a lens of PID so the addition of PID into the complex arena of child protection could be better understood; the practical implications for the professionals concerned are made clearer; and the significance ascribed by the reviewers to PID can be ascertained.

2.2.1 *Objectives and aims*

This data collection phase set out to achieve the following objectives by first identifying and sourcing SCRs involving the children of PWID and subjecting them to content analysis within the framework approach:

1) Describe the characteristics of the families concerned and the interaction between families and the CSWs involved in their case.
2) Identify the role CSWs play among other professionals involved with families headed by PWID and how PID is addressed in terms of parenting and children's wellbeing.
3) Determine how any issues in the handling of cases that were related to PID were addressed by the reviews.

The circumstances that lead to the authorship of a SCR are diverse and it is not the intention of this research to over-emphasise the pertinence of PID to the cases

included. Also, blaming PID for the outcomes described in the reviews is not the goal. The cases described are illustrations of the most extreme and devastating outcomes that child safeguarding professionals can encounter. As such, these are not exemplary of the cases usually experienced by CSWs who work with PWID, or the lives of families headed by PWID. However, SCRs are rich sources of information about families and service input, and their purpose is to inform and enhance practice by providing lessons to be learned with the view to improve the promotion of children's welfare. Taking these features into consideration, it is appropriate to use these reviews as a resource to examine how issues as specific as PID have been worked with, and pinpoint how reviewers have seen fit for professionals to proceed with these specialised vulnerabilities in mind.

The findings of this stage of data collection serve in addition to those of the other stages, the focus FGDs and the QBE. These findings inform on the circumstances and systems in which CSWs operate, providing further context to the process of making assessments.

2.3 Methodology

2.3.1 *Data Collection*

The database for the National Society for the Prevention of Cruelty to Children (NSPCC) was used to search for and gather the SCRs. The NSPCC has a national case review repository that houses and contains citations for SCRs. Under the guidance of NSPCC librarians, a search was carried out using terms to capture the required reviews. The inclusion criteria stipulated that the review detailed cases concerning families where one or both of the parents were confirmed or were suspected to have ID.

SCRs are formed of two parts, an Overview Report (OR) and an Executive Summary (ES). ORs usually contain more detail than do ESs. For this reason, ORs were preferred as they better suited the purposes of this research. However, until 2010 it was not compulsory for LSCBs to publish their ORs, leading to publication of the ED alone for the majority of cases prior to this date. In the interest of including the widest possible range of cases in the analysis, where ORs were unavailable, the ESs were used in their absence. This results in inconsistencies in the volume of data yielded from each case, which is a limitation that will be discussed at more length in a later section.

60 search results were retrieved, some of the reviews listed were available directly from the NSPCC and those remaining were sought from the LSCB in question. 4 were excluded due to repetition and the remaining 56 cases were checked to ensure they met the inclusion criteria. 34 cases were selected for analysis but it was not possible to retrieve 1 of the cases from its respective LSCB. Finally there were 33 cases, 8 of which were in the form of ORs and 25 were ESs. [For details of the inclusion process, please see Appendix 2.]

2.3.2 *The Framework Method*

The framework method was used to analyse the SCR data. The framework method is a widely used qualitative technique among health and social policy researchers. Developed at the National Centre for Social Research (Richie and Spencer, 1994), it is a matrix-based analytic method that allows for rigorous and transparent data management. The “framework” is central to the method – a thematic framework is developed and used to organise data into key themes, concepts and emergent categories (Richie, Spencer and O’Connor, 2003). The benefit of the framework method is that for data as vast and diverse as SCRs, the framework creates a new structure for the data to be systematically summarised and reduced so the research questions may be answered (Gale et al, 2013).

Using this method, each SCR was subject to a series of analytical procedures, and the products of these were used to form themes. First, the reviews were read and a loose coding framework was used to code specific parts of the data according to pre-established criteria. These criteria were intended to broadly capture information on "family", "service", and "review" characteristics. "Family characteristics" were any items about the individual family members mentioned in the review and how they engaged with the professionals and services mentioned. "Service characteristics" were those describing an action by any agency involved with the family. "Review characteristics" were those that pertained to the recommendations proposed by the review. An Excel document was created for each review, each with three pages to contain each of these types of codes. In doing this, the SCR data was greatly reduced, however, there was still a great volume of data, not all of which was relevant or necessary to meet the aims of this stage of research. The codes were subject to further filtering using a thematic framework [please see Appendix 2b].

The items remaining were only those relating to the families concerned and their service interaction; the actions of the professionals involved with families; and where the review addressed parental ID specifically. From these, descriptive accounts of the families and their experiences were developed, the role of CSWs among the myriad of agencies and how they worked with families was determined, and the extent to which PID was addressed by the reviews themselves was ascertained.

2.4 Findings

The findings from this research phase are limited to cases that met the selection criteria – those that resulted in the death or serious injury to a child where the parent(s) were known to have, or were suspected to have, ID. As such, these cases are not representative of the majority of cases where families are headed by parents with ID. The findings are not exclusive to families with ID, nor are the findings being presented

as directly attributable to child death or injury. The findings are presented as a means of providing insight into a very specific cohort of families, their circumstances, the services with whom they interacted, and the reviews of their cases.

2.4.1 *Families*

There were 33 cases included in this sample. Each case detailed a family, their involvement with various agencies, and the events that lead to the child in question dying or being seriously injured. A general understanding of these cases was developed based on their similarities and differences.

The families were varied and were subject to a number of diverse factors acting simultaneously. Parents did not appear as simply “parents with ID” but there were several elements constantly impinging upon their behaviours and their capacity to parent to varying degrees. This challenged the temptation to view families one-dimensionally as many cases were characterised by multiple vulnerabilities. These included alcohol and substance misuse, domestic violence, various forms of child abuse, housing and financial instability, intergenerational ID, parents’ own histories of abuse, mental health issues, criminality, poor living conditions, and social isolation. Various family members also had their own other forms of disability or long-standing health issues, such as deafness or epilepsy. As such, these families presented as highly complex cases and were engaged with numerous services for lengthy periods of time. Services would often be provided to several family members, including the parents, siblings, and grandparents of the children in question. Children’s social care services were often also involved with the siblings of the children in question.

Extended families featured changeably across the cases. Many of the parents had relationships with their own parents and wider families that were characterised by histories of physical, emotional, sexual abuse and neglect. Many of the parents had been subject to child protection procedures and had been removed from their own

homes and fostered as part of safeguarding measures as children. Some remained close to their families, maintaining contact and sharing housing, though some of these relationships remained to be abusive. These factors affected the extent to which wider family members could and should have been included in safeguarding planning for the children about whom the reviews were written.

Families' engagement with services varied. Their behaviours ranged from outright or aggressive avoidance and false compliance, to active help-seeking, regularly attending appointments, and using services appropriately. The extent to which parents were forthcoming about their general difficulties varied. Explanations for this include families' pessimism about whether services could have a positive impact due to their own experiences of service failure; fear of the potential outcomes of service involvement, such as child removal; or resentment over the perceived intrusion by services. Despite the provision of services, families often fell into a pattern of making small gains and then experiencing drawbacks – oscillating between improvements and declines in parenting quality and children's wellbeing.

2.4.1.1 *Presentation of parental intellectual disability*

The ID status of the parents varied and were described using the terms "learning difficulty" and "learning disability". These formed two almost distinct groups, though in some reviews the terms were used interchangeably. Those who had a statement of Special Educational Needs (SEN) during their time at school, attended special schools, or had not yet received formal confirmation of "learning disability" tended to be referred to as having a "learning difficulty". Others who had been identified to have a "learning disability", were those who had received some form of assessment and may have received benefits and formal supports from Learning Disability services either as a child or young person, or as an adult.

The extent to which the needs that entailed were reflected in the supports they received depended on two factors. The first was determined by how reconciled the parent was with their ID. Some of the parents had experienced extreme bullying and isolation that had led them to be fiercely ashamed or rejecting of their ID status and related services. Some were able to mask their difficulties or presented in such a way that their difficulties were not obvious. The second determining factor was the extent to which the professionals involved were sensitive to the indicators of ID and then their ability to translate this information into suitable services and supports.

2.4.1.2 C*hildren*

The children about whom the reviews were written tended to be of a young age. In the sample, those who were younger tended to have experienced neglect. Those who were older experienced neglect as well as physical and sexual abuse, usually perpetrated by the men living in their households. The sample illustrates the unique vulnerability of very young children in these cases [please see Appendix 2c].

One of the children, Child S (Rotherham, 2011) was both a child and a parent. Due to a range of reasons, she experienced parenthood while still facing a host of risks that heightened her vulnerability as a young mother and a child in her own right.

2.4.1.3 *Mothers*

The mothers in the sample appeared to have a distinct experience of pregnancies and perinatal care. They often presented late to prenatal services and their children were often born prematurely, leaving little time for pre- and post-birth planning. Many of the mothers experienced housing instability, alcohol and substance misuse, and domestic violence during their pregnancies as well as at other times. Mothers tended to experience high parity at a young age, some displaying indications of ambivalence towards their pregnancies, frequently missing appointments, and experiencing difficulties bonding and coping with their children. In several of the cases, the mothers

concealed their pregnancies. Some of the mothers disclosed these sentiments to professionals with varying results. The mothers often appeared to be in relationships with men who were frequently domineering and sometimes had difficulties identifying and prioritising their children's needs.

2.4.1.4 *Fathers and significant male figures*

The fathers in the reviews often had inconsistent or unclear roles in their children's lives. It appears that mothers tended to be thought of as primary caregivers while fathers' positions within their families were largely under-investigated by agencies. Fathers were often not included in capacity assessments and were peripheral to parenting interventions and supports. The fathers often experienced issues with substance and alcohol misuse, emotional difficulties and anger management, violence, and criminal activity.

There were often several men involved with the families in various capacities, including as extended family members or due to their relationship with the children's mothers. The mothers often had relationships and children with multiple men and the children often had contact with men with whom they were not related. The role these men had within the families was largely unconsidered by agencies.

2.4.1.5 *Ethnicity*

In the sample were parents from Bangladeshi and Pakistani communities who appeared to experience distinct obstacles. For parents from these communities, the linguistic barriers could be twofold. Firstly, those who did not speak fluent English would require this consideration to be met, facing potential social isolation where it was not. This would be additionally compounded by the need for simple language as would be required for effective communication with people with ID.

These individuals were likely to experience arranged marriages, living in joint families with in-laws, having wider family networks living overseas, and additional stressors

such as uncertain immigration status. There also appeared to be an inconsistent understanding among relatives of what ID meant for the family member in question. This raises questions of how someone's ID would be considered in the context of marriage and the expectations that entailed, and whether an individual's ID would be disclosed and reasoned prior to arranged marriage and subsequent parenthood. In these cases, possible cultural relativism from the professionals with whom families are involved is important to bear in mind.

In addition to these families, there were those where the parents or children concerned were of mixed heritage. In these cases, it is unclear how this might have affected their experience of parenthood and services. In some of these cases, the children and their parents experienced hostility and estrangement from their wider families.

2.4.2 *Services*

The multi-dimensional nature of the families about whom the reviews were written was often reflected in the number of services with whom they had contact. One of the aims of this phase of data collection and analysis was to identify the role that children's social workers (CSWs) played among these professionals. In doing so, insight was gained into how services interacted with each other and where families were placed between them.

It appeared that most of the professionals involved with the families worked as though they were firefighting – working to respond to immediate issues as they arose. This appeared to stifle their ability to stand back and observe the cumulative effect of events and establish a connection between these and children's overall wellbeing. This focus on the immediate meant that professionals often did not check family members' service history, and where they did, they often failed to meaningfully incorporate what could be learned into their current approach.

2.4.2.1 *Children's social workers*

CSWs are the focus of this study however, what became clear from this phase of analysis was that where CSWs were involved, they represented one of several professionals from a range of agencies. When they were engaged with families, their roles were defined largely by short-term involvement that lasted as long as the children in question were viewed as being in need. Their roles consisted of arranging the necessary assessments and supports, and monitoring families' progress.

The children were usually under the age of two when they died or were injured and the professionals involved with their families were often health visitors, general practitioners (GPs), and midwives engaged statutorily. CSWs tended to be involved with the older children in families. In the case of older children, referrals to children's social care originated from schools or GPs, among others. In both of these cases, CSWs' involvement would have required a referral from any of the agencies already working with the families. For some of the cases in question, for many reasons, these referrals did not take place, and when they did, were unsuccessful. What this meant was that for CSWs to become involved, the hurdle of reaching a point where the other professionals involved felt that CSWs' involvement was required, had to first be overcome. This depended on a range of factors, including the challenges felt by the other professionals themselves – the effectiveness of their engagement with families, their general experience and particular experience of child safeguarding, their awareness of their safeguarding role and those of other agencies, their supervision, and their caseloads.

The CSWs mentioned in the reviews often appeared to be newly qualified and already faced with burdensome caseloads. They were rapidly assigned and reassigned to new cases and had limited time to familiarise themselves with what were often lengthy and complicated cases. This also meant they were less able to form productive and effective relationships with the families with whom they were involved. They also

experienced limited management and supervision, and had limited experience of complex cases and all that they entailed.

2.4.2.2 *Effective multi-agency working*

The diversity of the factors faced by the families detailed in each case often resulted in their involvement with several different types of services and agencies. Each of these have their own system limitations such as administrative difficulties, limited supervision of staff, funding constraints, staff shortages, individual professionals carrying large workloads, and high service demand. The presence of several professionals from a range of various agencies often led to chaotic co-working. This was often due to differing priorities; buck-passing; communication problems; and failure to identify lead agencies. A frequent issue was that agencies would work in isolation. This meant that professionals were blinkered, operating in silos, unaware of the work other agencies were doing, failing to inform of developments or additional vulnerabilities within the families, and sometimes replicating each other's work. There was often an emphasis on short-term intervention, addressing issues as they arose, and closing or de-escalating cases.

Often, the way information was used appeared confused due to inconsistent record-keeping and it sometimes did not inform subsequent actions. In cases where parents had their own high volume of needs, children tended to become overlooked. This could be because parental vulnerabilities were more visible and seemed to be more immediately pressing, such as in cases of domestic violence or loss of secure housing. The presence of these more pronounced needs seemed to have the twofold effect of overshadowing the more subtle presentation of both PID and child neglect.

The absence of necessary agencies from families' service portfolio appeared due to a number of causes. Professionals already involved were not always aware of the specialist services available; specialist services were so rigidly ring-fenced by eligibility

and funding criteria that applications were often unsuccessful; there were numerous "failed referrals" where communication lapses meant referrals were not received; or professionals were so disheartened by series of declined applications that they would not attempt to secure these services. This meant that where necessary services were not secured, the burden of meeting these needs fell to the agencies already involved. This limited their capacity to fulfil their own responsibilities and lead to shortcomings in their work. Various aspects of families' vulnerabilities would be left unaddressed – those relating to both the parents and the children in question.

Adult social care services appeared particularly difficult to procure, and work between these professionals and those working for the children concerned appeared largely disjointed.

2.4.2.3 *Providing services to parents*

Understanding of PID and its assessment was inconsistent across the cases. Where it was acknowledged, the means of assessment and the subsequent support on the basis of parents' ID-related needs were often unclear. A pattern emerged whereby professionals appeared to operate on a superficial understanding of PID. In some cases efforts were noted to simplify wording and general communication to ensure that parents understood what was said. However, sometimes where PID had been noted, professionals' actions did not extend beyond this acknowledgement. Actions to ameliorate the instances where parents were not understanding or were exhibiting signs of their ID impacting upon their parenting were not demonstrated. The problem with this is that where parents are left unable to understand and are excluded from the processes relating to their children, they cannot be expected to make the changes required to ensure their wellbeing.

In addition to this, because of professionals' apparent reliance on superficial indications of PID, there were several instances where they underestimated the

difficulties parents were experiencing. This was either because parents deliberately down-played their difficulties, or were socially able enough for the professionals to down-play parents' difficulties themselves, or the absence of necessary support did not bring about events that provoked a change in approach.

For agencies to view recipients of their services as parents seemed to present a substantial challenge. This was particularly pronounced when a person had previously received services on the basis of their ID, or had received an assessment of their capacity. It was often unclear how these supports and assessments were revised in light of impending parenthood. This was evident when parents had received support from learning disability services as children or young adults and then transitioned into parenthood. The ability for services to adjust their support in response to these changes appeared limited. Instead, services appeared to view parents in a way that compartmentalised their disability rather than addressing their needs holistically. Often this meant that the impact of parenthood on their other vulnerabilities and the effect of their other vulnerabilities upon their parenting capacity was not registered.

2.4.2.4 *Parents' experiences*

Many reviews sought to include families' insights and experiences of the professionals and services, though these attempts were not all successful. Where parents did give their views, they reported feeling that they were not listened to or taken seriously. They often did not understand how they should change their parenting and they were told what to do without any explanation.

Parents felt that while some of their relationships with professionals were positive, they were particularly difficult to build. This was because they felt overlooked in favour of more dominant personalities within their families; or they felt judged, criticised, and without allies. Parents found productive working relationships were further undermined

by the frequency with which the professionals with whom they worked would change and be reassigned.

The issue of recognising PID without meaningfully addressing the person's subsequent needs also arose. This meant that parents felt professionals were aware of their ID to the extent that they would speak to them in a patronising manner while failing to adapt communication appropriately and ensure parents were effectively included.

2.4.3 *Reviews*

The reviews varied in terms of the weight ascribed to PID by the reviewers. The reviews themselves varied but all outlined their aims, "learning points" or findings, recommendations, and many contained an "Action Plan".

PID may not have played a significant role in all of the cases and readers' understanding of each case is dictated by the way in which events were outlined and understood by the reviewers themselves. We do not know anything of families' and professionals' experiences and understanding beyond what has been detailed in the reviews. However, PID is a factor that has the potential to impact upon parenting capacity and it is notable that the degree to which it is mentioned during the reviews varies to such an extent [please see Appendix 2d for table of review characteristics].

The reviews varied greatly in the depth and detail with which PID was described. Its interaction with parenting capacity, environmental factors, and the way it was understood and handled by the professionals concerned was discussed at great length by some. There were many reviews that factored PID into the lessons to be learned from the cases and significant insight was demonstrated by the reviewers about relevant good practice guidelines and academic literature.

2.5 Discussion

Framework analysis of SCRs lead to some key findings. The first of these is the rejection of the notion that families headed by PWID are defined entirely by their ID. The families were far more diverse, facing a multitude of issues besides ID alone. This has implications for the families but also presents significant challenges to the professionals with whom they were involved. The volume of issues confronted by the agencies, some more obvious than others, mobilised these professionals to address particular attributes of families' circumstances. Of these issues, PID may have been relatively easy to overlook. The issue that arises is that while difficulties are seen to, if PID is overlooked, a fundamental cornerstone of effective interaction is missing. When parents are not meaningfully involved in child protection procedures, are not aware of the changes they must make and why, they will not be able to make the improvements required for their children's wellbeing and safety.

This leads into the second finding, wherein multi-agency working is compromised to the extent where the necessary services are not provided and individual agencies are unable to fulfil their particular roles. The result of this is that parents are not provided with the appropriate supports to improve their parenting capacity, without which they cannot be expected to make changes. This also stretches professionals already involved far beyond their capacity, limiting their ability to carry out their own jobs. Working in isolation or without the necessary agency partners leads to ineffective communication and limited information-sharing, agencies working towards different goals, and missing supports being administered by individuals who are not trained to do so. These factors easily translate into what could be a chaotic and overwhelming working environment for those involved.

CSWs were professionals from one of several agencies that were involved with families. Their role consisted of assessing families' needs, arranging services, and monitoring the effect of doing so. Their involvement depended on whether referrals were made to engage them and in many of the cases examined, their roles were

minimal. They tended to be involved with the older children and, when they did so, encountered the multi-agency difficulties described in the previous sections.

The third finding was that the individual reviews accounted for PID differently in each case. It is unclear whether the weight ascribed to ID in each case was correct or appropriate. However, where it had been earmarked as an issue for investigation, it was considered in a way that signified the degree of importance PID could potentially have upon a case. This is important because the purpose of a SCR is to consider all aspects of families' service involvement. Even when PID turns out to not have a great impact on the course of a case, for it to be considered in the first place as an item with the potential to do so is indicative of reviewers' understanding of PID as an issue. The extent to which PID is then carried throughout the remaining review, into its recommendations and action plan is also subject to the interpretation of the reviewers. There is no reason why PID objectively should feature throughout every stage of a review. However, cases where it does not, but there is no accompanying mention of good practice in terms of how professionals and services assessed and accommodated the needs of PWID, give cause for concern.

2.5.1 *Strengths and weaknesses*

The key strength of this research phase is that its findings are entrenched in actual cases and actual professional practice. It reflects how the addition of PID operates within a child safeguarding setting and how it is responded to by professionals. It also provided the opportunity to consider PID on an alternative level – the review - beyond that of professionals and parents. It focused on how PID is understood and dealt with by the bodies intended to improve the practice of systems and the units within them.

In addition to this, the method of analysis chosen – the Framework Method – permitted the data held within each review to be condensed and reduced in volume. In doing so, the "framework" could be applied across the reviews and insights could be generated

from them according to a pre-established set of criteria. The framework method is that it is a deductive approach (Pope et al, 2000). As such, rather than in an inductive process where categories and themes are generated through working with the data, the framework was developed according to pre-defined objectives. This can be seen as a limitation as the findings are constrained by the purposes of the research, as they are outlined in the framework. In working with the data this way, some information remains nested in the data as the framework may not have been sensitive to all that it contained. However, this meets the needs of this phase of research where specific aims were to be met. Also, the mass of data contained within SCRs required a method that permitted and facilitated the analysis to only retrieve and work with what was necessary.

Another limitation is that of the 33 cases finally included in the sample, only 8 were available in the form of ORs, the remaining were only available as ESs, or were unable to be secured from the respective local safeguarding children board. ORs are far more lengthy and detailed than ESs which are deliberately brief. For this reason, ORs were favoured over ESs and where this was not possible, the ESs were included in their absence. This meant that the data drawn from ORs compared to ESs could be uneven as ESs may miss data that would have otherwise been included in an OR. However, ESs were used in spite of this shortcoming because otherwise, the cases themselves would not have been included in the sample simply because of their lacking an OR. Including the cases where only ESs were available allowed the inclusion of a wider range of cases in the sample, capturing greater diversity. This was considered to be more important than the volume of data that was to be yielded from each individual case. This was mediated by using the ORs whenever it was possible to do so, rather than the ESs. Use of either an OR or ES was recorded and considered during analysis.

CHAPTER 3

Questionnaire-based experiment: Methodology and findings

3.1 Chapter overview

This phase required recruitment of children's social workers (CSWs) from six local authorities operating in England and their completion of a short, online questionnaire.

Social workers' decision-making is affected by a wide range of factors including cognitive structure; individuals' heuristics and schema; their personal values; the agency and legislative context; and characteristics of service users (Drury-Hudson, 1999, p. 148). With this in mind, this stage of the project represents the first step in providing an empirical account of the decision-making mechanisms adopted by CSWs when they work with families where the parents have intellectual disabilities (ID). By presenting participants with cases and options in the questionnaire, the aim was to ascertain whether CSWs, using the limited information included in each vignette, assess children to be at greater risk on the basis of their parents' possible intellectual status. The information from this phase was considered in combination with the findings from the other phases of data collection, the focus group discussions (FGDs) and serious case review (SCR) analysis. The findings together form the foundation for an over-arching theory of CSWs' decision-making with regard to parents with ID (PWID).

In this chapter the aims, design, execution, and findings from the questionnaire-based experiment (QBE) are discussed. The theoretical underpinnings of this phase of data collection are described and the methodological strengths and weaknesses are outlined.

3.2 Outline and rationale

The QBE involved 191 CSWs recruited from six local authorities in England. Each participant followed a link to a website where the experiment was hosted in the form of a questionnaire. Upon starting the questionnaire, participants were presented with questions relating to their demographic background, their social care career, and their personal experience of disability. They were then asked to risk assess 9 fictional child safeguarding vignettes. They indicated their assessments by choosing one of a selection of 4 assessment options that they felt best described their view of each case:

The options were:

[1] This situation requires no intervention,

[2] This situation requires an “early help” intervention,

[3] The child is “in need”,

[4] The child is at risk of “significant harm”

All of the participants were shown the same 9 case scenarios, however, the questionnaire programme randomly presented half of the participants a version of the questionnaire with 5 of the 9 vignettes containing an additional disclosure of suspected parental ID (PID), and the other half of the participants were shown a version where the remaining 4 vignettes contained the suspected PID disclosure. This way, the assessments given for the cases where PID was disclosed and for those where it was not could be compared, and the effect of the disclosure on the assessment ascertained. The term, “assessment”, is used in this research to refer to a CSW’s assessment of families’ or parents’ support needs and the level of intervention and urgency that is required from social care actions.

3.2.1 *Objectives and aims*

The intention of this data collection phase was to achieve two main objectives:

1) To determine whether the disclosure of suspected PID affected the assessment given by the participating CSWs.
2) To determine whether the assessment given by participants changed according to which child safeguarding scenario had been depicted when suspected PID was disclosed.

3.3 Questionnaire design

The use of a "questionnaire-based experiment" (QBE) in this research combines the benefits of the survey tradition with those of experimental design – the result is a modified "factorial survey". Factorial surveys are used to determine "the underlying principles behind human judgements (or evaluations) of social objects" (Wallander, 2009, p. 505). This phase of data collection builds upon the methods used by Proctor and Azar (2013) in their study of child protection service worker decision-making.

Within this methodology, participants are presented with vignettes - descriptions of a "constructed world in which important factors are built in experimentally" (Hox, Kreft and Hermkens, 1991, p. 493). These vignettes are systematically constructed using factors thought to be relevant to individuals' judgement process and participants are asked to rate them according to a specified scale. The factors contained within the vignettes are subject to controlled manipulation though participants continue to indicate their judgements using the same assessment scale. Subsequently, the researcher can identify the impact the factor variation has upon participants' assessments.

This type of design is frequently used in social work research to establish the impact of specified case components upon participants' decision-making in social care settings. This has resulted in studies of how social workers' professional assessments are affected by the gender of victims and perpetrators in cases of sexual abuse (Hetherton and Beardsall, 1998), the race and poverty experienced by families under scrutiny (Stokes and Schmidt, 2011), or the conditions under which elder abuse takes place

(Killick and Taylor, 2011). Vignettes were used in all of these studies and their factors manipulated to change the genders, race, or circumstances pertaining to those described. The impact of these changes upon the assessments made illustrates the pertinence of each factor in question. In this research, the factors of study are PID disclosure and the child safeguarding scenarios; and the scale is the 4 point ordinal assessment measure of family needs, for example, early help or significant harm.

3.3.1 *Developing vignettes*

The vignettes included in the QBE were composed of 2 factors of interest – PID disclosure and case scenario.

Following conversations with CSWs prior to the design phase, it became clear that risk pertaining to suspected PID is not fixed but instead differs according to the situation. For the QBE to capture such nuanced decision-making, a wide range of child safeguarding scenarios were tested so that the experiment reflected the types of family situations ordinarily encountered by CSWs and the significance of PID across these could be detected. The risk assessment criteria used by the Children and Family Court Advisory and Support Service (Cafcass, 2012) provided the basis for 9 safeguarding scenarios depicting a 7 year old child living with his parents, both of whom were suspected to have ID, in a diverse range of situations that may present risk to the child.

The suspected PID disclosure is integral to the experiment, permitting insight into the impact of such a disclosure on the assessments. “Suspected” PID was used in the vignettes rather than stating that “the parents are known to have ID” following conversations with CSWs during the design phase. They indicated that in terms of PID, they were far more likely to be presented with cases where parents were either undiagnosed or their needs did not place them within the necessary diagnostic criteria to access relevant support services. Normally these services require the recipient to

have an intelligence quotient (IQ) below 70. This would affect how participants would be able to support families in practice and subsequently how risk would be assessed, ultimately resulting in a different outcome for the child.

For example, a parent with an IQ below 70 would be more likely to access a range of specialised services to support their parenting, and their children's needs would be addressed as a result. Their case would not present as a great concern and would be considered as such by the CSW in question. However, a parent with an IQ of 75 would not be eligible for specialised parental support services. Their child's assessment would reflect that, despite there being a difference of only 5 IQ points between the 2 parents. In the case of the parent with an IQ below 70, their assessment would be led by the security provided by a clear diagnosis and protocol. For the latter, the assessment would be led by foreseen difficulties in support provision. So, for the QBE to capture the continuum of assessments, untied to an "under 70 IQ diagnosis and the prescribed subsequent actions" logic, the "suspected PID" wording was used. The validity of this was confirmed in consultations with CSWs. [For further details of scenario development, see Appendix 3.]

3.3.3.1 *Assessment options*

Rather than providing numerical Likert scales for participants to give their responses to the vignettes, a modified Likert scale was used. Numerical Likert scales are less informative of participants' answers than vignette-based subjective threshold scales because they require interpretation by the researcher to fathom what the participants meant in choosing a certain number (Heine et al., 2002; Van Soest et al., 2007). Instead, marking the intervals on a Likert scale with mini vignettes that each outlined a specific response rather than asking participants to rate their response numerically is more unequivocal and helpful for drawing meaning from participants' answers (Van Soest et al., 2007). In this research, participants were given a range of response options in the form of mini-vignettes that detailed a specific child protection action. In

practice, CSW assessments vary according to the severity of the risk presented to a child and there is guidance on appropriate action to be taken in specific circumstances (DfE, 2013). Using the “no intervention”, “early help”, “child in need”, and “significant harm” options removed the ambiguity about what participants meant and participants also were familiar with and could be guided by the options presented. [For details of assessment options development, please see Appendix 4.]

3.3.2 *Manipulation of vignettes*

The distribution of the QBE and the allocation of vignettes was carried out using the randomisation capability using an internet-based survey software programme (Qualtrics, 2015). This software was used because of the multi-site nature of the research phase and the need to pose minimal disruption to participating children’s services. Qualtrics was chosen because of its randomisation capability, the accessibility and flexibility of its interface, and its collation of data as it is produced.

Each participant was shown 9 vignettes and gave 9 assessments, resulting in 9 observations from each person taking part. Two versions of the QBE were made, each containing the same 9 scenarios – one version included the disclosure in 4 vignettes, the other version including the disclosure in the remaining 5. The disclosure of suspected ID was included as an additional item in the final vignette:

(Seven-year-old child living with both parents) +/- (disclosure) + (scenario)

Participants following the link directed to the website on which the QBE was located, were randomly presented with one of the two versions. [Please see Appendix 4b.]

The random inclusion of the PID disclosure in half of the vignettes presented to participants created two sets of assessments, one where PID had been disclosed and one where it had not been.

Due to this process, the participants each had an equal chance of being directed to either set of vignettes, reducing selection bias (Altman, 1991, p. 1481). Due to the

computerised allocation of the QBE, the randomisation was double blind reducing bias still further (Altman and Doré, 1990, p. 151). The order in which the vignettes were presented also changed to alleviate any bias in this regard (Krosnick, 1999, p. 545).

3.3.3 *Pre-testing the questionnaire*

An important consideration was ensuring reliable, valid, sensitive, and unbiased data was collected (Collins, 2003, p. 229), which suited the needs of the research. This required taking measures to pre-test and validate the QBE ahead of experimental use.

QBE items collecting information related to participants' experience of disability, personal demographics, and social work career were taken from pre-validated surveys designed specifically to these ends – the Public Perceptions of Disabled People questionnaire (Staniland, 2009), the National Survey of Public Attitudes to Disability in Ireland (NDA, 2011), and the Social Workers' Workload Survey (Baginsky et al, 2010).

The length of the questionnaire was altered due to the negative impact a long series of questions may have on response quality and general participation (Herzog and Bachman, 1981; Krosnick, 1999). The design of the task-based portion of the QBE was sensitive to sources of "sabotage" from social desirability. The assignment was made as realistic as possible; the preferred responses were not obvious to the participant; and the task was lengthened and ensured to be adequately challenging (Rust and Golombok, 2009, p. 158). Cognitive interviewing techniques were used to improve the validity and reliability of the questionnaire. The researcher informally went through the questionnaire, question by question with volunteer CSWs, encouraging them to speak aloud their thought-processes as they considered each item (Desimone and Le Floch, 2004). This allowed insight into whether each item was interpreted as had been intended and detection of any flaws related to the cognitive process (Willis, Royston and Bercini, 1991, p. 251).

3.4 Study population and sampling

3.4.1 *Study population*

The study population were CSWs recruited from children's social services in England. Services were chosen using non-probability sampling guided by data from the Cafcass Care Demand Review (Cafcass, 2013). Within these services, probability sampling was used to recruit individual participants.

The shortcoming of using non-probability sampling is that the representativeness of the sample finally attained is questionable and as a result, the conclusions drawn may not be generalisable to the wider population (Krosnick, 1999, p. 541; Yeager et al, 2011). However, this method was settled upon for practical reasons following a process of elimination and after making this decision, efforts were made to achieve the highest possible degree of representativeness with these practicalities in mind. National CSW bodies were considered as networks for distribution, and the British Association of Social Workers, The College of Social Work, and the Health and Care Professions Council were contacted. When this was unsuccessful, children's services were contacted directly, presenting the advantage of having more control over to whom the QBE would be distributed. The national networks were unable to use specialised targeting making recruitment criteria difficult to uphold but to not use these channels meant sacrificing a larger pool of potential participants. Also, recruitment through specific services meant that findings could be contextualised within known localities and relayed back, which would not have been otherwise possible.

The aim remained to recruit from the largest possible pool of CSWs due to the unoptimistic response rate forecasts following consultation with social care contacts. However, this was tempered by the research needing permission from the Association of Directors of Children's Services (ADCS), which is required when studies include more than three children's services departments. A final compromise was drawn at 23 children's services after discussion with the ADCS, balancing the need to fulfil the

research aims while still considering the strain under which children's services operate. Cafcass Care Demand data was used to select two local authorities from each region, those with the highest and lowest rates of Children in Need (CIN) per 10,000 children, to invite to participate in the QBE. This was to capture a range of geographies and care burdens experienced by participating services. A further 3 local authorities were approached due to their size, diversity, and the researcher's familiarity with their respective localities. The process of contacting, inviting, and liaising with services took place over 3 months and was recorded and monitored by the researcher continually, resulting in 6 participating services. [For invitation letter sent to services, see Appendix 5.]

Children's service	**Region**	**Number of CSWs employed**	**Rate of CIN per 10,000 children and regional average**
1	Northeast	120	325.0 (443.8)
2	Northeast	70	734.9 (443.8)
3	Southwest	100	171.3 (320.0)
4	Southeast	300	211.6 (295.7)
5	Yorkshire and Humber	190	542.5 (346.3)
6	West Midlands	145	528.3 (343.7)
		Total (925)	*National average* (343.4)

3.4.2 *Sampling and recruitment*

Following introductions from the children's services directors, relationships were formed with managerial staff from each participating service. The link to the website housing the QBE was sent by email to CSWs employed in each service by their respective managerial teams. [Please see Appendix 6.] Working closely with these individuals, the recruitment criteria was maintained and a recruitment protocol was developed whereby the link would be sent monthly along with reminders. The frequency of these reminders was adjusted according to the participation rate

registered at Qualtrics, an indicator of recruitment success from each area. A database was made to monitor participation in the QBE and the service in which they worked. This information was relayed to the managerial staff and they increased the number of reminders sent to their CSWs when recruitment was low or to compensate for low recruitment in other regions. This took place throughout the time the QBE was live. The final number of those included was 20.6% of the total study population (191 participants), with great variation across regions.

Children's service	**Final number of participants per service in sample (n=191), *n* (%)**	**Percentage recruited from service (%)**
1	43 (22.51)	35.83
2	32 (16.75)	45.71
3	3 (1.57)	3.00
4	53 (27.75)	17.67
5	12 (6.28)	6.00
6	47 (24.61)	32.41
Prefer not to say	1 (0.52)	

3.4.3 *Questionnaire distribution and data handling*

The questionnaire was live for 3 months and hosted on a secure and trusted website. The unique website link was sent to potential participants by email. [For the complete survey, please see Appendix 7.] Due to data protection compliance, the contact details of the CSWs employed in participating services were not available to the researcher. Instead CSWs were contacted and sent the questionnaire link by their own managerial team. To prevent the same individuals taking part several times, a condition was written into the questionnaire software whereby the link could not be accessed more than once from the same IP address. Participants were informed of this but there is a chance this undermined completion of the questionnaire. An unknown number of participants may have begun the questionnaire and, unable to finish at that time,

closed the window and were unable to retrieve the page at the same computer. Unless these individuals accessed the link from a different IP address, their input would have been lost.

Participation was voluntary and anonymous. The questionnaire began with extensive information about the wider research project, the QBE component, the individual's role within the study, and the terms to be agreed by the individual prior to taking part. The participant was next directed to a page where they had to indicate their informed consent which, if not given, automatically terminated the questionnaire. Participants were free to terminate the questionnaire whenever they wished. The participants were aware they had the full permission of their children's service to take part, that there would be no personally identifiable information collected, and their participation would remain confidential and anonymous.

Data collected from the QBE was not shared or used for any purposes besides those outlined in the original ethical permissions; and was stored in password protected data storage drives in accordance with the Data Protection Act. Participants were assigned unique identifying codes and any information potentially related to their identities was deleted.

Missing data was minimised as the questionnaire software allowed the researcher to impose rules on compulsory and non-compulsory items. This minimised the items skipped by participants while taking part in the QBE. Only the responses by those who had completed the vignette task in QBE were included in the analysis. The data collected was moved from Qualtrics to Microsoft Excel where the initial data management took place. It was then moved to Stata 13 where the remaining cleaning, handling, and analyses were carried out.

3.5 Analytic strategy

Stata 13 was used to analyse the data. Participants' assessment choices were analysed using ordinal logistic regression. This type of analysis identifies the unique net contribution of the factor of interest, the PID disclosure, upon the assessment choice. A model was constructed to contrast the impact of the disclosure of assessment choice compared to where there was no PID disclosure. The disclosure variable was binary, coded 0 when PID was not disclosed and 1 when it had been.

3.5.1 *Clustering*

There were two elements of the study design that led to concerns about clustering, where data forms groupings of similarity – intragroup correlation, caused by dependence within the sample:

1) Participants were recruited from 6 participating children's services. It is possible that each service has a particular ethos or manner of practice that is shared by those in its employment. As a result, participants from each service might make assessments similar to one another and these similarities may cause 6 clusters of dependence to form.
2) 191 participants took part in the QBE, making 9 risk assessments resulting in 9 observations per person and 1,719 observations in total. Each person was likely to risk-assess in a certain way, linking their observations to themselves. This created 191 sets of nine observations which may cause clustering around the participants.

Both of these give reason to reject the assumption of independence, requiring certain adjustments to be made. Left unaccounted for, clustering can lead to incorrect estimates of the standard error and incorrect type I error rates (Kahan and Morris, 2013), invalidating standard statistical methods and giving misleading conclusions. The power of the study may be reduced by inflated standard errors and the reduced effectiveness of the sample size (Lee and Thompson, 2005).

With regards to clustering around the regions, this was accounted for by recruiting as many services as possible so the effect of the intervention (the PID disclosure) was distinguishable from the natural variability among the clusters (Ukoumunne et al., 1999, p. iii). The clustering effect would have been magnified if the regions themselves were the unit of intervention, such as an arrangement where the intervention was given by region, and resulting in 3 services with the intervention and 3 without. Instead, as the intervention was given by the individual, the randomisation would have reduced this risk further by limiting bias, as would the decision to include a mixture of PID and non-PID vignettes in each version of the QBE. Additionally, the clustering by region would largely have been caused by participants working under one team manager and their practices being affected as such. However, recruitment was carried out across a number of teams, diluting the clustering effect by team-manager.

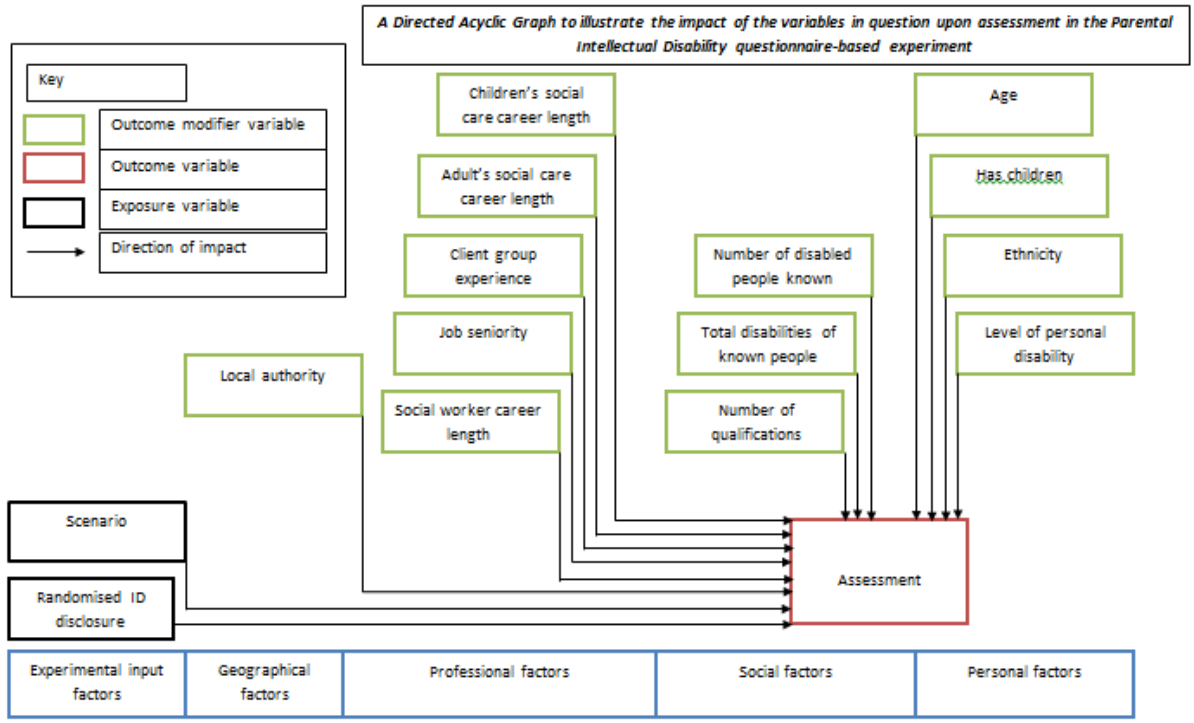
The clustering around the participants would have been caused by gathering repeated observations from the same people (Neuhaus and Kalbfleisch, 1998, p. 638). This was accounted for in the analysis by including the *vce (cluster)* command in the syntax in Stata and linking it with participants' unique identification code. This command specified that the standard errors allow for clustering by "relaxing the usual requirement that the observations be independent" and indicating to which group the observations belong (Stata, 2015).

3.5.2 *Potentially confounding variables*

To avoid bias, the administering of the PID disclosure was carried out using randomisation. In doing so, the characteristics of the participants that might influence their vignette assessments were distributed randomly between the disclosure and non-disclosure groups. This way any difference in the assessment, or "outcome", could only be explained by whether PID had been disclosed (Roberts and Torgerson, 1998).

Following extensive literature review and discussions with children's social work professionals, a list was compiled of factors understood to affect CSWs' assessments. Items were included in the QBE to ensure its sensitivity to the personal, social, professional, and geographical factors that could affect individuals' decision-making. Among these, participants were asked for their social work career length due to the emotional impact of social work causing general emotional trauma, or "case-hardening" (Horwitz, 1998; Lloyd, King and Chenoweth, 2002) caused by "years of exposure to the workplace" (Horwitz, 2008, p. 15); they were asked about the diversity of their social work careers and the extent of their experience of various client groups based on key informants' assertions that this had an impact; and were asked about their personal experience of disability based on the principles of intergroup contact theory (Pettigrew, 1998).

These were incorporated into the directed acyclic graph below to illustrate the potential causal links that cause outcomes of interest (Greenland, Pearl and Robins, 1999) and indicate where they may be confounding (Shrier and Platt, 2008).



To ensure randomisation had been achieved, the background data were included in an adjusted model to check for any effect upon the assessments. Also, the assessments from when ID had been disclosed and when it had not been were compared to ensure there were no significant differences between the groups.

3.5.3 *The Parallel Lines Assumption*

This study collected ordinal, non-dichotomous data. The outcome variable is the assessment, in which there are 4 items – “no risk”, “early help”, “in need”, and “significant harm”, signifying a rank order. These 4 are necessary to ensure the QBE is representative of the spectrum of choices actually available to CSWs, capturing the nuances of their assessments better than would a binary option. The aim of the analysis was to find the extent to which the explanatory variables predict the outcome variable, the assessment. This required a statistical approach that accommodated the particularities of the variables in question, such as ordered logistic regression.

There are several different models appropriate for analysis of ordinal dependent variables, each with characteristics rendering them suitable for particular types of data. An important consideration when choosing a model is whether it operates using the parallel lines assumption, also referred to as the proportional odds assumption. This assumes that the relationship between each pair of outcome groups is the same and that the coefficients describing all of these relationship combinations are the same, resulting in one model and one set of coefficients (ucla.edu, 2015). This would mean the effects of the explanatory variables are proportional across the different thresholds of the outcome variable. Where this assumption is violated and different models are required to describe the relationship between each pair of outcome groups, an approach that relaxes this assumption is needed instead.

Overlooking a violation of the parallel lines assumption would result in biased estimates and the effects of particular independent variables being obscured. In such a

model, the positive impact of a variable at one level may be countered by its opposite effect at another, resulting in a non-significant effect. In an alternative model where the parallel lines assumption is relaxed, there would be two separate significant effects. Use of such an alternative model reduces bias in the coefficients and uncovers more nuanced relationships (Fullerton, 2009, p. 311).

To test whether the parallel lines assumption is violated, the *omodel* command in Stata was used to perform a likelihood ratio test. A non-significant result would indicate that there is no difference in the coefficients between the models, indicating the assumption had not been violated (ucla.edu). However, an approximate likelihood ratio test of proportionality of odds across the response categories gave a significant result (prob>chi2=0.0050), indicating a definite violation of the assumption for the independent variable under study – the disclosure. As a result, a generalised ordered logistic model was needed, using *gologit2.* In this model the parallel lines assumption is completely relaxed for all of the variables. The variables are subject to a Brant test in Stata which indicates precisely which of them violate the assumption. This is important because *gologit2* relaxes the assumption completely and indiscriminately, even though the assumption might not be violated by all variables in the model. g*ologit2* can overcome this by fitting partial proportional odds models so the assumption is relaxed only where necessary using the *autofit* command (Williams, 2006, p. 64).

3.6 Results

3.6.1 *Explanatory variables*

Information was gathered on participants' personal and professional backgrounds to provide information on the diversity that had been captured during recruitment. [For participant characteristics, please see Appendix 8.]

The disclosure of PID had been carried out using randomisation, resulting in 1,719 assessments. This created two sets of assessments, one where the PID disclosure had been made and one where it had not been. To ensure that there were no significant differences between the participants from whom the ID and non-ID assessments were taken, the two groups were compared. Using chi-squared tests, no significant differences were found on the basis of participants' children's service, gender, ethnicity and job title, among others, between the two groups. T-tests revealed that there were no significant differences between the two groups in terms of the length of participants' social work careers, their time spent in adult and children's social care, the number of client groups with whom they have contact, and the number of disabled people they knew in a non-professional context [see Appendix 9.] As a result, it could be concluded that randomisation had been achieved.

The scenarios in the vignettes were included in such a way that each participant received all 9. This meant that there was no difference on this basis between the vignettes used to make assessments among the participants. For these reasons, the PID disclosure alone was included in the final model. The model was then subject to a test of proportionality of odds to check for a violation of the parallel lines assumption. The data was then fitted to a generalised ordinal logistic regression model.

3.6.2 *Findings*

An ordinal logistic regression showed that PID disclosure had a small but significant effect on assessment (OR: 1.225; $p < 0.000$; CI [1.104, 1.359]). The table below illustrates the predicted probabilities within this model. Across the vignettes, where PID was disclosed, there was an 11.4% probability that the assessment would be "no risk", compared to a 13.6% probability if the disclosure had not been made – it was less likely that the case would be considered "no risk" when PID was disclosed. This pattern is the same for "early help". Where PID was disclosed there was a 30.5% chance of the case being considered to require "early help" compared to a 33.3% probability

when it was not. However, when PID was disclosed there was a 29.3% chance of the case being considered “in need” compared to the 28.3% chance of being so when there was no disclosure. The effect of the PID disclosure was most pronounced at the top of the scale where when PID was disclosed there was a 28.7% chance of being considered significant harm compared to a 24.8% chance when the disclosure had not been made. Overall, where the disclosure was made there was less chance of being assessed to be in one of the lower two categories compared to the non-disclosure group, and a higher chance of being placed in the higher two categories than the non-disclosure group.

Disclosure made	**No Risk**	**Early Help**	**In Need**	**Significant Harm**
PID disclosed	0.114	0.305	0.293	0.287
PID not disclosed	0.136	0.333	0.283	0.248

However, ordinal logistic regression models use parameters representing the exposure (the PID disclosure) odds ratios as being in the highest categories of the outcome variable (the assessment) – the parallel lines assumption. The model was tested to see whether this assumption had been violated. A significant result (prob>chi2=0.0050) indicated that the parallel lines assumption had been violated. The data was then fitted to a generalised ordinal logistic regression model where this assumption would be relaxed. A partial proportional odds model was not needed as the disclosure variable was the only explanatory variable included, and it had been found to violate the assumption.

In generalised ordinal logistic regressions, positive coefficients indicate that higher values of the explanatory variable (the disclosure variable) make it more likely that the participant will be in a higher category of the outcome variable (the assessment) than the current one. Negative coefficients indicate the opposite, that a higher value of the explanatory variable will increase the likelihood of being in the current or lower category (Williams, 2006, p. 63). The coefficients in this model indicate that the

assessment was likely to be in a higher category than “no risk” when PID was disclosed. This effect is the same for the other categories, that when PID was disclosed the assessment was likely to be in a higher category than “early help” and “in need”. However, the model showed that while this relationship was highly significant in the lower categories, the significance of the PID disclosure decreased as the assessment category increased.

Assessment	**Coefficient**	**Z**	**P>[z]**	**95% Confidence Interval**
No risk	0.590	4.23	0.000	0.316,0.863
Early help	0.145	1.95	0.051	-0.000,0.291
In need	0.115	1.47	0.142	-0.038, 0.926

3.6.3 *Interpretation*

These results indicate that there is small but significant association between PID disclosure and CSW assessments. The ordinal logistic regression indicated a strong association between PID disclosure and an assessment indicating higher support needs and greater urgency. The nuances of this relationship were uncovered by the generalised ordinal logistic regression wherein the effect of the PID disclosure was most likely to increase the risk assessment from a lower category to a higher one but had lesser impact where the assessment was already one indicating high risk.

Assessment	**ID undisclosed (n=862)**	**ID disclosed (n=857)**
No risk	135	80
Early help	263	285
In need	243	253
Significant harm	221	239

These changes in assessment indicate that the CSWs, when presented with a case and told that the parents in question have ID, were more likely to consider the family to have higher support needs than those where ID was not mentioned. However, this was only the case when the families were depicted in a scenario that, when presented alone, was objectively considered to be low risk. In these situations, when PID was mentioned, it contributed significantly to an assessment of higher risk. When families

were depicted in a scenario that was objectively considered to be high risk with no mention of PID, the additional disclosure of PID did not significantly contribute to the higher assessment of risk.

This indicates that PID is only important and relevant to assessments when there are no other great concerns at play. When there are other more substantial signifiers of potential harm to a child, PID becomes less important. Appendix 9b illustrates the spread of the assessments across the categories according to the vignettes displayed.

As such, it can be concluded that PID has a significant effect on assessments of cases that would otherwise not be considered to be of great concern, and an insignificant effect on assessments of cases that, when presented alone, would be considered highly risky. This effect is demonstrated in the above table by the "uncle" and "unemployed" scenarios. In the case of "uncle", where the hypothetical 7 year-old child is left unsupervised with an uncle deemed to be a "risk to children", that scenario alone was considered enough to warrant choosing a "significant harm" assessment. The PID disclosure had limited additional impact. However, in the case of "unemployed", where the father of the 7 year-old child has lost his job and the family may be unable to pay their rent, the effect of the PID on the lower level assessments is evident. More participants assessed the family to require "early help" or as "in need", and were less likely to choose "no risk" than if PID was not disclosed.

3.7 Discussion

Analysis of the QBE data showed that PID disclosure had an impact on CSWs' assessments. CSWs were more likely to choose assessment categories indicative of higher support needs and greater urgency when PID was disclosed. This effect was clearest at the lower end of the assessment categories where the disclosure escalated the participants' assessments. In the higher categories, the contribution of the PID

disclosure to the assessment was not found to be significant – the degree to which the disclosure made an impact was unclear.

These findings indicate that PID is considered by CSWs as a factor among the other defining characteristics of a case. Its relevance is only determined relative to the other factors at play. This might mean that in the absence of other starkly worrying factors, PID might be subject to more investigation. This is not necessarily an indicator of negative or discriminative assessments, but a demonstration that CSWs are aware these parents may have additional support needs that would need clarifying. In cases where there are other factors that alone would result in a “significant harm” or “in need” assessment, it is unclear whether the PID disclosure is included in the assessment and would, therefore, be catered for in practice, or whether it would be overlooked in favour of addressing the other factors.

3.7.1 *Study weaknesses*

A limitation of the questionnaire instrument is that there was no elaboration on the assessments made during the QBE. The addition of a qualitative item that allowed participants the opportunity to explain their choice of assessment would have provided more insight. This was considered during the questionnaire design and such an item would have contributed to the length of the questionnaire and the time required for its completion. These may have had a detrimental effect on participation and the added length would have made the study less attractive to children’s services during recruitment. Instead, in-depth insight into decision-making was secured during the FGDs.

Another limitation of the study was its susceptibility to various forms of bias – social desirability bias, sample bias, and self-selection bias. In terms of social desirability bias, this would be due to the hypothetical nature of the assessment task. Participants were asked for their judgements of each situation but they may have answered in such a way that was not representative of their actual professional behaviours (Nederof,

1985). This was accounted for in the questionnaire where participants were asked to answer as honestly as possible. Also, efforts were made to present the subject of PID neutrally, without any hint of what would constitute a “correct” answer.

Sample bias may have been caused by there being only 6 participating services, and those finally recruited may not have been representative of the national CSW population. Efforts to minimise this are detailed in the earlier sections but, in spite of these, the bias may not have been alleviated. Also, those within the final sample may have been subject to self-selection bias as their participation may have related to a pre-existing interest in PID. This could not be avoided as the purpose of the research had to be disclosed in order to ensure there was informed consent. However, during recruitment the children’s services framed study participation as universal rather than on the basis of any specialist interest in ID and parenting.

CHAPTER 4

Focus group discussions (FGD): Methodology

4.1 Chapter Overview

The case scenarios used in the questionnaire-based experiment (QBE) depicted a fictional 7 year old child involved in a range of child safeguarding scenarios. These were presented to children's social workers (CSWs) participating in a series of focus group discussions (FGDs). Using FGDs, data could be collected on the aspects of each case that the participants felt gave cause for concern; the level of need presented by the families; and how these needs would be addressed in practice. Participants would often draw on their own personal and professional experiences of parental intellectual disability (PID) and the services at their disposal with which they could ameliorate children's circumstances. The aim was to collect information on how these specific circumstances were assessed but further to this, the vignettes were used as conversation-starting devices. This way information could be collected on participants' general understanding of ID and parenting, and the settings and resources with which they work. This was so a theoretical framework could be developed based on the gathered concepts from which an understanding of how PID was encountered, understood, and assessed, could be derived. FGD data is used to aid in the interpretation of the questionnaire-based experiment (QBE) findings. FGDs permit insight into how PID is understood and explain on the factors that form how CSWs assess and interact with families where the parents of the children in question have ID.

This chapter details the aims, methods and justifications for using FGDs, a qualitative data collection technique, as part of the investigation into how CSWs assess parents with intellectual disabilities (PWIDs). The methodological strengths and limitations are considered and the preliminary findings from this phase of data collection are outlined.

4.2 Data collection

4.2.1 *Objectives and aims*

The FGD are intended to achieve two main objectives:

1) Investigate how the participating CSWs assess each situation by presenting the 9 fictional child-safeguarding vignettes from the QBE;
2) Gain insight into how CSWs discuss their understanding of PID and their experiences of such cases by using the 9 vignettes as springboards for discussion among the participants.

4.2.2 *Methods*

Qualitative methods allow exploration of participants' perspectives and understandings, presenting an ideal way of collecting data and building theory on CSWs' understandings and assessments of PID. There are several methodological techniques that can be adopted to collect and analyse qualitative data, however, this research question requires a method where data collection and analysis is not limited to the issues predetermined by the researcher but allows for the emergence of new themes. Inductive approaches, whereby data is collected to generate new theories, differ from deductive approaches where the aim is to use pre-existing knowledge and understanding to develop tools with which the data tests existing theories. The ideal method would facilitate the emergence of categories without the constraints of pre-existing groupings (Mayring, 2000). To this end, grounded theory procedures were used. This enables data collection and analysis to be carried out systematically and simultaneously to identify relevant aspects of the topic as they emerge and immediately re-incorporate them into the study design. This ensures that as the research progresses, it encapsulates "all of the possibly rewarding avenues to understanding" (Corbin and Strauss, 1990, p. 6).

4.2.2.1 *Introduction to qualitative methods and FGDs*

The use of FGDs is crucial to this study because of the unique form of data collection that the method represents. Where the purpose of the serious case review (SCR) analysis was to investigate how PID was detailed and reported in the reviews themselves, and the aim of the QBE was to answer definitively whether PID disclosure affected assessment across a range of safeguarding scenarios, the FGDs intended to gain insight into why CSWs assess PWIDs as they do. FGDs, as a qualitative method, "emphasise participants' perspectives and allow the researcher to explore the nuances and complexities of participants' attitudes and experiences" (Hughes and DuMont, 1993, p. 776). By using these 3 research techniques, the question of "how do CSWs assess parents with intellectual disabilities" can be answered as comprehensively as possible.

Qualitative research does not aim to be generalisable or to enumerate; through sampling it works towards representing the widest range of perspectives and experiences, emphasising diversity rather than frequency in the wider population (Ziebland and McPherson, 2006, p. 407). Qualitative methods enable researchers to "understand social phenomena … giving due emphasis to the meanings, experiences, and views of all the participants" (Pope and Mays, 1995, p. 43). As such, the aim of this phase of data collection was not to reach conclusions applicable to the entire social work profession but to attain the widest possible range of individuals to explore the diversity within this particular population and improve understanding of this particular issue (Marshall, 1996, p. 524). Instead of generalisability, transferability was the goal. Through purposive, theoretically grounded sampling, ensuring the required qualities are held by participants, data is collected and insights are generated that might be transferred to similar settings (Malterud, 2001, p. 486).

FGDs have been chosen as a means of accessing this data for a number of reasons. FGDs can be defined as a "method of group interview which explicitly includes and uses the group interaction to generate data" (Pope and Mays, 1995, p. 43). The focus

group method allows participants to “explore and clarify their views … explore the issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities” (Kitzinger, 1995, p. 299). In the context of this research, this requires the assembly of groups of CSWs employed by 3 different geographical locations within a particular county council.

4.2.2.2 *Study population*

The study sample was drawn from the population of CSWs employed by one county council. A county council is the larger of two different forms of local government, the other being a city council. County councils are responsible for the services across the entirety of a county, whereas the city councils cover smaller areas (www.gov.uk, 2015). Social workers can be employed by both of these. The CSWs invited to participate in this study were employed by the county council to work in children’s social care. The county council is made up of 3 geographically defined areas and the focus group participants were recruited from each of these. Despite the focus group participants being drawn from only one of England’s 152 children’s services, the diversity represented by the 3 geographical areas contained by the county council in question made it a desirable pool for recruitment, varying both in population density and cultural and socio-economic demography. This diversity is important on two levels, firstly in terms of the social workers themselves but secondly, in terms of their work environments and the service-users with whom they have contact and of whom they have experience.

4.2.2.3 *Sampling and recruitment*

Several considerations were made during the sampling and recruitment:

1) attaining a diverse range of participants;
2) drawing participants from all 3 localities;

3) including enough participants for the scenarios to be repeated a minimum of two times each without participants being told the same scenario more than once;
4) including enough people in each discussion for conversation to be easily facilitated;
5) ensuring there were a few enough people to create a setting conducive for sensitive topics to be discussed, for all participants to have time to talk, and for each scenario to be discussed in the most possible detail.

There were also external considerations such as those outlined by the county council to ensure their involvement in the FGDs would be feasible. The discussions needed to take place during office hours for their employees to take part, taking them away from their usual work. As a result a balance had to be struck to suit the interests of both parties, curtailing the length, number of FGDs, and number of participants required to the greatest extent possible while ensuring the data collection objectives are met. [For the FGD recruitment materials, please see Appendices 10 and 11.]

Participants were sampled through senior social work staff working in each of the 3 county council areas. Participants chosen from each area took part in a FGD that was held in their area office, alongside their colleagues – a stipulation of the county council. Purposive sampling was used whereby “decisions concerning the individuals to be included in the sample are taken by the researcher, based on a variety of criteria which may include specialist knowledge of the research issues, or capacity and willingness to participate in the research” (Oliver, 2006, p. 245). Recruitment criteria was established following discussion with experienced members of the social work field and literature review. Individuals were invited to participate on the basis of their social work experience, their client group team, and job title. Due to data protection restraints the participants were not contacted directly but by their respective social care

staff. The sampling criteria were upheld through close work with these staff members. Finally, 3 focus groups, each with approximately 5 participant CSWs, were assembled.

Consultation with the County Council concluded that 3 focus group sessions would be adequate, capturing the diversity necessary for data collection without presenting too great an imposition for the service. Holding multiple sessions mediates the risk of internal or external factors of which the researcher may not be aware, and ensures that there are others if one discussion does not go as planned (Hancock, Ockleford and Windridge, 2007). Including 3 sets of participants meant that the scenarios could be repeated in case there were different reactions from different groups. The length of the sessions was fixed at two hours due to participants' workload pressures; and the fact the sessions were to take place during working hours on council premises. It also meant the burden of participation was spread evenly among the three localities within the service.

The group size of 5-6 participants balanced the need for the largest number of participants and having small enough group to facilitate discussion of a complex and potentially sensitive topic that requires tapping into people's personal and professional experience. Additionally, there were 9 scenarios to discuss during 3 sessions, each to be presented at least twice. The groups needed to be small enough for this to be accommodated (Krueger and Casey, 2009).

4.2.2.4 *Format of FGDs*

The vignettes created for the QBE were used in the FGDs. However, rather than manipulating the PID disclosure as had been done in the QBE, all of the scenarios contained the disclosure that both parents of the child in question were suspected to have ID. This was because the primary aim of the focus groups was to facilitate in-depth conversations about understanding of PID and how it factored into participants'

decision-making in the different scenarios, rather than to quantify the difference the disclosure made.

Finally, there were 3 focus groups, two lasting for two hours and one lasting for one hour. The sessions were audio-recorded with the participants' permission, presenting the twofold benefit of sparing the need to take notes during sessions and allowing facilitation of the discussion instead, and also having the benefits of verbatim transcripts for analysis.

Holding each FGD in the familiar setting of each participant's respective area office minimised issues with travel. Participants were seated around a large meeting room table so all could address one another in a manner similar to their own team meetings. Refreshments were available throughout to avoid interruptions and to ensure participants were comfortable, and breaks were encouraged (Hancock, Ockleford and Windridge, 2007). FGDs began with a brief introduction, a session outline, and the opportunity to ask questions. All participants had been given information sheets and consent forms far in advance of the discussions to save time. [Please see Appendix 12 and 13.] This ensured that they were aware that their local authority permitted their participation and that they were protected by an anonymity and a confidentiality clause included in the consent form. To minimise the researcher's input toward the discussion, the topic guide consisted of only the list of scenarios and a further statement inviting participants to discuss their thoughts. The scenarios were read aloud to the group and discussed one by one, moving from one to the next when participants felt there was nothing further to share. Probing was used where discussions did not appear to be exhaustive and encouraged those who were less vocal to become more involved in conversations.

The order in which the scenarios were presented was decided using a random number generator ahead of each session. The discussions took place over a two month period

allowing the opportunity between sessions to begin analysis, forming ideas that were relayed into the discussions to follow and ensuring previously unknown information could be explored in more detail where necessary – a key feature of grounded theory research (Corbin and Strauss, 1990, p. 6).

4.3 Analysis

4.3.1 *Transcription and initial coding*

The session recordings were transcribed verbatim and the contents read and reread. A loose coding frame of 9 broad categories was generated from the data based on recurrence and similarity of items held within the focus group content. These categories were used to begin arranging the transcribed data. The quotes contained in each were grouped according to their likeness and separated where there were differences. These subcategories are referred to as “codes” and the categories finally contained a combined total of 97 codes. The quotes contained within the codes were each assigned a unique identifier, holding details of the original transcript location and code for reference.

The decision to code without use of computer-assisted qualitative data analysis software (CAQDAS) was made, not because to do so would be a better or worse method but rather, because it suited the data collection programme. CAQDASs “facilitate an accurate and transparent data analysis process whilst … providing a quick and simple way of counting who said what and when … a reliable general picture of the data” (Welsh, 2002). They serve as organisational tools rather than a means of analysis in their own right and do not supplant knowledge of data analysis methods – “the researcher must know what needs to be done, and do it … software provides the tools to do it with” (Weitzman, 2000, p. 805). As such, CAQDASs are best used when the extent of their capabilities are fully understood. Due to there being only 3 sessions, the volume of data accumulated was not so vast that it precluded other forms of

organisation and could be handled with limited effort. The sessions took place over a two month period and working with the data at the first opportunity, after the first session, without CAQDAS made sense. Instead, the functions within Microsoft Word and thorough record-keeping served the research purposes to satisfactory effect.

4.3.2 *Constant comparison method (CCM)*

In CCM, “comparing and contrasting is used … forming categories, establishing the boundaries of the categories, assigning the segments to categories … The goal is to discern conceptual similarities, to refine the discriminative power of categories, and to discover patterns” (Tesch, 1990, p. 96). In CCM, “the researcher simultaneously codes and analyses data to develop concepts; by continually comparing specific incidents in the data, the researcher refines these concepts, identifies their properties, explores their relationships to one another, and integrates them into a coherent explanatory model” (Taylor and Bogdan, 1984). This method was useful because though the data was drawn in a semi-structured manner using topic guides, extensive pruning was needed to meaningfully answer the research question. Use of this method meant the data became manageable as part of the interpretive strategy (Basit, 2003, p. 144).

The codes that composed the themes and sub-themes were constantly shifted, relocated and reassigned to different, more appropriate categories, or dismissed due to repetition or irrelevance. The products of each of these stages are compared to those from the latter, and material is refined to a greater extent at each stage. This is because with the addition of each new item to a category and checking the items against those added previously – “this constant comparison of the incidents … starts to generate the theoretical properties of the category” (Glaser, 1965, p. 439). The process allows categories to be contextualised within the larger phenomena under study, the factors that lead to its presence and the degree to which it might exist, its impact, and its relation to other categories. Internal validity is upheld as the variety within the subject is described and conceptualised (Boeije, 2002, p. 393) and CCM facilitates this

by enabling identification of distinct items and placing them within the nascent theoretical model.

This process began during coding, where the initial groupings were formed, and continued throughout the writing stage. It ended when the addition of new items did not require creating new categories nor contribute usefully to the existing ones. The by-products of this process were a series of notes through which the development of themes and categories can be traced. [For details, please see Appendices 14-17.]

4.4 Discussion

In this section the strengths and weaknesses of the FGD data collection and analysis are discussed and the findings of this research phase are briefly detailed.

4.4.1 *Strengths*

4.4.1.1 *Sensitivity to diverse views*

FGDs draw data in such a way that is of great benefit to this project. Those working in children's social care represent a homogenous group insofar as they have received similar basic training, share a set of common concepts and principles, work with the same client group – children, and face similar workplace pressures. By virtue of sharing these attributes, they operate upon similar understandings to one another, use the same terminologies and meanings and, as a profession, share the same goals – to strive to achieve the greatest benefit for children. That being said, they are also a diverse group of individuals from a range of professional and personal backgrounds that may lead to an array of motivating factors and behaviours making each distinct. FGDs allow the opportunity to view how participants express their experiences and concepts and determine which are and are not shared (Hughes and DuMont, 1993, p. 776).

4.4.1.2 *Capitalising on group dynamics*

Answering the question of how CSWs assess cases concerning the children of PWID requires a method that produces data indicative of the individual as part of a professional group rather than an individual in a vacuum, such as would be attained through methods such as one-to-one interviewing. Though participants have valuable individual insights, data drawn from one-to-one approaches are too introspective and reflective than was required for the purpose of this study, placing too much emphasis on unique, personal opinion. This phase necessitated access to participants' decision-making processes and subsequent actions rather than their emotional responses to cases. Though emotions may affect decision-making, they needed to be interpreted in the context of participants' professional role rather than their private thoughts. CSWs are a professional group trained to handle their work in a particular way and while their emotional responses may factor into their professional behaviours, the intention of the project was to centre on their professional capacity, thus becoming more widely applicable. Where approaches like Interpretive Phenomenological Analysis "focus on the particular rather than the general" (Larkin and Thompson, 2012, p. 102), FGDs place the participants within a group context, immediately situating their responses as such.

CSWs usually work in teams, possibly normalising the FGD setting as participants liken it to their own work format. Though FGDs appear familiar, they encourage "people to engage with one another … and draw out the cognitive structures that have previously not been articulated" (Kitzinger, 1995, p. 301), capturing group information-sharing and decision-making, dynamism and challenging of ideas and the formation of views. The result is that the data collection is catalysed by participants being accustomed to the format while extracting views that are more considered and tempered by the group, and the researcher has access to the fruits of these interactions.

A benefit of FGD is the absence of one-to-one scrutiny such as there is in interviews. Criticism of CSWs by the media and public is well documented and FGDs may be a less interrogatory medium with an empowering effect (Kitzinger, 1995, p. 300). FGDs project the impression that the group itself is important and of value, holding a highly sought-after and particular insight. The emphasis on the researcher is far less as they remain largely silent, and to the greatest possible degree allow the group to navigate and direct the flow of conversation as they see fit.

4.4.2 *Weaknesses*

4.4.2.1 *Challenges to validity*

While the group dynamics of FGDs embody one of the method's strengths, a shortcoming is that the "articulation of group norms may silence individual voices of dissent" (Kitzinger, 1995, p. 300). This effect is amplified when participants have prior knowledge of each other as they did in this study. Pre-existing relationships can be useful, increasing rapport and ease during sessions, but they might pose difficulties. Tension between colleagues or the limited effectiveness of the anonymity and confidentiality assurances because of prior knowledge of each other might cause participants to be less forthcoming in expressing their opinions because of discomfort or fear of repercussion and judgement. This is where the facilitator must encourage those discouraged from fully taking part so the data is illustrative of those from whom it was sought. However, this can only happen insofar as the facilitator is aware this quietening is taking place.

4.4.2.2 *Data is drawn from a hypothetical and artificial environment*

Though FGD format may mimic the participants' own work environment, FGDs and the posing of fictional scenarios remains to be a staged, hypothetical event. The participants' are encouraged to be more pensive, giving more thought to decisions than they might normally, and their answers might be subject to pressures of social desirability (Nederhof, 1985) imposed by their colleagues or the researcher. The result

is that products of FGDs are removed from participants' actual practice, and the effect and extent of this is unknown. Such "ideal world" type information is still endogenous to the participants and is indicative of their depth of insight, demonstrating that such decision-making and actions are within their capacity. However, the extent to which the principles drawn from the data can really be applied to their work is also unknown.

An alternative might be to use naturalistic observational studies, though these, unlike FGDs, do not allow the researcher to control and structure the content of the interaction (Hughes and DuMont, 1993, p. 777). This research aimed to examine decision-making in particular cases, those involving PWID, in specific scenarios. For the researcher to wait for these to arise by chance in controlled, replicable, real-life conditions presents considerable challenges. The ethical considerations inherent in observing work with vulnerable children and parents are substantial, as are the practical limitations involved in fieldwork with CSWs; and the feasibility of carrying out such burdensome work with local authorities who are already under strain would render this phase impossible within the parameters of the current project. FGDs presented the means to create the desired research conditions in a manner that was amenable to those involved and met the research aims to an acceptable degree.

4.4.2.3 *Self-selection bias*

Non-probability sampling was used in this research phase, whereby decisions about those included in the study sample are made by the researcher based on specified criteria (Oliver, 2006, p. 245). These criteria were adopted to capture a range of children's social care professions and levels of career experience and were adhered to by the staff involved in recruitment. However, in the interests of informed consent, involvement was voluntary and the purposes and intent of the research were fully disclosed to those contacted prior to their taking part in an FGD. Therefore, it is possible that those who had accepted the invitation to participate had a pre-existing interest in PWID or ID in general, and were more willing to do so on this basis. This

leads to self-selection bias where “the extent that respondents’ propensity for participating in the study is correlated with the substantive topic the researchers are trying to study” (Olsen, 2008, p. 809). Because the resulting sample does not represent the entire target population, the data drawn from it will be biased. The conditions of ethical approval for the research meant that circumventing this bias by involving participants without their full knowledge of the research content was not an option. Instead, efforts were made to recruit as many participants as possible from a range of sites and backgrounds so that even within the confines of participant self-selection, maximum diversity might be obtained.

4.4.2.4 *General criticism of qualitative methodologies*

A difficulty with conducting research with qualitative components is the almost instant pitting of the methods against those of quantitative approaches. While quantitative methods are considered imbued with “scientific logic, neutrality, and truth”, their qualitative counterparts were relegated to use in exploratory studies, pilot tests, and cases studies at best and at their worst, viewed as “unsystematic, impressionistic, and unreliable” (Hallberg, 2006, p. 142). This is due to a misfit between the standards to which quantitative and qualitative work are held, whereby the “usual canons of ‘good science’” apply equally to both fields but need “redefinition … to fit the realities of qualitative research and the complexities of social phenomena” (Corbin and Strauss, 1990, p. 5).

Efforts to counter negative views are complicated further by the common misunderstandings that surround the most prominent of qualitative approaches – grounded theory – “the discovery of theory from data” (Glaser and Strauss 1967, p. 1). It is from within this field of thought that the FGD data collection was conceived and conducted. Grounded theory, rather than an explicit qualitative method, is a “general methodology for developing theory that is grounded in data systematically gathered and analysed” (Strauss and Corbin, 1994, p. 273). The ontological and epistemological

interpretation of the theory varies among its adherents (Annells, 1996, p. 379) and beyond this, the practical execution of research carried out under the banner of "Grounded Theory" often deviates so far from the theory's original principles that the final work cannot be recognised as such (Corbin and Strauss, 1990, p. 6). Because of the frequency with which the latter takes place, the very mention of using grounded theory in research can prompt a sense of uncertainty as the term has become a misnomer (Baker, Wuest and Noerager Stern, 1992, p. 1355). Despite this ambivalence, the use of grounded theory in this research was considered appropriate and, as such, the data collection and analysis were conducted as inter-related processes, "grounding" the theory in the study setting.

A criticism of qualitative analysis is that its outputs are determined by researchers' subjectivity. This can lead to bias, undermining objective understanding of the issue at hand. However, subjective processes including perception, analytical reasoning, synthetic reasoning, and logical deduction can contribute to objective knowledge and "enhance objective comprehension of the world" (Ratner, 2002). Additionally, an advantage of recognising the chance of subjectivity is to "reflect on whether it facilitates or impedes objective comprehension … [The] distorting values can then be replaced by values that enhance objectivity" (Ratner, 2002). In this research, this meant careful reflection upon the researcher's own biases and employing independent colleagues to check the codes and categories formulated.

4.4.3 *Introduction to findings*

From the FGD data, themes were generated detailing CSWs' assessments of cases concerning the children of PWID. In the following chapters, the factors composing their parental capacity assessments, the support and time they are able to give families, and the constraints involved with these are presented in detail. They provide context and explanation for the findings from the questionnaire-based experiment and the serious case review analysis, and this will be discussed further in Chapter 7.

CHAPTER 5

Focus group findings: Parental capacity assessment - Information gathering, assessment, and decision-making

5.1 Chapter overview

This chapter discusses how participants gather and use information. The factors that contribute to decision-making are also described.

When a CSW involved in child protection is referred a case, they must work with the information at hand to build an accurate picture of the family in question and decide how to proceed. This requires gathering information from a number of sources which is then evaluated for quality and content. The process of information gathering is continuous and assessments are constantly reviewed in light of new information and changes within the family. The participants navigate through the mass of available information guided by their own understanding of each family's needs while prioritising children's wellbeing.

Parental Intellectual Disability (PID) may be known beforehand or discovered during the course of children's social care involvement. In either case, the participants appeared to assess the impact upon individuals' capacity to parent their children safely, bearing in mind the accompanying factors that also influence parenting capacity. PID disclosure is incorporated into participants' decision-making in various ways because PID may be one of many components in a family's circumstance to be considered, weighted, and addressed accordingly. Participants' decisions are also led by factors such as their own judgments of information quality, the emotional impact of their work, and scrutiny of their working practices.

5.2 Information gathering and assessment

5.2.1 *Identifying Parental Intellectual Disability (PID)*

The participants' experience was that parents' ID was often unknown prior to contact with social care in reference to their children. The task of detecting ID and acting accordingly then would fall to CSWs. When first assigned a case, participants familiarise themselves with the family and the concerns at hand. Some issues are more glaring than others and participants described how at this early stage, undiagnosed ID was not a usual consideration and was commonly unnoticed. Detection requires that participants are able to recognise signs of ID, which people can be adept at disguising:

"[After being involved with mother since pre-birth] baby is now 6months, it was only two months ago that it became apparent that the mum couldn't read or write, because … no one had thought to ask her, … because it's not automatically something you would ask." *#82p69B*

"'We knew she'd gone through mainstream school …' '[so] you…assume, don't you?' 'But she might have failed everything at school … she might be one of these that never … got to a statement [of Special Educational Need].'" *#82p69B*

The participants felt that parents' unease with disclosing their difficulties contributed in part to problems identifying ID. They were thought to be reluctant, embarrassed, or fearful of admitting when they did not understand:

"[Parents'] not wanting to say, 'I don't understand what's going on.'" *#13p29C*

"'I ask people if they understand but … just to get rid of me, because I go on a bit, they might just go yeah.' '… maybe they're just embarrassed to say that.'" *#13p69B*

Parents might adopt techniques to navigate contact with professionals or mask their difficulties, complicating parenting capacity assessments and limiting participants' confidence in their findings:

"They can mask their … ID as well, because they've learned to manage their environment, and … on first appearance, you wouldn't necessarily know; it's not until you get to know the families." *#8p5C*

"Mum's quite capable, well ... she seems capable … but … you could question that." *#8p40C*

The result was that participants felt they could not rely on parents' assurances, limiting the prospect of genuine progress with families:

"They haven't really understood, although they have made out that they have understood, but they haven't actually, really." *#8p13A*

"You can explain all of that and you get that level of understanding and you think, ah, I think we've cracked it now … , [so] you put a contract in place … to do very attainable tasks and then, you realise halfway down the line that actually, they haven't really understood." *#86p13A*

However, participants also used tactics to discretely verify parents' needs while not causing offence:

"[On broaching the subject of LD with a parent] I'd … approach that like, '… how did you do at high school?' And sometimes they just tell you then that they had extra help." *#2p70B*

Parents' tendency to mask disabilities was not specific to interaction with CSWs but rather part of a pattern that forms over time, in response to an unaccommodating social climate that has readily overlooked their difficulties:

"'Because it's not seen, and it's … hidden in a way, isn't it?' 'And they are normally very, very good at hiding.' 'They've probably coped all of their lives with not telling people.'" *#8p69B*

5.2.2 *Relevance of PID*

The standards to which PWID were held, the relevance of ID, and what constituted "adequate parenting" were discussed at length. The participants considered the relevance of PID in each scenario.

Participants first outlined the troubling aspects of the vignette and attempted to delineate what may have originated from PID from what was culturally "normal". Participants tried to separate the normative from problematic,

"But it is a practice for some religious [reasons,]… for … people in other countries anyway, so why would we intervene?" *#75p6C*

"'Or do they think that's the norm?' 'It's very much a cultural thing … isn't it?" *#75p8C*

They tried to understand and address where PID may impact, pinpointing where issues possibly stemming from ID end and other factors begin:

"Is that [the] family's values and they haven't been given any alternative option so ... they see that as the best way to bring their child up?" *#75p29B*

"Respecting their culture … but also educating them about choice and impact." *#75p30B*

Everyday problems can be amplified when examined under a safeguarding lens and participants seemed to try considering a range of possibilities, retaining a sense of perspective, before settling on conclusions:

"'[When a child is preparing their own meal,] if that bit was understood and unpicked then it might look very different.' 'It might be that Gran's been ill this week, she normally … does the cooking in the house.' 'And it could be that he's … refusing to eat anything but a bowl of cereal and refusing to do anything but do it himself, is that a parenting issue?' 'I think different things can mean a lot of things to a lot of people.'" *#75p15A*

"[Where there are fights between siblings,] I've known children to be quite hurtful with each other … [and] if I looked at it from a child protection point of view, there's something horrendous that is going on, but actually, it's just normal play fighting and they've got hurt." *#75p59B*

5.2.3 *Impact of ID on parenting capacity*

Participants stressed that there are several factors involved with child safeguarding to which no parent, regardless of ID status, is immune. The standards to which parents are held must be universal and participants appeared wary of being more stringent or lenient on these parents than they would be with parents without ID. The children of any parent may be subject to grooming and parents themselves may be disarmed by risky individuals:

"Even parents without any intellectual difficulties are groomed by perpetrators." *#74p25A*

[About a child in contact with a risky adult] "[There are] parents who don't have intellectual disabilities who say … they couldn't have done it, no, it's wrong ... and, therefore, they're going to carry on having contact with the child." *#74p23A*

Any parent could fail to respond appropriately to safeguarding risks. PWID experience the same peaks and troughs as other families, and participants were mindful that PID is not always the root cause of parenting difficulties:

"'I've had an 8 year old run rings around their parents [with ID], because she knew that she could.' '[Yes], but we [also] have that with [non-ID] parents.'" *#74p47C*

"'[Where there are siblings fighting,] you might have a 15-year-old girl sharing a bedroom with a 7-year-old … that could cause a lot of … friction' '… they've got all these kids in one room and they've had enough of each other." *#74p50C*

Participants reminded themselves that cases must be placed in the wider societal context, requiring “adequate” parenting rather than subjectively “good” parenting:

“‘We’re thinking … worst case scenario, but actually a lot of parents don’t do homework with children …’ ‘that [wont] … put you on a child protection plan, a lot of parents shout or argue a lot, and you wouldn’t necessarily put them on a child protection plan.’” *#75p15A*

“That’s normal kind of childhood stuff … [It is easy to] forget … that lots of these things are childhood experiences … [Otherwise] we could all be jumping at everything.” *#75p60B*

5.2.4 *Children’s and parents’ needs*

The participants considered several issues when safeguarding children. Regardless of their parentage, their safety is prioritised, decisions are made dynamically, and the child is kept central. Participants appear to strongly empathise with children, their position within their families, and how their and their parents’ requirements can be dually accommodated as children’s’ needs evolve over time. Participants attempt to equip children and parents with the means to reinforce and sustain the family unit. This requires identifying areas requiring assistance and matching them with sources of help that are available on a long-term basis.

5.2.4.1 *Parents’ recognition of children’s needs*

Children are inherently vulnerable regardless of their parents’ intellectual ability and the participants appeared to also understand children’s vulnerability in the context of their parents’. For PWID, their vulnerabilities could be related to symptoms of their cognitive impairment, such as information processing and application, or indirect factors, such as social isolation and economic disadvantage. All of these can impact upon parenting capacity with subsequent impact upon children’s wellbeing.

Parents’ ability to identify threats to their children’s safety is considered first and extra considerations are where there is PID. Participants seemed to feel PID could pose an

insurmountable barrier to parents being able to recognise their children's needs. This could be in terms of children's development and safety:

"The children … are really under-stimulated and … developmentally … not on track, it's the fact that [the mother is] … not seeing that her children are flat and under-stimulated." *#61p22A*

[About a mother with depression] "'Would a razor blade or a box of tablets be left around?' 'She might not get it …' '… that [these things] could get in the child's hands.'" *#63p38B*

Or, being able to effectively protect their children from serious abuse.

"It's really difficult when you work with parents with learning needs who are associated with adults … who pose a risk to children and getting them to understand … And sometimes you just have to take the children away because … as much as you try, they just don't get it." *#63p54C*

This pessimism could be due to participants' experience of parents being unable to overcome their difficulties despite being given support:

"'She couldn't understand the concept of him not choking on solid foods, she had a real issue about … understanding the dangers …' 'She wouldn't feed him any solid food … she was too nervous.'" *#63p20B*

However, participants would encourage parents to be mindful of their children's needs, emphasising how integral this is to the child remaining in their care:

"It is about the parents turning it round for the children, and if they are not able to do it … we can't carry on working with them." *#56p33C*

A cumulative understanding of vulnerability emerged - that when parents are disadvantaged, their children face the same disadvantage as part of the same family unit. This is compounded by children's age and dependence on their parents for safety, and additionally so when their parents' ability to recognise and address risk is compromised.

An example is a family's socio-economic status, to which their children would be equally party:

"If [parents] have no money, no food ... we would be looking to protect that child and make sure that they were fed." *#63p48B*

Extending this further, participants felt these families were often victims of anti-social abuse and reflected on how children might be uniquely affected by this:

"[Is] this… quite a vulnerable family? … The glass has been broken by somebody else, a neighbour? Are these victims?" *#63p2B*

"[Are other children] bullying … saying horrible things about [the child's] parents? … perhaps [the parents] are not managing their money very well, so we can get you this and this, don't tell your parents." *#63p45C*

Participants were concerned about parents' ability to adopt age-appropriate parenting methods and the implications of not doing so:

[About a child's social life:] "Do [the parents] know where they are? What arrangements [are] in place, do they have a phone, are they calling their parents, what time are they back? All those sorts of things that you'd … be talking to parents about, and getting an understanding of actually how safe is this child." *#63p46C*

"It's a hard thing, because [children of PWID] wouldn't have parents to give them support with school or homework ... All those things that they need, discussing friendships and things, it's quite a lonely place." *#63p48C*

A major concern was the risk of sexual abuse to children. Parents were thought to be targeted by potential abusers for access to their children, leading to two levels of grooming - of both the parents and their children:

"My experience … is [that] parents who have got learning needs … predatory people … prey on these parents to get to the children, sex offenders … they've actually groomed the parents to get to the child." *#63p53C*

All of these elements act within the vacuum of the family unit but several other factors influence children's wellbeing such as their own resilience, protective familial and social factors, and the provision of support services. Without these, an assessment could be quite different.

5.2.4.2 *Taking cues from children*

The complex presentation of some families can lead to children being overlooked. Confronted with the emotional investment and sheer volume of work to be done with parents, participants often reminded themselves that they must remain child-focused:

"You can be sympathetic, but you can't be too sympathetic when they've got children, [you] … feel sorry for [parents, but] you've got to think … it's about the children ... so they may have this disability but … you have to weigh up [whether] they can

responsibly support … and look after their children and keep them safe … because with … any client group that we work with, you do feel for the parent." *#56p36C*

"If you give [parents] more chances … and you keep saying, 'Oh, let's give her another chance,' year after year after year, the child is left in that situation, by the time you move this kid … they are damaged." *#56p38C*

"With regard to parenting, you can't make concessions … if that's what the expectation is, this is how we need you to parent your child to keep them safe … You can't make concessions on that." *#56p14A*

Participants' actions are guided by children's cues, events are recorded and their impact registered:

"You make a record … so you can see … that this is happening again, there's no changes, and the impact … on the child's development." *#56p24C*

"'It all depends on the presentation of this child … if you've got a … really stressed child … who can't concentrate, who's upset all the time, then again you're looking at a different thing because actually, what else is going on ...?' '… if he's kicking off at school … or hitting …, shouting at other people ... because that's what he's hearing at home, …' '… or if … his actual physical presentation is not good ... then there's a level of neglect ... on top of what's already going on …' '… dirty clothes and things like that.'" *#56p45B*

The child's understanding and point of view is treated with great significance:

"Talking to the child … actually getting his take on it." *#56p2B*

"What does the child know about it, what is the child saying?" *#56p32B*

"What does that [chronic arguing] mean for that child, he might not understand that at all." *#56p46B*

Participants tailored their approach to individual children's needs and capabilities:

"[For this particular case] we weren't looking at … safety planning, or anything of that nature … the child's older and had the capacity … so it depends. Some of our children they wouldn't have even had the capacity … so it would depend on each case." *#56p43B*

Engaging with the child is the main focus and time allocated to family members is to benefit the child:

"This one-to-one work [with parents] … you're very privileged if you get time to do that work, if you are doing any work … it would be with the child, because you have to prioritise them." *#56p27B*

5.2.4.3 *Children's needs surpassing the abilities of their parents*

Participants felt that children of PWID who did not themselves have ID or developmental delay inevitably 'overtook' their parents, changing the family dynamic:

[About a mother who is not coping:] “What’s not helped … is that her oldest child is developmentally delayed so the other children are … overtaking him … [So] she’s not done that before and I think that is … why she’s struggling.” *#61p23A*

“As soon as they hit a certain age, we talked about taking over … being intellectually more advanced than their parent, that’s when … the difference … is the factor.” *#61p30A*

This seems to result in two broad outcomes – children exhibiting challenging behaviours in the absence of discipline or adopting responsibility to compensate for their parents’ difficulties. Parents were thought more able to cope with the demands of babies compared to the complex demands of older children. Parents’ ability to adjust according to children’s evolving needs and understand their growing emotional and intellectual intelligence was questioned:

“‘Your baby can be … predictable … [If a baby is upset] … you can … work out if … you’ve fed the baby, try the nappy, there’s a few options. But when you get a toddler or …’ ‘a child who’s walking, running, and running in the road ... windows ... that’s when you start to realise … that maybe somebody isn’t clocking those risks.’” *#61p26B*

“‘Seven year olds are pretty emotionally intelligent and even if mum hasn’t directly said how she’s feeling, it would be very obvious [to the child] …’ ‘… [and] mum might not get that … because of her own functioning.’” *#61p37B*

As a result, participants felt parents were increasingly challenged by their children as they grew:

“She’s finding it increasingly difficult to manage him as he’s getting bigger, … so, you’ve got this whole neglect thing, and as he’s getting older, he’s getting even more difficult … he’s got autism and he’s quite capable as well … he is a bright spark … so … he’s keeping her on her toes and she’s finding that … a really big struggle.” *#61p30C*

Participants described how children naturally test boundaries to learn limits for themselves and when parents lose control of their children during this phase, the result is a “role-reversal” where children wield more power than their parents. This appeared to be a common occurrence and many of the hypothetical scenarios were met with the question,

“Is this child out of their parents’ control?” *#61p47C*

Children’s unmet needs can result in behavioural difficulties that require intensive work to reverse:

[The parents are] "Unable to stick to implementing the boundaries, over and over … again, so the child understands … it's sort of a role reversal." *#61p53B*

"I worked with a family where … the children were a bit older than 7 but they've … been in control of the household finances, and they were spending money on what they [wanted] and going with mum … and choosing the shopping, and being very in control, to the point where Money Management have had to take over all of the finances, do the shopping … pay the rent." *#61p52B*

In these cases, the parents appear to be in a weakened position in relation to their children:

"'[Parents] need some routines and boundaries in place …' '… we need to help these parents … get control back ... from this seven year old and put boundaries in place … Because … it looks like they are being managed.'" *#61p51B*

"[The] daughter was 13 ... 14 … and hadn't got an intellectual disability whereas mum did and … could outsmart her mum massively, had total control of that house … Mum wasn't able to set out any boundaries, and we don't know … the level of the parents' intellectual disabilities … but a seven year old will probably, if they haven't got intellectual disabilities themselves, know how to play their parents … and it's giving them back that control." *#61p51B*

In these circumstances, some parents decide that their children would be best placed outside of their care:

"The children … [are] hitting and … as [they] … are getting older … they are overtaking mum, they are far more knowledgeable … they are … telling mum what to do, mum can't cope, so mum is … contacting the local authority, [saying] … you've got to take him away … because … this isn't working." *#61p6A*

"She actually decided, I can't do this … she voluntarily had that child adopted." *#57p21B*

Alternatively, when some children were able, they assumed household duties:

"You need to start identifying caring roles, … looking at … if the children are … practically doing things, … are they having to attend school meetings and relaying that information, … and identifying what kind of emotional … caring role they are providing." *#61p7A*

Participants appeared wary of these two patterns and included them in their assessment.

5.2.4.4 *Tension between children's and parents' needs*

The needs of parents and children are not mutually exclusive and while CSWs' primary role is to ensure children's wellbeing, this is often best done by improving parenting

capacity. Participants hoped to preserve the family unit and enable children to remain as long as it served their best interests:

"You are focusing on the child and the protection of the child but equally … first … you need to look at how you can support that child to … stay within their family, not to be … going down the child protection route when people … don't understand." *#58p18A*

In practice, however, balancing children's and parents' needs is difficult. While effective parental support is installed, children can be left in poor conditions for too long and expectations of what they can withstand can be too high. Remaining sensitive to this appeared to be a substantial task:

"We're looking to support [the mother] around things like boundaries, because she's keeping her youngest lad up in [his bedroom] room, we think, excessively long." *#58p30C*

"You do have to balance … [the parents' needs] … But … you have to think, this is about a child's life." *#58p23C*

Despite wanting to continue working with parents, the effects of leaving children in poor care are long-lasting and this is factored into decision-making:

"'We have to keep the focus on the child' … 'It's very easy to get … tied up … yes, the parents do need the support but even with that … Are they good enough parents to the children, are the children suffering from neglect?' 'Children's lives are just so short.'" *#53p22C*

"This young man has been … on a holiday … with an organisation, but some of his behaviours on that holiday are very clearly as a result of the neglect .... He's not under the care of his mother any more, but you … think … should I have taken the decision [to remove him] … earlier …?" *#53p23C*

Objective decisions about children's coping capacities are further complicated by the concept of 'young carers'. Young carers are under 18 and have social care support to care for relatives with substance misuse issues, disability, or illness. Children of PWID can qualify as young carers and assume household roles that would traditionally be taken by adults. One must ascertain whether a child is being officially supported in their young carer role and if they are able to cope with the demands this entails.

Participants were aware these young carer roles might emerge:

[At age 5] “They’re probably talking for their parents … taking over more understanding of the situations than maybe their parents, maybe not, but they could and that’s important.” *#54p9C*

While discussing the responsibilities children can be expected to handle, participants drew on their own experience of young carers and acknowledged that there is a high acceptability threshold for them:

“Actually, an awful lot of seven year olds … if they’re young carers … [would do] some level of ... food prep.” *#54p45B*

Participants questioned how much work a child could reasonably undertake. Tasks were considered in terms of what was realistic and children were not expected, for example, to be able to master food preparation, parenting roles, or cope with serious mental illness to a significant degree:

“He’s making his own meals … but … there’s a health issue … if he’s … obese because he’s making his own meals and … just eating … crisps and chips” *#55p27C*

“‘The sister could have easily taken over the parenting role of this young boy … and … obviously doing her best but not having a sense of [what to do] …’ … ‘… she’s trying to do the best she can.’” *#55p7A*

[In a case where a mother is suicidal] “[Does the child] know where to go … what to do if mum is either incredibly unwell or actually has died?” *#55p36B*

The emotional impact of young carer-type roles may lead to children being overwhelmed, feeling unable to rely on their parents, or frightened and worried about them:

“[Possibly] young carer again … this little boy … [may have] smashed [the window] out of frustration” *#55p2B*

“Just giving an example, if I went home and didn’t do something, I don’t think my daughter would think for one minute that [she should] … get up and do that, she’d still be quite confident mum would do it. So, it’s over a period of time that a child will begin to change and think … I need to do this myself, so that … does indicate that … something’s not been right for a while.” *#55p10A*

[When a mother has mental illness, the child might be] “Missing school because he is frightened to leave her in case she does something.” *#60p36B*

5.2.4.5 *Assessing families’ support needs*

The assessment process evaluates families’ support needs, continually monitoring the effects of service provision, and adjusting service-input. This begins with continual

information gathering, sifting through what is useful and deliberating on how to proceed. Participants constantly ask questions and examine cases from different angles, beginning with what could be gleaned from the parents themselves:

"I'd be looking at if the parents understand the risk … because that would be a worry if they didn't understand the risk ... acknowledging it." *#19p23A*

"Were they able to get [their child] to the hospital … [do] they require advice …? Is that something they were able to work out on their own?" *#19p1B*

"Do they have somebody to advocate on their behalf? If they're not able to express to us exactly what's going on in their lives? How they do or don't have capacity to look after their child and do they have somebody … that supports them?" *#69p3B*

Participants took cues from families and the information gradually shaped the path of investigation:

"If there is a broken window that hasn't been mended, what else is going on in that child's environment, are there other considerations … is that just one of many things? We don't know, do we?" *#70p2B*

"Do they realise that that is dangerous for a child? And if not, you'd have to be thinking … what else do these parents need?" *#70p2C*

Families' current level of service involvement is evaluated and gaps are identified:

"Talk to the parents … meet with them, because … this incident has happened but there's probably been a lot going on over the years in the family home, and trying to see how they've got to this point and what support that needs to be put in place." *#69p50C*

Extended families are also rich sources of information:

"Draw everybody in and all the support networks … the people that understand where [parents are] intellectually because they've grown up with those people and … understand their capacity." *#49p32A*

Parental capacity assessment started with evaluating individual capacity and how the parenting role is shared:

"'But there's two parents … So presumably one's there …' '… you really need to know what [is] the other parent's [capacity]'" *#49p20C*

The participants seemed assured that where there were two parents, each would offer individual strengths that, when combined, would result in adequate parenting. Cases of single parenthood caused concerns as there would not be someone to counter the other person's difficulties:

"You'd need to think about the co-parenting … they [might] ... interact … well and … somebody who is not good at one thing, the other person might … make up for that." *#49p19A*

"If it was going to result in a break up, you'd need to think of parenting capacity as a single parent … and how … you see the child best placed within that." *#49p19A*

If parents are coping, they are encouraged to continue and positive elements are noted:

"'If dad ... is … supportive with his child, and he is able to ... be there ... and help explain … why mum is being like this … [His] protectiveness …' '… we would [want] the family to manage that themselves, and let dad protect his child and not … have us to do that.'" *#49p39B*

[When a child is doing their homework without their parents' help] "He may well be getting himself up but he didn't get himself up at the age of four or five when he started school, someone has initiated him actually going to school, and they obviously see some importance, for the child to go to school." *#70p16A*

5.3 Factors affecting decision-making

Participants' decisions were informed by the information available. The information is first vetted for quality and pertinence, and subsequent actions are carried out with these in mind. They also described issues that frequently plagued PWID and their families, such as socio-economic disadvantage and isolation. These were so commonly encountered in practice that, when parents were noted to have ID, participants were alert indicators of these and were sensitive to how they might compromise parenting capacity. Further to this, participants were wary of how the presentation of PID may mask parenting difficulties actually caused by these other more subtle factors.

Participants' decisions were also be affected by their own emotional responses. They empathised strongly with parents and children, and the turmoil of entire families. This resulted in hastened contact with families to quickly meet the interests of children; prolonged work with parents driven by hopes of eventual progress; or a combination of the two where participants wish to keep families intact while meeting the sometimes conflicting needs of all family members.

Close scrutiny from Family Courts and the public works in addition to the above factors. It appears that the participants make decisions by balancing each of these while striving to ensure the welfare of the children concerned.

5.3.1 *Quality and utility of information*

The credibility of sources and the quality of information is considered prior to its use. This is because of possible bias or misinformation from other professionals and those associated with the family:

> "A lot of people make assumptions ... so where has that information come from?" *#23p4B*

> "The doctors wrote all over the place the parents have learning disabilities and they didn't, so … checking those facts … and actually [have you] … got a mum [who] is struggling with the situation?" *#74p3B*

Others may tolerate lower parenting standards, jeopardising their reliability to contribute to assessments:

> "[One must] pick up whether [people] are going to excuse behaviour because of any disabilities." *#25p25A*

Participants decide how information is best used by identifying salient items and considering the required actions. When information pertained to future risks, participants were wary of pre-emptive action but were mindful of failing to act:

> [About a child's arranged marriage] "I don't think there is a role for us yet … unless they're concerned about them taking the child away from the country …. I don't know." *#76p6C*

When information relates to a future risk, participants work preventatively by educating and entrusting parents with children's safety. When unused, information can be lost as cases are closed:

> "It's helping the parents understand that the abuse is not going to take place then and there; it could take place in 5 years' … a perpetrator can groom a child within supervised contact effectively and then … when social care have gone and everything has blown over and they haven't been found guilty, … that [is] … when … there's a great deal of risk, when people start to forget." *#76p28A*

These decisions are particularly difficult when participants can foresee future parenting difficulties but hope to prolong the period children spent with their parents. The relative risk of each choice is evaluated:

> "That's the interesting thing in terms of neglect, where you've got them at a younger age ... It's … hard … to say, looking into the future. So they're doing alright at the moment but it's not going to work out ... Child protection for the child, that's quite a difficult route to go down ... But then you've got the longer period where they've got their parents." *#76p48C*

However, though the participants appeared to abide by the principle of children remaining in their parents' care where possible, decisions can only be based on available information and absolute certainty is rare:

> "These sorts of questions are just so difficult because it could be all sorts of things, couldn't it, at the end of the day." *#76p17A*

5.3.2 *Issues unrelated to PID*

Participants were reluctant to tailor responses solely around ID for fear of overlooking other issues:

> "She has got an intellectual disability, she can't read or write but actually, she's quite lazy … she … can't … be bothered, and that's nothing to do with her intellectual disability." *#74p61B*

Focusing on PID alone can leave other causes unaddressed, resulting in inappropriate support. Decision-making hinging only on PID would be discriminatory.

> "Every single … support [this family has] been offered, all of the work …, everything that's ever been assessed … has all been around their intellectual disability, and that is a factor but it's not the whole picture, there's also a lack of motivation, really poor parenting when they were growing up so they've not learned to parent … lots of other factors but everything's been focused on disability, absolutely everything." *#25p61B*

Placing undue weight on PID may lead to leniency and lowered parenting standards:

> "[Do] you think, that we sound quite understanding? ... because it says they might have intellectual disabilities? ... because we rush out [normally] when it comes to forced marriage … and obviously they're seven [years old]." *#25p31B*

Participants described the impulse of other professionals to link families' difficulties to PID, but expressed how CSWs are uniquely placed to be receptive to the all of a family's needs rather than to cater to just one:

"That's part of the assessment process … you … have to analyse it … you have to try and find meaning to it, … it's only natural that people would try and seek … reasons … [but] we don't always have the answers, that's the key." *#74p62B*

"They don't want to think the unthinkable ... and this is what we have to do as social workers, other people don't want to do that … it's easier to … link it ... [to] the disability." *#74p64B*

In some cases there was ambivalence about how PID factored into decision-making and participants stressed that their treatment of PWID would be no different to that of others:

"This whole thing about the intellectual impairment, I don't know how much it fits automatically with my decision-making; … this would be the same for any parents." *#18p21C*

"The suspected intellectual disability doesn't change what we would do … I don't think … [when] somebody [is] … at risk of self-harm ... that the disability thing is necessarily relevant … our response would be the same." *#18p37B*

The participants appeared reluctant to emphasise PID in relation to other issues at hand. Instead, they appear to address the ID as concerns relating to it arise:

"I wouldn't be focusing on the intellectual ... capacity of the parents … If they seem to have functioned up until that point … I wouldn't … look at that as an issue.." *#74p1A*

"I'd only maybe be thinking you maybe need to do some extra work if I was feeling that they weren't grasping the reasons [for my concern]." *#24p4A*

5.3.2.1 *Socio-economic disadvantage and vulnerability*

Mentioned several times were the additional vulnerabilities faced by PWID. These are unrelated to their disability but instead associated with it. Therefore, PID alone was not considered to be a major cause of support needs but rather the families' tendency towards disadvantage:

"'It's not just about the learning disabilities; there are lots of other social and economic things.' 'But probably they are all inter-related with the learning difficulty … more likely to be vulnerable, have housing issues, benefits issues.'" **#***11p25B*

The presence of sometimes numerous associated vulnerabilities can result in complex cases:

"'Parents who have learning disabilities and how they do struggle on a lot of levels … being more disadvantaged in terms of work opportunities, income, children's outcomes … so we're just trying to support [the mother] as best as we can ... but it's mixing with

all the other bits and pieces.' 'Nothing ever as simple as it is on a piece of paper.'" *#11p22C*

In the absence of such factors and with the necessary support, PWID may not come into contact with children's social care at all:

"There must be lots of parents … that have got learning disabilities but they must have such good family support that you'd never find out, they didn't need our support." *#74p25B*

5.3.2.2 *Social isolation and lack of parenting models*

The parents were thought to be more socially isolated and lacking support networks than parents without ID. As a result, parents were considered likely to seek support and closeness from those working with their children, or elsewhere:

[A mother who is close her social worker] "The bigger picture is the lack of support where somebody else might ring their own mum or a friend … she has to tell a professional because she … sees that as a friend maybe." *#12p11B*

Parents' isolation might make them more vulnerable due to the potential dangers encountered while seeking friendship and social connection. Parents may be unable to discern whether information comes from dubious sources:

"They are isolated socially they don't learn anything different … that would impact on their parenting and their understanding of life and then with the whole … explosion of internet … they're getting onto Facebook, they get in a real muddle … the pop-ups … that they … click on and they don't realise and they get in a muddle." *#12p31C*

Parents were considered more impressionable due to a possible interaction between the lack of social ties, exposure to suspect information, and the cognitive effects of ID:

"Did they hear someone say it, because people tend to pick up stuff, don't they, so maybe they know someone who has done it and they thought, 'Oh, that's what we're going to do.' 'The vulnerability of these … people with intellectual disabilities.'" *#9p8C*

"They learn how to live from the soaps … if it's on the soap, that's how you do it. So they are not able to understand that … is not the best way … they take everything at face value … I've certainly worked with young adults who … copy that sort of behaviour and they just think that's how you behave." *#9p30C*

A further danger caused by such isolation is that of being targeted by those wanting to take advantage of their vulnerability:

[A mother with ID, her] “Husband who’s mixed in … domestic abuse, he’s always smoking cannabis, they’ve got no money, they’ve got three kids and they’ve all got disabilities, they have huge amounts of money coming in and I can’t see where it’s being spent … it all goes into his account, she [cant] … advocate for herself in her family situation.” *#22p22C*

“But [PWID are] just even more vulnerable to being groomed by perpetrators … [they’ll say,] they are such nice people who have been to see me … and they said that they’ll take [the child] out for a walk.” *#22p26A*

In addition to parents’ limited social ties, they are often disadvantaged by their own upbringing. Participants described how absence of parenting models during parents’ childhoods meant that they were often ill-equipped to parent own their children, forming part of a cyclical trend:

“‘What is that … teaching that child, … what is their parenting going to be like …? Because that can get on a vicious cycle.’ ‘… she experienced neglect [as] … a child and now she is chronically neglecting her children, and it isn’t just down to the intellectual side of things … there’s a lot more to it.’” *#15p63B*

5.3.3 *Emotional impact of work*

Working in social work seemed to emotionally impact upon the participants. This played a role in their assessments and working with PWID appeared to present additional, unique challenges. They appeared to empathise strongly with children and parents, hoping that they succeed. To this end, they work more intensively than they would for other client-groups and were compelled to advocate on parents’ behalf. Such emotional entanglement can cloud objectivity and parents finally are given too much time to improve their parenting, jeopardising children’s welfare. Participants’ work is closely inspected by courts and society, with particular scrutiny of their work with PWID, in relation to parents and children. Certain outcomes are sources of great regret and this can influence practice.

5.3.3.1 *Empathising with the child*

Participants appeared to take their child-safeguarding role very seriously and were anxious to not overlook any indication of risk. Many would try imagining every

eventuality to prepare themselves for the worst and so they can be sensitive to all signs of concern:

"It's so you can cope if it is the worst case scenario, so when you go home at night ... you've … prepared yourself ... It's like our own coping strategy." *#97p35B*

"'[Everything] crosses our mind …' 'You'll hope for the best but you have to have the unthinkable in your mind ...' '… you have to do that so you've covered all bases really, if you don't … [you may miss something].'" *#97p34B*

They empathised strongly with children and frequently noted that those who have PWID might be "voiceless" or left wanting:

"If they've got parents with intellectual disabilities, you'd hope that young carers [were] … involved … that would be another place for the child to have a voice." *#93p8C*

"When … decent boundaries [are not] in place, we see kids … going extreme … But they actually, really want parents … to take control. They need that safety and ... they don't get it. So they just keep pushing more and more." *#93p53B*

Participants used PID disclosure to explain some children's behaviours such as when they take on self-care practices or parental roles in relation to their siblings, or behaving in an out-of-control manner. However, they also would look beyond PID and considered other causes for children's behaviours.

"'[When a child is acting out] … that could be quite a natural thing … because all children …' '… push boundaries …' '… they get to the point where they test, don't they?'" *#93p52B*

5.3.3.2 *Empathy towards parents*

At times, participants seemed more optimistic about what could be accomplished when working with PWID than parents without. For PWID, their difficulties may due to a missing support component that, if arranged, would improve parenting whereas where parents do not have ID, their acquiescence might be harder to overcome.

"[The child has] … been telling us for weeks that the window … not be repaired, but there is nothing wrong with mum and dad's intellectual abilities, they just can't be bothered."

They seemed personally invested in their roles, resulting in enthusiasm for affecting positive change. They often imagined themselves in the parents' position and incorporated that perspective into their assessments. They seemed to see ID as a

lifelong struggle that is frequently misunderstood, for which society did not adequately cater, and presented people with a unique set of needs:

> "A family who couldn't speak English, you wouldn't not get an interpreter for them, would you? But why then would we expect a parent with an intellectual … disability to turn up at a conference and understand what was going on?" *#90p68B*

This empathy allows participants to understand and share parents' feelings; they are able to walk through each stage of child protection alongside parents, see the origins of behaviours and anticipate their reactions. This awareness and recognition of parents' feeling allows participants to adjust their approach based on parents' cues where appropriate, resulting in more productive working relationships.

They felt parents might be ashamed or fearful of disclosing their difficulties, and noted they might behave similarly if in the same position:

> "They've probably coped all of their lives with not telling people [about their ID] because it's not something you'd shout about, is it?" *#90p69B*

Parents might be wary of services and their consequences and participants were sensitive to parents' circumstances and the issues they might face:

> "I went to go and tell a mum with a learning difficulty that I was putting her daughter on child protection and she started screaming …, absolutely wailing … she thought, my saying child protection meant that I was going to remove her daughter there and then." *#27p11B*

> "'[A cycle of] poor experiences, so for her so, the expectation that she would have of what a mum does would be, wouldn't be the same as you or I would have, and that's based on her own experiences.' 'Her own values and education.'" *#90p9B*

They related to how being subject to child protection procedure would feel, and perhaps because of this empathy, go beyond their usual duties:

> "The parents are really doing everything they possibly can, and working with everybody that they possibly can." *#90p58B*

> "It is quite difficult … when … children [are] in care and a parent [wants] to save their [child], see their child, it can be really hard for them." *#90p18C*

> "We did masses of work around it … we did … a progression ... made the solid foods go from ... literally liquid to small chunks, oh we did loads, so we did it slowly over time and worked through work sheets, what you could choke on and what you couldn't, all sorts." *#89p21B*

This appears to be because the "usual" approach did not always work and participants needed to be creative, drawing on their own ideas:

> "You have to work that much harder with these families … it's more intensive and you really [need to] be there to support them and make sure ... that it works." *#89p35C*

Participants recognised that they are uniquely placed to protect parents' interests, particularly when they work with other professionals. They recognised when parents had low self-esteem and encouraged them to dictate the terms of their service interactions, as parents without ID would. The participants defended parents in situations where they felt people had low expectations of what PWID could accomplish or treated parents unfairly:

> "Other agencies … if it's a grey area, something that they haven't … pinpointed, they might just then latch on to the fact that they've got a learning disability, which is really discriminative … [parents] might not be doing it because they can't be bothered, [or] … because they don't agree but they don't have the confidence … or the language to challenge it." *#23p62B*

> "[Other professionals] jump on them for every little thing that they do ... and actually, the other parents might do very similar things, but they've been targeted because of the [ID]." *#96p61B*

Participants felt compelled to advocate on parents' behalf as parents were seen as "voiceless" and patronised. They sought to use their position to empower parents and acknowledged that they must advise responsibly:

> "We … need to give people … voices if they don't have them … as long as they're given the right advice, that's the other thing." *#96p68B*

> "If ... [a PWID is] … struggling to cope and the only placement … available for that child is [far away] … then … have [parents] got the capacity and the ability to say, no, and challenge the local authority?" *#96p67B*

It may be tempting to overlook ID, possibly because of its subtle presentation and the dauntingly large mass of accompanying work required to effectively include parents in procedures. However, the participants seemed hopeful parents could overcome their difficulties and would do all that they could to that end. This seems to be because they felt parents' issues may originate from ID, a trait outside of their control, for which it would be unfair for them to be penalised or be deprived of the opportunity to improve:

"'[It] is very important … if parents do have an intellectual impairment … give those parents a voice … to understand and being able to be a part of that process and not isolated and … walked all over because …' 'that would be the easy way about it.'" *#96p34A*

"You try … because these parents don't mean not to do it and so … you try your best for them." *#91p33C*

Participants seemed genuinely pleased when parents progressed. This may be due to the volume of work and effort required, the closeness developed with families, and their desire to have a positive impact:

"'[The mother has] got one of her children now [after all of her other children were removed]; she had another one, who's with her …' 'Oh, brilliant, fabulous, so it took a long time but she's got there … oh, I'm really pleased about that…because I was really with her, I was with her when she actually decided, I can't do this ... she voluntarily had [her third] child adopted.'" *#88p21B*

It seems working with PWID can feel like working against impossible odds, where favourable outcomes are rare and routine procedures are highly problematic. These working conditions in combination with emotionally charged and highly empathic working relationships seem to promote over-optimism and unrealistic expectations of parents' capacity to change, where CSWs relate strongly with parents and are desperately willing them to succeed. Accepting when efforts no longer have sufficient effect appears to be a difficult process:

"Especially if you've been working with somebody for quite a while, [and] you … have to turn around and say …, 'We can't do this anymore, and we are going to have to take this particular route,' 'it's not easy.'" *#91p36C*

[A mother who had received lots of support] "Bless her, and even the last bit she couldn't ... after seven months she couldn't get the bottle right ... and I finally had to pull the plug [because] the baby was ... given Calpol by the bottle! So, you can't, you can't keep going ... and it was just sad really." *#91p39C*

This can lead to a sense of conflict where participants believe parents could achieve necessary goals if given more time:

"You have to keep it child-focused …, certainly, but, even just another week [working with parents] would have done!" *#91p32A*

Remaining objective as time mounts is a difficult task and parents can be given too much time as a result. Participants remind themselves that their evaluations must

adhere to an impartial standard of parenting, otherwise children are left in poor conditions for too long:

"We try, and that's certainly the case that I was involved in, there was criticism that actually, we spent too long trying to turn it around with the parents, we left those kids in that situation for too long, we should have got them out earlier, so it's a … real balance ... we've got to keep that focus on the kids and their needs." *#30p32C*

Finally, participants clearly regretted how events for some families transpired. Children could be left in their parents' care for too long or families were let down by the lack of appropriate support:

"'[The mother is] getting a disservice from us … because this isn't our expertise, and we are entering a child protection arena that ... with the right support may have been avoided ... So she's really been let down by the services …' 'And it's really difficult because … that child could … be removed from her mum ... with the right service ... she could be supported [and] ... if that didn't work then at least we'd know that we've tried everything, but if there's not a service there, it's quite a difficult thing to … reflect on and do really, that we are doing the right thing by a child'" *#92p8B*

5.3.3.3 *Scrutiny*

Participants appeared resigned to criticism relating to their working practices and their impact on families. As a result they seemed to feel they were in a thankless position and worked defensively, anticipating disapproval:

"I think we can't win … on the one hand you can say, have you been too sympathetic, have you left this child here for too long? And then when you go to court you're being asked, 'What support [have you given the parent]?' 'Why didn't you do it before?'" *#95p38C*

In child protection work, a final decision on a child's wellbeing by a Family Court is always a possibility. With this in mind, CSWs must keep accounts of their interactions with families, gradually building a dossier to inform a judge's ruling:

"When we get onto a child protection route ... it sounds awful but ... we're protecting our evidence from that point forth, ... to make sure that mum or dad has had every opportunity and we can communicate that effectively." *#78p17A*

Standards of practice upheld by courts ensure parents are given a fair chance of retaining care of their children, have been meaningfully included in the processes, and the participants must be able to defend their work:

"When you finished an assessment, especially when … [it] is going to be used in a child protection … I've [said to parents,] here's the report, I need to give this to you … however, here's a really simple breakdown, bullet point of ... what I'm actually saying … so that they can go into the conference with that, because obviously the report is for professionals and the family." *#78p16C*

"It's not just about identifying the neglect; it's how we've responded … and how we've supported the family to make that change." *#78p24C*

There are clear consequences of failing to adequately meet parents' needs:

"I saw a social worker getting roasted in court once … I think the mother had learning needs and they hadn't addressed it ... so ... I went for my first visit to see how [it was to be a] social worker ... in court and that's what I saw and I thought, 'Oh my god!'" *#95p37C*

Fear of admonishment presents an incentive to demonstrate efforts to work with the disability in mind:

"That's why we put the services in, that's why you support them, so you [can] say, 'Well, we did this and we did this, we done that for six months but nothing changed,' so you can't just roll out, ah, I think they've got disabilities. So that's why we have to work with them … [Otherwise] you get roasted!" *#95p37C*

Providing evidence of ensuring equal opportunities is integral to a case "holding up" in court. If such evidence is lacking, work with the family must begin afresh:

"When you're in court … being asked questions about what has been done to ensure that that person has actually understood and if it hasn't been demonstrated effectively enough, then you go back to point A again." *#95p15A*

However, there appears to be further tension between swift action for the child's benefit and the time required to implement parental support and build strong cases:

"You … think, well, should I have taken the decision … earlier than I did, but it's about evidence a lot of the time … It's about having clear … significant evidence." *#79p24C*

"Use stuff right from the start ... [So] you've got [parents] understanding what's going on ... But that sort of thing takes time to organise!" *#79p39C*

5.4 Discussion

Based on the findings of the focus group discussions (FGDs), it is clear that a number of components are incorporated into participants' decision-making. The process requires extensive information-gathering, including establishing the extent of PID, the degree to which it impacts on individual's ability to parent and determining its relevance

in light of any other issues families might exhibit. CSWs must essentially build a complete picture of families, starting with only the barest of information.

The participants demonstrated an almost constant tension between the considerations made for parents and those for children. They viewed families holistically, recognising that the needs of both were inter-connected – supporting parents is often to the benefit of children. Problems arise when the urgency of immediate risks to children outweigh the benefit of ongoing work with parents – parents are given opportunities to improve their parenting but this is not to be done at the expense of children's long-term wellbeing. However, the difficulty is that circumstances are not always as clear as this, risks to children might emerge gradually and subtly or parents demonstrate change that is not sufficient over long periods of time. These patterns are easily discerned in retrospect but not so in the midst of a case. There are a number of other forces at play such as becoming personally emotionally invested in cases or acting cautiously in the face of intense scrutiny. Participants strive to attain a balance that best suits the needs of children who deserve the best possible parenting and for parents, the chance to be supported in their role to the best of their ability. At times, because of the prominence of parents' needs and the empathy they evoked among the participants, remaining objective as these close, often long-term, interactions developed, proved difficult. The result is that children can be left in poor parenting conditions for longer than can be justified by their parents' progress.

CHAPTER 6

Focus group discussion findings: Support, time and resource pressures

6.1 Chapter overview

In this chapter the allocation of support for parents with intellectual disabilities (PWID) and the obstacles faced by the children's social workers with whom they encounter are described. These factors include those presented by the families themselves, other professionals, and the availability of the relevant services that affect the procurement, delivery, and uptake of support. All of these factor into child- protection decision-making as they dictate the viability of supporting these families in a manner that would allow for children to safely remain in their parents' care.

6.2 Support for families, PART A: Obtaining access to services and effective engagement

After assessment, the participants connect families with the necessary support so that, where appropriate, families can function safely without active intervention from children's social care (CSC). In cases where parents have ID, securing long-term support appears to be crucial for children to remain in their parents' care. Without this, children may be subject to child protection procedures for long periods of time and face the possibility of being removed. This is because participants found that after years of safe parenting through early childhood, children's needs as they grew up could extend beyond their parents' ability to meet them. With this in mind, the participants aimed to equip children with information and the general means to promote resilience and increase their ability to cope and flourish within their family unit despite their parents' difficulties. They identify reliable sources of support and guidance for children other than their parents. Such support may be located in the extended family and available services.

Securing long term support for children and parents respectively, each present challenges. For children, usually there are a number of universal entities such as schools or activity clubs that can be readily engaged to additionally promote wellbeing. Formally involving services in addition to these can create cases that are difficult to steer, where there are several professionals with overlapping responsibilities and their own individual restraints. With regards to providing services for parents, participants face issues with availability and access to services; and difficulties surrounding effective, productive co-working with Adults' Social Care (ASC) professionals.

6.2.1 *Support for children to remain with parents*

The families headed by PWID with whom participants had contact often faced the grave outcome of children being removed from their parents' care, framing the importance of effectively delivering support. Participants found that as children progressed from early childhood to young adulthood, their needs became increasingly complex and for some PWID, beyond their parenting abilities. As such, the aim for CSWs is to secure long-term support for families that evolves with children's changing needs and provides parents with the best chance of retaining care of their children.

6.2.1.1 *Promoting resilience in children*

Participants view children of PWID as particularly vulnerable as they might lack certain supports to navigate the trials of growing up, such as school and friendships:

"It's a hard thing, because they wouldn't have parents to give them support with school or homework ... All those things that they need, discussing friendships and things, it's quite a lonely place." *#59p48C*

"I think, it's tough for kids like that, and they often start to fail at school, they don't turn up for lessons … if you get through to senior school, it's really, really hard for them … because they just haven't got that back up at home." *#59p49C*

As a result, participants focus on replacing the missing components by enlisting existing actors in children's lives or social entities, such as relatives or club leaders to supplement children's developmental and social needs:

"For a child becoming more able than their parents … think about things that can help that child to cope … what other things can they get involved in, can they do cubs, can they getting involved with swim club, to make sure they've got stuff going on that that keep[s] them in contact with other positive adults to help them think about how they grow." *#59p48C*

"If [parents] can't do it, ring other family members or other people that can help them, to support them to do it." *#59p51B*

Young carer support would meet the specific needs of a child who has parents with a disability:

"[With young carers,] they would have the support network … the activities but they'd also have people, getting to know their mentors, they'd have people to talk to about things … to help them have a voice …, or [discuss] concerns about their parents." *#59p8C*

Participants described how children are educated about risks so they are not so reliant on their parents to beware of them:

[Relating to predatory adults] "The child is only seven, so they'd just need to know that you just can't sit there on your own." *#65p51C*

"Work with some protective behaviours, work with the child … what's good touch, bad touch … always tell." *#65p23A*

Participants also work with children so they can handle issues relating to their parents, limit immediate risks, and prevent negative long-term effects:

[Supporting a child whose mother has mental health issues] "So this child knows … I'll go to grannie's or grannie comes to stay, or ... dad then goes down to these shifts at work ...What helps this child become resilient, where is the support network for the child ... what plan of action does the family take on ...? Because if that's [organised], children … are perfectly fine and manage very healthy lives … but if that doesn't exist and this child is … holding this parent up, then … it's a different situation." *#65p39B*

This approach appears to demonstrate acceptance that parents' difficulties may be long lasting and instead focusing efforts on children is more fruitful:

"This child is very healthy, very resilient, and … understands … this is my mom, I can't change it … living with my mom is a bit like a rollercoaster but there's lot of positives as well, and ... That seems to have had a really, really positive impact because, my

approach before would have been just to firefight and manage mom, which is impossible." *#65p42B*

"I worked with a ten year old … her mom had self-harmed for all of her life … she'd had so much input from mental health services … and there was no change so … it wasn't going to change, the focus then was trying to make sure the child was protected and safe … emotionally." *#65p41B*

6.2.1.2 *Using family networks*

The extended family is assessed to see which relatives can support parenting, and their roles in securing children's wellbeing are formally recognised:

"Use the extended family to see … who could give support, what support can they give and is it realistic? Because sometimes families can do that." *#49p25C*

"Do parents need more support, … respite with family members ...? I'd be thinking along the lines of a family conference." *#49p56B*

Relatives are approached and acquainted with families' circumstances, ensuring there is no ambiguity about the child's needs and the risks at play. The participants create accountability for the child's wellbeing and those not able to support the parents are also identified:

"Family group conferences really work because … the incident can then be told to everybody, and everybody understands what took place and there is no hiding from that and it's what they can do to protect … on that basis." *#49p27A*

"'"Hearing from other family members who will not always inform social services but other family members saying, this is totally unacceptable and this is how it's going to be and as a family this is what we are going to do, so." *#49p25A*

Relatives then have clear roles, forming a robust safety mechanism around the child so risks are not unnoticed:

"[Otherwise] people will tend to assume that other people will watch [over the child] or [that] it's just safe." *#49p27A*

"So that you're doing everything you possibly can do to keep that child safe and also to make the adults more accountable for their actions." *#49p24A*

"Talking to other family members … the family need to be aware of how to keep this child safe." *#49p25A*

This is particularly important when risks lie within families, allowing social workers to work directly with specific relatives and having the additional effect of alerting the family of the social workers' presence:

"It's reinforced very clearly to [the risky adult] … this case is on our radar, we will be doing checks and you have been told." *#49p24A*

"It's about saying to [the risky adult], don't put yourself in that situation, risk an allegation … get them to agree to step away as well. Because it's one thing telling the parents but if they will agree to take that step back." *#49p27A*

This is part of the wider process of supplying the parents with the means to meet their children's needs and monitor their success in utilising them.

Participants appreciated extended families as potentially rich sources of reliable, long-term support, particularly when compared to formal service provision. The drawbacks of formal services such as eligibility criteria and time-limited provision do not apply to family support, making it an invaluable asset:

"'Family group conferences [are] … the most effective means of support … with parents [with]…learning difficulties.' 'It doesn't matter how many services you put in place, and how well those services support that person … at the end of the day those services aren't going to be around forever and it is family members who … are certainly more reliable.' 'They may not stay there all the time … when there's a crisis they all come and pull together again and sort things out.'" *#49p32A*

"'If there isn't family to …' '... Fall back on …' '... it's really difficult actually, isn't it? When you've got an adult ... that doesn't quite meet the criteria for adult services.'" *#49p9B*

"Grandma was the protective factor in it all, if it wasn't for her, that little boy wouldn't have been with his mum." *#49p12C*

Family support can also work well combined with formal support provision:

[A case where a family's support was being withdrawn] "And that's really hard because actually, dad was a hugely protective factor in this family, mom had her own learning needs and mental health needs, but he was the person that kept that family going." *#49p35C*

[A Special Guardianship Order] "If you're able to use that within the extended family … so that … daughter, partner and child could live with her parents, so that you've got the family bringing the child up, rather than [just] the parents." *#49p42C*

6.2.2 *Securing support services*

Social workers work with a range of services and professionals, and participants described connecting families to necessary support. The participants then secure contact hours and the case is formally closed. These other bodies can then monitor families and flag up reassessment needs with social care teams when necessary:

"They had hours … from Mencap, and so I could still make contact … even though they're closed to adult services [and] they don't constantly have a social worker. But if the need arises … they'll be reviewed …The social worker is not actively working with them … they … arrange the service and Mencap is picking it up and doing the work." *#44p5C*

6.2.2.1 *Securing support for children*

Options besides direct social care are explored to support children, bolster parenting, and cater for areas that parents were less able to fulfil. Childcare and education services appear to be a key resource, best placed for this role as they already have a higher level of contact with families than CSWs normally would. Organising and formalising these supports addresses the prominent concern among participants that children's developmental and educational needs are met. The social needs of the children were also considered to prevent their becoming isolated:

"'Schools nowadays; they … have nurturing groups for … kids who … have difficulties at home … bring all that into the child protection plan …'… being the agency that sees that child most regularly … [school] would also be able to liaise with other professionals if there was any other significant change … monitor the situation.'" *#45p11A*

"Look at school and see if there's extra support there, where they can do their homework with teachers and things like that … It's not necessarily just left down to their parents." *#45p44B*

"Find other things for [the child] to do … a cub group, or something ... to get him meeting other people his age." *#45p51B*

By procuring services and connecting them with children, CSWs activate a safeguarding responsibility for the child in the actors involved. This seems part of a process of "spreading" responsibility for the child – responsibility first lies with parents; it is passed to CSWs on referral; CSWs connect families with services who then have an obligation to ensure that child's wellbeing; and parents then have a corresponding obligation to support the child to receive these services. The result is the creation of several pockets of accountability towards the child, for their security and wellbeing. Participants also trusted that other services and actors have their own procedures that work in the best interests of parents and children:

"You … have to rely on solicitors to break it down for them … it's part of their job … each parent would have a solicitor and their job is to make sure their client understands." *#48p17C*

Where other services are best placed to take on certain roles, CSWs would only be involved insofar as they would signpost parents and delegate accordingly:

"The benefits agency … has services that if you have a learning disability or any ... form of incapacity, they have … specialist advisors that can help you. So I'd be turning to … the job centre and ask for a specialist assessment of some description." ca*#48p49B*

"'If he's lost his job ... and he's potentially been discriminated against, there'd be support from some sort of advocacy as well …' 'there's [Citizen's Advice Bureau].'" *#48p49B*

Participants described how contact and expertise of other professionals can supplement and reinforce their own roles with families:

"They've got a really good psychologist … in [a different locality], whose specialism is … parenting assessment … she will help [when she can]." *#66p19B*

However, working with other services can be awkward due to their large caseloads or their own difficulties in engaging parents:

"I sat in a meeting with a huge number of professionals … nobody … wanted to take responsibility for this going to a Team around the Child … They wanted it to be child protection and nobody wanted to cover it." *#46p35C*

"With an adult with a learning disability … the mental health service would often say, well you just manage that ... you're already involved." *#46p41B*

"Health visitors … because they want to stay on side with the families … they'll either do something anonymously which makes it very hard ... They don't always want to come forward with the things that we might be concerned about and yet … health visitors are the ones that are in a lot [of contact] with the families with young children." *#46p25B*

Often, several different services support families and the result can be a complex jigsaw of provision and monitoring, requiring intensive work from several professionals:

"'We get people in to make sure that … we've assessed the best way of communicating with them …' '… I'm communicating with all the professionals …' 'I'm … working on … a massive multi-agency hit … and every time somebody goes out to check in with her, and we are going to get an advocate in for her.'" *#36p20A*

The multi-agency, multi-professional working can make a case unwieldy, time-consuming, and difficult to manage:

"'You can have too many people involved, can't you?' 'In a meeting with a huge number of professionals around the table, five children, all with different needs." *#36p35C*

6.2.2.2 *Securing support for parents*

CSWs work with the intention of equipping families with the means to navigate through difficult periods and parent safely in the future:

"If we are looking at client support and longer term, [what are the] areas where they need additional support?" *#69p4B*

"Is … support for mum enough so that dad can concentrate on the child … protecting the child … the upbringing and all the care, if mom isn't able to do that because she's not in the right place?" *#69p21C*

After the degree of ID is established, parenting capacity is considered on a case by case basis to determine support needs and match parents with services:

"'You said "suspected to have intellectual disabilities", so we don't know ...' 'You'd assess and know for sure … before you [proceed].'" *#71p28B*

"'Because there are different levels of ... difficulties,' 'whether it is a level that is actually affecting the parenting.'" *#71p3B*

Participants described providing parents with parenting models to mimic, emphasising their role in educating parents.

"It was like teaching them … making up our tools … back to basics, all the things that your mom taught you." *#15p20B*

"That's really important … the teaching side of it …, the impact of … your behaviour has on your child." *#52p41B*

The final aim is for parents to manage without social workers' direct input:

"We would be wanting the family to manage that … themselves, and let dad protect his child and not necessarily us have to do that." *#3p39B*

Specialised services such as those provided to people with ID are allocated according to strict criteria. Users must have an ID diagnosis, an IQ of less than 70, established prior to service uptake, which can be a significant obstacle to accessing support. These specialist services are often provided by ASC, a separate body to CSC that operates largely on a voluntary basis.

Participants frequently refer parents to services as part of their job. These services often have acceptance criteria, for example, for prospective recipients to have formal diagnoses warranting support provision:

"The term intellectual impairment, if you'd said learning disabilities, I would have been operating under the assumption that they've got some sort of a diagnosis ... But we do have a broad range … [of] people … with borderline learning disabilities, that isn't actually a learning disability." *#72p3C*

"It's … a big thing in children's services, the difference between learning disability and learning difficulty, an intellectual disability, and determining a learning disability … they'd have an adult social worker or an adult social care team open to them on some level, learning difficulty not so much." *#72p4B*

They appreciated that rigid criteria often did not reflect parents' needs, which were often more fluid than the benchmarks allowed:

"'She is too high functioning for the learning disability team …'… but can't read or write.'" *#72p8B*

"'They wouldn't necessarily meet the thresholds for learning [disability] ...' 'and people don't fit into the little boxes.'" *#72p5B*

When ID is confirmed, it appears support provision is assumed:

"If you'd said learning disabilities, I would have been operating under the assumption that they've got some sort of a diagnosis and as such then they should then have some sort of involvement." *#40p3C*

However, securing diagnoses for parents can be daunting. Limited availability of diagnostic services creates a gap between parents' needs and provision capability. Participants reported not attempting to obtain services on parents' behalf for fear of wasting time in doing so:

"Unless these parents were actually known to adults services ... to try and get a capacity assessment on a parent that is not known to any adult services would be nigh on impossible." *#40p13A*

"If it's absolutely obvious [that the parent has ID] … that's the only way you can really work … The only … time we refer them to adults is when we absolutely are certain." *#40p17A*

In the absence of appropriate services or due to eligibility issues, participants described working with parents themselves:

"From my experience of working with parents with learning needs, none of them have met the threshold for … adult services or any other services like that, so … I've had to rely on doing the one-to-one work myself." *#36p29C*

Specialised services each have their own eligibility criteria and an ID diagnosis does not guarantee access to all services. Where families have multiple needs requiring expertise from several areas, there are several sets of criteria to meet. Where these are not met, holes in support coverage appear.

Families' needs remain despite support being denied and in such cases, parents experience inequality of opportunity:

"'They'd need to have a moderate learning disability to be eligible for adult's team … if their IQ isn't below 70 then it's not definitely a no but it's unlikely that they'd get support …' 'There are massive gaps in services [for] people who have a learning difficulty … usually there just isn't anything there.'" *#40p5B*

Where there are gaps in services, participants provided alternative support consisting of a patchwork of available services:

"There's no real support out there … so I'm trying to use connection floating support as a roundabout way of supporting her and … in the assessment [I've mentioned that] she's got borderline learning disability." *#43p13C*

"You have to be a bit creative about how we try and use the services that are available but it can be difficult with families with complex needs." *#43p7B*

Participants described how parents can receive help via their children's need:

"We are in quite a lucky situation because we have the care services for the child so we are looking at modelling with the care worker for this mother." *#43p30C*

"She's had that from Home Start with voluntary sector, so it's been the service for the child but she's, I think it's helped quite a lot for her." *#43p42C*

6.2.2.2.1 *Working with Adults' Social Care (ASC) professionals*

Services provided to adults, including specialist parenting support for PWID, appear to be administered by ASC. When CSWs are involved with children from families with PWID, their role is to connect parents' with the necessary services. In doing so, CSWs transfer responsibility for this support to their counterparts in ASC and the two teams work in tandem – ASC with parents and CSW with children. There appeared to be a

number of mediating factors for joint-working, such as establishing and maintaining relationships with adults' social workers, securing funding, aligning their respective interests and priorities, and overcoming scepticism about the viability of joint working.

Participants felt they must be resourceful when securing support services for parents. This included limiting expenses, persuading ASC colleagues to be flexible about eligibility, or using existing professional connections to complete tasks:

"'You might need to get a mentor … or their Mencap worker … if they meet the criteria' '… you can get an advocacy which we have to pay for …' '… if they've got a Mencap worker you can just use them … that's what I have found very useful! Otherwise you're paying an hourly rate!" *#66p28C*

"If you know the right people in the learning disability team then sometimes … you can ask for a little bit of help … so if they've just missed the threshold … but we have identified that there is an issue and they can see there's an issue … they will offer you a little bit of support, if you ask nicely." *#66p8B*

"We worked very closely with the adults' social workers and I've got relationships … and so I could still make contact … if I need to see those parents, I would arrange to get a Mencap worker … to talk with the parents." *#67p5C*

Effective relationships with ASC are vital but difficult due to teams constantly changing, and participants working as intermediaries between ASC and CSC admitted facing challenges:

"'It changes all the time …' 'It depends on who's in the team … how much they're willing to bend [about eligibility criteria].'" *#67p16B*

"'How many years have we been trying to … work in building relationships with adult services and …, even though it's a full time job for you … it's tricky' '… I wouldn't say we're still a hundred percent clear, ourselves …' '… this is why our roles have come about … to try and link better together.'" *#67p15B*

Participants appeared sceptical about working with adults' teams as they were perceived to have different priorities and their work seemed at odds:

"'I went to review a house with [a mother] … and the learning disability team wanted [her] to have this house because they thought it was perfect for her but I didn't think it was ideal for the children …' '… there's different priorities … in different teams.'" *#46p18B*

"'There isn't much collaboration between children and adults services, is there ...?' 'Really?' 'Not at all …?' 'Not in my opinion.'" *#85p16B*

Finally, participants felt families were most affected by poor inter-service working, making some more determined to hold ASC accountable:

> "It's like … you're working against each other … [ASC] gave the impression that [the mother] should [do one thing], but … I was telling her … the opposite and this poor woman was stuck in the middle." *#85p18B*

> "I would always advocate on behalf of the parent, because … that's going to have a positive impact on the child … what are … services doing to support this parent … Do they have a care plan … crisis intervention when they need it, all that kind of stuff." *#47p40B*

6.3 Effective engagement and families' service uptake

A CSW's role in child protection seems to be composed of an initial assessment followed by a series of trial and error experiments with various support services administered to attain a safe level of parenting, all within a time frame that is conducive to the wellbeing of children. If parents make the required improvements they continue to be supported to do so and if not, alternative supports are sought. With the addition of each support, families' progress is monitored and the impact is noted. Where all options are exhausted, or parents are unable to make changes in spite of support, or where children's wellbeing remains compromised, child protection procedure is escalated and children being removed from their parents' care becomes likely.

For these, there must be reliable and accurate assessments so the correct services are allocated and parents must be motivated to take up services and willing to improve their parenting. To this end, participants' must form open and productive working relationships with parents so they are more inclined to take up services and be receptive to advice – their engagement must be effective. The non-mandatory nature of some parenting support services present a barrier to effective engagement, but finally, participants made decisions incorporating parents' willingness and the efficacy of the support they are offering.

6.3.1 *Effective engagement with parents*

Ensuring children's wellbeing requires effective parental engagement as parents serve as a conduit for CSWs to provide support to children. However, there are obstacles to overcome - interaction can become fraught because of perceived intrusion into the family:

"[It can] be very hit-and-miss …, whether the parents feel that it's useful for their children or if they feel that it could be a possible threat … an intrusion … I found that with a number of families involvement can be … difficult." *#4p9C*

Or, parents are reluctant to engage with particular professionals, or use tactics to avoid contact:

"[I work well with her] but mum would not have spoken to [someone else], if she'd gone in as an initial visit, mum wouldn't have said anything to her." *#4p12C*

"I've got families and if they know I'm coming to visit, they hide ... Because they don't want to see you. Even when I had arranged a mentor or an advocate to visit with them, they'll be in the house but they won't answer the door. And they'll tell someone later … I didn't want to see them." *#4p10C*

In turn, participants described their own strategies:

"You've got to be creative about it! Find out where they go so you might turn up, you know they visit someone on a regular basis you turn up there, say, oh, just kind of popped in to see you. Or, I've tried to arrange a visit when [another professional is visiting]." *#2p10C*

Participants described redressing concerns so they were more appealing to parents, incentivising protective behaviours and engaging others:

[About a case where a relative is a "risk to children" and in contact with the child] "You can say to parents, look, if you're allowing unsupervised contact …, they are breaking their bail conditions … and I think that … [can] be more of an incentive." *#2p24A*

[Where a person who is a "risk to children" is in contact with a child,] "It helps parents if someone else is saying, this can't happen. Because then they can almost offload that ... [and] say that, well, I really want you to come round but actually the social worker says no." *#2p26A*

"You could include the [risky adult] in the agreement because presumably, if he's … [committed a crime against a child or young person] ... you could threaten him with going to the police." *#2p53C*

Participants appeared more willing to use imaginative means with PWID than with parents without, adapting the usual methods and ensuring input remained appropriate over time:

"I think you can be more sympathetic … to the situation, and … you work out how you are going to work with them." *#2p36C*

Finally, the aim is for parents to be informed and involved in decision-making relating to their children:

"Mum got a lot of services in her own way and actually helped support the decision-making for the future of the child." *#50p21C*

6.3.1.1 *Adults' Social Care (ASC) service uptake*

Participants' experience of ASC was that their services were often voluntary, so even when support is organised, parents' uptake is not guaranteed. Marrying the voluntary nature of some parenting support services with the reluctance of some parents to engage can undermine the objectives of child protection. This is because where CSC can adjust the level of obligation to take up its services depending on the urgency of cases, ASC cannot – they require consent. When parents decline opportunities for support, the work falls to the children's professionals who would need to compensate for the missing ASC component:

"One of my mothers … she was all lined up for going to specialist counselling, she wouldn't go! I don't need it; I don't want to talk about that, so that's that." *#5p26C*

"[About ASC,] 'Their whole ethos and the legislation that they work to is very different.' 'It's not about them having a responsibility to engage with the client, it's about the client engaging with them.' '[When an adult withdrew from services] … the focus was all children's services … [the] family support team [was] involved, and they were supporting the children.'" *#47p29A*

It seemed participants felt they could not rely on joint-working with ASC services as only when parents' capacity to consent is questioned would their services be non-optional:

"My experience of adult services is that, if you are deemed to be eligible then, yes, they will provide a service but if you don't engage then that service is withdrawn." *#5p29A*

"'If [parents] say no … that's it …' 'Unless you can identify a risk to that adult …' '… but even then …' '… The thresholds are high.'" *#5p7B*

Participants had experience of parents declining support, and proposed that the elective nature of ASC services may not be appropriate for PWID as they seemed more inclined to refuse services:

> "I have had … [a] parent [who] was known … as a young adult … to adult learning disability services … but then disengaged and … later in life … went on to have quite a few children but never did reengage with adult services." *#5p30A*

> "'[Responsibility falls to the service-user] which isn't always the right way round when you are talking about people who have got learning difficulties … they naturally back away from those sorts of centres … because they're too difficult to engage with ... There's no choice … if it's child protection, …' '… but the other, very much is.'" *#5p29A*

Working with children presents options unavailable to those working with adults because as long as there are safeguarding concerns relating to children, CSWs must remain involved regardless of parents' willingness. In the face of resistance from parents, child-safeguarding provides a route into families:

> "'If it was unsafe ... you'd have to do safeguarding …' '… put it in as part of a child protection plan, and say that that's what they needed to do to meet the needs of the child … they wouldn't particularly have a choice from a children's point of view, but from adults point of view they would.'" *#5p7B*

> "[When parents are resistant,] you've still got the child line, you've still got the framework for the child." *#5p41C*

CSWs must persist when parents appear to disengage:

> "Because we don't have [child protection] on the family anymore, it's just child in need so we have to work on good will with her to try and get her to move forward with things." *#5p13C*

Parents' engagement and adherence to plans are recorded throughout CSC involvement. All events, positive and negative, are catalogued and may finally contribute towards an overall case for the child to either remain or be removed from their parents' care:

> "[Written agreements] would be part of our evidence to show …, this is what you signed up to, you said that you'd keep this person away but … you've broken the agreement and that's part of the evidence that we would use." *#5p54C*

6.3.2 *Reassessment and monitoring*

Continuous reassessment is a significant feature when working with families. Monitoring over time and carefully noting behaviours and outcomes allows participants to look across families' histories, view them within their own context and hold them to objective standards. This requires meticulous attention to detail and for CSWs to be able to stand back and review cases. Parents' capacity to improve is reviewed as support is provided and improvement must suffice the child remaining at home:

"'The children … [moved from Child Protection] to Child in Need because they were making progress, developmentally, it was that specific …' '… but … in the longer term … [it is] whether that movement is enough.' *#80p33C*

"Is it making any impact, because sometimes you can put a lot of stuff in, and actually it doesn't change … anything." *#80p25C*

Reassessment is particularly important in cases of neglect. The subtle absence of necessary parenting actions compared to the more unequivocal signs of other abuse are less easy to register:

"'Neglect … can be so hard to evidence sometimes you just think this has been going on for such a long time and there's no major incident here, but these little things …' '…they add up, and just have to keep making a record of it … keep an eye on it, and evidence in … and also how much support's been put in place, all these things.'" *#79p24C*

"You make a record of that, so you can see … that this is happening again, there's no changes, and the impact of that on the child's development." *#80p24C*

Ultimately, the participants aimed to ensure families receive support that reflects their needs and cases are escalated or deescalated accordingly. Support must be constantly justified and is warranted by progress or adjusted when there is deterioration, otherwise it can be argued that conditions for the child are not improving and services are having no effect:

"Two learning disabled parents … we put in huge amount of support, with keeping the house tidy … but it's reached a point now where … they cannot, with all the guidance and support that they've been given, keep the house at a reasonable standard, so it is about to go to child protection." *#34p40C*

The difficulty is remaining sensitive to the degree of change required from parents and judging whether thresholds are met:

"'[The question] in the longer term [is] whether that [improvement] ... is enough,' 'and the difficulty with longer term is … being more accepting of the behaviour.'" *#34p33C*

6.3.3 *Removing children*

Removing children from their parents' care is not always in the child's best interests, rather, preserving the family unit is the goal:

"What could be good is if there were units … where these families could go where they've got 24/7 support and care … where … parents … and … children live … so these children could stay together." *#62p41C*

"'If you get the parents the right help, removing that victim child out of the household is the last thing you'd want to do …' 'You'll want to keep the children together!'" *#62p58B*

In fact, removing children could be symptomatic of a lack of appropriate support rather than an indication that the child could not thrive in their parents' care:

"It's really difficult because ultimately that child could potentially be removed … because there isn't the right service." *#62p9B*

"That happens with families where there are parents with learning difficulties … we either haven't got the resources or they are within timescales that we can't meet." *#29p32A*

Removing a child does not guarantee a better life than that with their parents, and participants stressed that doing so is the last option to consider:

"If you remove the children from that situation, what does their future then look like?" *#62p33C*

"it's not an easy process to get a child removed … it's a huge, huge piece of work … it's nothing that just happens, you know, they've got learning disability, we'll just remove the children, it's nothing like that at all, … huge amounts of work goes in to really trying to support and help these parents, we find all the resources available to give them a good shot at it." *#62p36C*

"And if that meant removing [the child], you would, but that would be a last resort." *#62p48B*

Despite being adamant that removal was not an 'easy' option, it seems common for families to be involved with CSC for prolonged periods of time and without positive outcomes. Participants had experience of working with families from whom several children were removed:

"I've been involved with a family where I knew mum, and prior to coming to me she had already had three of her children removed." *#64p17C*

Some families exhibit a constant fluctuation in need with a tendency towards situations worsening rather than improving, despite service input:

"We are constantly talking about whether this needs to move back to CP and be a child in need." *#64p30C*

"That might be the one that will go to child protection, the little sister as well." *#64p47C*

In these cases, parents may not be able to demonstrate that they can safely look after their children:

"Unfortunately, the majority of the children aren't with her now because she just couldn't … She still hasn't accepted that this perpetrator had done what he'd done. It was her children that had made it up." *#64p28A*

"She … wouldn't do it … it actually ended up being really sad, all of her children ended up being removed." *#64p21B*

Some participants appeared to be resigned, that these were unavoidable outcomes and their attempts to alter the course of events were futile:

"It's really difficult when you work with parents with learning needs who are associated with adults … who pose a risk to children and getting them to understand, that can be hard. And sometimes you just have to take the children away because you know; as much as you try, they just don't get it." *#64p54C*

Some families required such long-term, intensive help that several children were removed before the parents improved their parenting and could care for their remaining children:

"She has come through it but it's taken four children … five?" *#64p22B*

A trend emerged where participants saw children being removed from their parents at similar ages, when their needs overtook their parents' capacity to fulfil them:

"They were supporting the children until the situation worsened and then … the kids started all coming into care as soon as they reached a certain age … that's when the difficulty is the factor." *#64p30A*

At this stage, the participants appeared to work against two opposing forces – parents' difficulties adapting to children's evolving needs and the principle that children should remain with their parents. Participants spoke about this with a sense of inevitability:

"I think that is one of the dangers … children who are more able than their parents, or becoming more able, and finding the right time to make decisions about [their long-term future]." *#64p47C*

As a result, some participants appeared pessimistic when discussing outcomes unless there was long-term, continuous support available:

"For the children to remain in her care …, for their entire childhood, I think is quite a longshot really." *#64p30C*

"[Long-term whole-family foster care placements] would be the only way you could do it, so these children could stay together, because their parents … they're not going to be able to get to that, they need someone constantly checking that things are okay." *#64p41C*

6.4 Support for families, PART B: Resource and system constraints

The participants often felt that their work with PWID was stifled by the lack of support to do so. They felt restricted by limited resources and expertise, and by financial constraints, and this could result in child protection outcomes that reflect service shortcomings rather than parenting deficiencies.

6.4.1 *Availability of specialist expertise and scarcity of resources*

Participants felt that they were often limited in their work with PWID due to the lack of specialist expertise and resources available. They could not rely upon the presence of individuals familiar and able to fulfil the needs of PWID or the necessary services, leaving teams without such experience at a loss - a disadvantage that would be passed onto the families with whom they had contact.

6.4.1.1 *Specialist expertise*

It appears that of the families with whom the participants usually have contact, those headed by PWID represent only a small subsection. Working with PWID seems to be a

specialised area and not all of the participants had been trained to undertake such work. As a result, confidence working with PWID varied according to the extent of their own individual experience. Those most assured in their work with these families were the individuals who had previous experience of working in Adult Learning Disability services or had worked with children with disabilities and their families. However, there were those who, despite having lengthy careers in children's social care, felt ill-equipped to provide the necessary support. These individuals found that such expertise was difficult to source and even those proficient in this work were often without the practical tools required to carry out the required assessments and provide learning resources to parents.

6.4.1.1.1 Information-seeking behaviours

In the absence of formal training in how best to work with PWID, participants might garner experience anecdotally, through the diversity of cases they encounter throughout their careers, by virtue of having worked in other related, specialist areas, or through proximity to colleagues with the necessary experience. The experience and expertise at participants' disposal varies greatly, and finally, discrepancies in skill and specialism can be to the detriment of families. As individual professional experiences vary, the skills available within teams are governed by chance:

> "Because the social work degree is now generic … unless you've worked in … a specialist area ... you might not have gained the experience … to tackle some of these difficulties. Or, you haven't had a case [that is] … really challenging and you've had to learn … because they're so varied, each case that you get." *#77p14B*

> "'Because we're all working within the children's disability team … if the parent has some level of disability, it is slightly easier for us …' '… because we've already have worked in that field' '… but [for] those in the general [teams that would not be the case].'" *#77p14B*

> "[We might not have the] expert knowledge … and we are lucky in our team because [another participant] is experienced in terms of … adults with learning difficulties … [They] adapted [paperwork] and used pictures and really basic language and it was brilliant, but I wouldn't have thought to do that!" *#77p12B*

CSWs, for whom the children concerned would be a main priority, would normally defer to ASC for issues relating to parents. However, participants found their ASC

counterparts were also uncomfortable with some specialist practices. Assessing "parenting capacity" appears particularly problematic because neither CSC nor ASC felt this fell within their remit.

"'I worked as a care manager in learning disability team and … if you want to … talk to somebody about parenting capacity … [they'd say,] that's not our department, we don't want to comment …' 'talk to children's …' '… so if a children's social worker came and said … this case is open to you but I'm … going to start working with the children, can you tell me about their parenting capacity … they wouldn't want to.'" *#46p17B*

For ASC professionals, who specialise primarily on the needs of their respective client groups, parenting by people with ID represents a grey area that is yet to be fully accounted for by services. Therefore, cases requiring expertise relating to adults with social care-related needs in parenting roles appear to fall outside of professionals' scope:

"[In] the learning disability team, they've only got two social workers … and they take on ... the real high end stuff and then the lower end stuff is with the care managers … but … because it's such a multidisciplinary team … you might have a parent who's got a learning disability who's open to that team but isn't open to a social worker, isn't open to a care manager but is open to speech and language. So even though they are open to that team, we are not going to be able to talk to a speech and language therapist about their parenting capacity." *#46p17B*

Consequently, the participants would themselves assume responsibility for ensuring they had the relevant knowledge and relied on their own resourcefulness:

"There isn't anything … available for [this mother], and … I've been discussing it … at length with [a colleague] and with my manager and … in my supervision, she said we have to be the experts ourselves on this, in terms of trying to help support this mum." *#84p22C*

"We don't have that here, we are the resource!" *#84p14A*

They actively sought information to better cater to the needs of parents and were willing to approach colleagues with specialist information and resources to offer. They would also draw on their own personal and professional experience where applicable:

"We've still got … [a Parent Assessment Manual], but we've got the really old version … so I went upstairs and was like, tell me about PAMS stuff because we've got a really old copy, so they let me … photocopy all of their copies and stuff like that, so I went off and did it." *#84p19B*

[About simplifying information for parents with ID] "You've obviously managed to do something with colour coding, it would be quite interesting to … share." *#87p15C*

"I have got a long history of working with adults with learning disabilities and I've got a sister-in-law with learning disabilities as well." *#68p18C*

However, despite efforts to address the lack of expertise, participants did not always have the time, guidance, or capacity to inform and equip themselves sufficiently and provide the best service to parents:

"We almost need … a specialist … children's social worker with the learning disability … expertise, but with the training behind that ... to give the families the right service … because otherwise I think we are all far too busy and we can't put in the time we want to put in." *#84p26B*

"We tried to put a request … to buy the new copy [of a specialist parenting assessment tool] for our team … and the funding wasn't agreed. We've just got my photocopied, tatty version [laughs] and I'm the only one … who's … done it in the last year, and … I'm not trained on it, I've just literally had an hour's chat." *#84p20B*

" We are lucky in our team because [another participant] is experienced in terms of … adults with learning difficulties … So that family actually did get a better service because of that, but that's the first time I've ever seen anything like that done and I've been in that team for seven years so, it's not the norm." *#84p12B*

The lack of support to properly perform their roles often caused frustration as they were continually confronted by obstacles:

[Regarding a mother with borderline ID] "[I ordered an] assessment … into subsections of … her capacity … And I got a generic, "It'll make it more difficult to care for her children."… Nothing very insightful or helpful in terms of her capacity and … dealing with certain things." *#84p4C*

"I've rung [other teams] to say, can you photocopy [these learning aids], because we've got the stuff upstairs … No, you can't, but they don't produce a nice book that you can give to a parent, which they used to ... So that's £45 … it's a lot of money, they have some free resources but the parenting stuff, you have to pay for. So that makes it more difficult." *#84p14C*

In the absence of these skills and resources they were ultimately unable to deliver appropriate support to families:

[A mother with ID] " [Is] getting a dis-service from us, because we don't know how to make sure that she understands what is expected of her because this isn't our expertise … and we are entering a child protection arena that … with the right support may have been avoided." *#41p8B*

6.4.2 *Finances and labour constraints*

The lack of specialised skills seems compounded by limited finances and workload pressures. The expense associated with the specialised support required for PWID was a distinct concern and appeared to be an inhibiting factor:

"You can get … a "You and Your Child" Easy Read book but it's so expensive, and … you have to buy it for each family … you've got to find money and I've tried." *#38p14C*

"'I think we could all be very creative about how we support these families, but … when it comes to financing it … you need so many more workers who can actually spend the time doing the work … [it's] labour intensive ...' '… it's then having those resources, and we are always in a culture of not having enough resources or enough money.'" *#38p42C*

Large workloads present a further obstacle - neither the participants nor their colleagues felt they could afford to take on more cases:

"It is about resources … resources are tight and people are working really, really hard, and they think, 'I can't take another one.'" *#38p35C*

"They've got a really good psychologist … she will help but obviously she is massively hard-pressed, well, we've all got our own things to be dealing with." *#38p19B*

"'We're quite lucky that we've got family support workers in our team as well …' 'We've got one ... we've got half … 'Yeah, that's not even one!'…'she doesn't have the capacity to do any more, does she? She's back to back …' 'We are utilising her ... yeah ... we need more I think.'" *#38p26B*

The natural inference is that cases may not always be handled by the appropriate teams. Participants' workloads seemed to curtail the detail to which cases are assessed as they cannot cope with additional work and are unable to investigate further. It also increases the threshold of risk pertaining to cases that warrant the participants' attention – those exhibiting low level difficulty are treated as a lower priority than those with more immediately serious issues:

"God, if we had a referral for every parent that wasn't helping their child with their homework …! We'd be inundated, even more than we are already!" *#38p45B*

[About checking a parent's learning ability] "'You don't want to open a can of worms with something like that too!' 'Make more work for yourself!'" *#38p70B*

Regional differences in resource-availability means CSWs are enabled within their roles depending on their local authority:

"'When I worked in another local authority there was … a programme that we could use that could help us write reports with pictures and different things, which you don't seem to have here.'" *#39p14C*

Parents face similar location-based differences, affecting their ability to access support:

[About support groups for PWID] "'I haven't come across that anywhere else …' 'No, I haven't heard of anything like that at all … no.'" *#39p31A*

[About placements] "That's one of the big issues …, parents don't want to be going off to the other side of the country … where they're in a strange environment, and … they [might] have difficulty adjusting to new environments themselves … [but] it's not a resource we have locally." *#39p41C*

Inequalities in resource availability are especially pertinent during assessment when parents' compliance with the terms of child protection plans is a large component. PWID may be disadvantaged by external factors compromising their ability to access support successfully.

However, parents can become dependent on services and individual professionals, and participants were aware of unnecessarily prolonging the time spent working intensively with families:

"I worked with [a family] on CP [child protection] … [and] tried to close it to a TAC [Team Around the Child] and the family ... were not happy … I went from her screaming and shouting at me on a CP plan … trying to close the case and her saying, but I need help, so … it's that balance." *#3p34C*

A balance must be attained whereby CSWs are able to connect families with long-term support where necessary while ensuring that services are only used as long as they are required.

6.5 Time

The concept of "time" was discussed repeatedly and at length by the participants. CSWs are employed by different teams, one of which is child protection. The ambit of child protection is to be prescriptive and specific, equip families and facilitate their being able to ultimately safeguard their children without the social worker's direct involvement. Risks are quickly mediated and swift changes are implemented to assure

children's developmental needs and wellbeing. The arrangement of resources, timelines and service structures all support this style of work whereas teams operating on a long-term basis have systems that reflect service-users' continuous support need. A fundamental difficulty with child protection relating to PWID appears to be that child protection is inherently fast-paced and aimed at closing cases and moving on. Parental intellectual disability (PID), however, is permanent and families' needs are likely to be long-term and as such, are mismatched. In this section the marriage of these two is discussed – the pace of child protection, parents' needs, and pressure upon services that this represents.

6.5.1 *The pace of child protection*

The rapidity required of child protection work is reflected in how participants discussed the hypothetical scenarios. They were quick to close cases and frank in their assessments as large caseloads require they only work with families that justifiably demand their attention:

"It would be a very ... quick assessment of the situation, then if parents responded by doing something … Then it could well be ... closed." *#28p1C*

"If that came to the assessment team and there were no other concerns, they wouldn't do anything with that." *#28p46B*

There appeared to be a shared mentality wherein participants worked on a prescriptive, temporary basis:

"The nature of the game, it's the nature of the funding and you don't just keep people open, they arrange it, they assess them, they sort out what they need, they provide the need and they close the case." *#29p4C*

"It doesn't matter how many services you put in place and how well those services support that person ... at the end of the day, those services aren't going to be around forever." *#29p33A*

"They can get closed quite quickly ... I was involved with a family with parents with LD and their children … we got mother reassessed so she was then open to adult services, they put in services but they don't carry all these cases … so she has that, but she actually is now closed to adult services." *#28p4C*

Participants described allocating support with the intention of enabling parents to function without their input:

"'Get mum to … get herself some support' 'and there might be someone to support her, rather than it being a social worker coming in.'" *#28p20C*

"You're trying to get parents to take responsibility. It's not about just having money to throw at a family; it's about helping them use what is available in the community." *#28p49C*

Participants would defer to other professionals where appropriate:

"No further action. It's for the school." *#28p47C*

"'They wouldn't come into our team but we could signpost them to other things …'… it's dealing with the immediate issues.'" *#28p48B*

The rapid pace of child protection assessment is underwritten by timelines to which the CSWs must adhere, causing some practical difficulties:

"You've got more time in the other teams but certainly from the assessment point of view, we've got 35 days." *#29p11C*

"We have the privilege of time ... because we are a long term team [the children's disability team], but when you're in the assessment team … that's harder ... because you're having to do things ... on a fast forward timescale, and I mean, you have to get them in and out." *#29p13B*

6.5.1.1 *Time constraints*

Fast-paced work presents unique difficulties when families such as those with PID require extra time. In these circumstances assessment teams, often the first point of contact, are not facilitated to work at a manageable pace for parents and direct families towards the necessary services or teams:

"We've got 35 days and when families are not opening the door … or … they are not able to take on board the things that we're saying because of the difficulties that they have, it is really hard to work with those families … I find it difficult because you have to be quite forceful because you need to get things done." *#86p11C*

Time is required to acquaint with families, identify gaps in parenting and when PID is unknown, detection can take time:

"You might question what the intellectual … disabilities are … I think it's really hard to pick [apart] … it's not until you get to know families that you start to realise that's where the gaps are." *#31p2C*

Even with a diagnosis, lengthy and close interaction is needed to understand the impact on parenting capacity. It appears that parenting difficulties are not usually evident until children are older:

"It … takes some time … before the impact is evident of that adult's disability on their parenting and, therefore, on the child so, with a baby, we might manage ok … it's only when things get … below [an acceptable standard]." *#31p26B*

Specialised assessment tools such as the Parent Assessment Manual (PAMS) designed specifically for PWID, require more time than those for families without ID. Participants found the volume of time required presented a significant hindrance to parents being assessed properly:

"It actually takes … a lot of one-to-one support which, as a service provision, we don't have time to do." *#73p23B*

[About PAMS] "And it's huge, it's a big piece of work … we just had the time, the privilege of the time, to do it." *#29p20B*

Participants indicated that productive working relationships with PWID took more time to form than with non-ID families. These relationships are further strained by the quick pace of child protection which is often incompatible with parents' abilities and strengths:

"We were trying to get [a mother] to move forward … the problem is, [when I told her] some things need to be done quickly because of your children's needs ... she would just get very angry, start shouting, and the communication became very, very difficult." *#29p12C*

"She had a well-established working relationship with whom she trusted and we had to go through her, but still, everything is much slower than I would have liked it to have been, because this was lead paint and I was looking at the research, horrendous long-term consequences on [the son's] cognitive abilities but yeah, slower than what I would have liked." *#29p13C*

Rigid timeframes can undermine parents' progress as benchmarks become unrealistic, resulting in PWID being at a disadvantage:

"Things move quite quickly once you're in child protection … your visits are fortnightly and your meetings are six-weekly and you've got your case conferences again before

you know it and we are asking them to implement a lot of change quite quickly … having [a PWID] ... speak to us was really eye-opening and made us really reassess … our expectations." *#29p31A*

Participants felt they were not accommodated within their professional role to do the volume of work required for parents such as these:

"We all ... know about … advocacy and stuff like that, but when … you've got 50 different cases … and you've got people going on at you the whole time, and then before you know it ... you're coming up to a child protection conference and you've not ... got an advocate for the parent with an intellectual disability, and … it needs constantly reinforcing that these … parents need a voice." *#29p68B*

They felt this prevented them from working towards conclusions that best suited families:

"'Timescales ... can actually be really unhelpful.' 'It impacts on practice and … on the families greatly … you can't get the proper assessments done in those timescales at all … you're scrimping on them and you're not actually getting what you need at the end of it." *#29p32A*

Finding a balance between providing parents a fair chance to improve parenting before escalating child protection procedures while moving swiftly to promote children's welfare appears a difficult task:

"Do we have the time, is always the question … to give these parents and leave the children in the home? Sometimes we don't have that much time." *#29p32C*

These difficulties are compounded by the workloads and time pressures placed upon all social workers, in addition to the extra time participants required to adapt paperwork themselves and give parents information in simple terms:

"[Statutory] paperwork would be overcomplicated … so I've really simplified the document and colour-coded them to try and make them more accessible and understandable for her." *#37p13C*

"A written agreement was created about what exactly was expected … and it was spelt out to this mom like, you must change the nappy three times … adapted it and used pictures and really basic language." *#37p12B*

All information given to parents must be accessible so they can be meaningfully included in procedures relating to their children. While acknowledging this, participants admitted not having time or finding some procedural content to be too complex to translate into simple language:

"'I've sat before the conference and gone through the report and explained, and when I'm saying this, I mean X, and when I'm saying this, I mean this' '… it works for her, but it was a lot of extra work." *#37p16C*

[Regarding jargon] "We are all hard pressed for time and we don't necessarily have the time to really explain." *#37p12B*

"Certainly when you get into the court arena and you do court reports, you … have to rely on solicitors to break it down for them because … you can't do those reports in simple language." *#37p17C*

However, participants are also mindful that while additional tasks, such as colour coding and simplifying paper-work, require extra time and make for lengthier assessments, ensuring these methods are used when parents' ID is first suspected would be the most time-efficient:

"[Effective work with PWID] takes longer, so because it takes longer you are in a way giving them more chances." *#30p39C*

"That's why ... from the start, you're using stuff that's friendly to them to understand, you're using advocates, so that right from the start ... you've got them understanding what's going on … [and] you could probably get through it quicker." *#30p39C*

6.5.1.2 *Pressures of long-term support*

Despite child protection work being largely carried out on a short-term basis, participants felt fruitful relationships with PWID are best accommodated in long-term settings:

"If you're working with parents with learning needs … it can take years … I worked for … a lady with a learning disability whose son also had a learning disability … I've worked with them for about five, six years?… Sometimes it's a long term relationship … that becomes more productive, but when you're going in having to do the hard-line [assessment] stuff … it's not easy." *#33p12C*

However, long-term support relationships can present substantial undertakings for relatives and professionals, limiting the feasibility of this type of provision:

[About a mother whose child was removed years ago] "Even now, even though they are closed to me, mom pops in with a little gift [for her daughter], and I mean even now, I have a guitar under the desk at the moment which I need to deliver to her … if I were to leave and can't deliver the gifts, I don't know." *#33p18C*

"Is there someone who can do homework for the next 16 years, because that's what you've got to be thinking about, it's not a year or two, it's long term and it's huge commitments that you're asking families to take on, they have to really, really seriously

think about it, because people will be like, oh yeah, I can do this, but then actually, 6 months in, 'Help, I can't do this anymore.'" *#33p25C*

"You have to work that much harder with these families, and it, it's more intensive and you have to really be there to support them and make sure ... that it works." *#36p35C*

6.5.1.3 *Effective communication with parents*

Effective communication appears to be integral to effective and timely child protection. When parents are suspected to have ID, the immediate focus for participants is to ensure effective and appropriate communication so parents can access support within a time frame that suits the interests of their children. Participants spoke about using Mencap workers, jargon-free language, simplified paperwork, and taking extra time to explain paperwork to parents:

"'It's a big thing, we all know not to do it but all use "the language"… the social work language ... [and] for this case, we talked about "lack of supervision" and actually, does a parent with a learning disability …' '… know what that means?'" *#1p11B*

"I … stopped sending out our paperwork because … it's not very user-friendly! And instead bullet-pointed it on a blank piece of paper … because within our paperwork, it's not that clear … what the plan is and there is a lot of jargon … because we need to record our information … !" *#1p21A*

While participants appeared ready to adjust for learning needs, doing so could be awkward even when PID was established. Participants were wary of patronising parents who at times did feel this was the case:

"I've been working with a woman for about the last 4 months and … her previous social worker gave her visual aids and they were really, really good and … [but] she said that they were patronising and she don't want them … I would always … ask people, do you understand? … people probably think [it's] patronising … but [you must] ask people …, 'Do you know what I'm talking about?'" *#7p13B*

Effectively communicating risk can be difficult and participants described parents' issues handling and incorporating new information:

"If ... they've got a perception of something being positive, [they have difficulty] delaying [it] … or it's a more immediate response. For them to put that to one side and to think about something else, they do find [it] more difficult." *#10p53C*

"Someone with intellectual disabilities might find more difficult and problematic to have an understanding that you've got an uncle or … a brother who you like but is a risk, whereas their initial perception is, it's their brother, they like them [but] … there's a

possible risk in the future … I'd be worried if the parents ended up minimising these sorts of things." *#10p52C*

Despite adjusting their communication methods, participants felt parents still tended to become overwhelmed by the volume of information and urgency with which it is given:

"Their capacity to handle it is much more difficult … that mum with the borderline learning disability … was saying, when you start putting pressure on me, I cannot handle it, it is too much." *#16p12C*

"'Some of them don't like to be overloaded with information, some need information to the nth degree' 'some need it visually, some need it in written form.'" *#14p31C*

Participants explained that this is particularly problematic when there is much at stake:

"I'm slightly concerned about [a mother's] capacity, and just explaining to her what child protection is without scaring her, … trying to get across to her the message of actually, things are stepping up now, we are really concerned, we need you to make changes … is actually quite a difficult thing because I don't want to be scaremongering her, but equally, I really need her to understand what's going on, and that's quite a difficult balance to get." *#86p12A*

6.6 Discussion

The primary objective for the participants was making arrangements for families and enabling children to remain with their parents. To this end they explore a number of options that reflected the specific needs of families which, in their experience, tended to persist throughout childhood. These tended to be prescriptive, ensuring children's development and wellbeing, and creating safeguarding responsibilities in other professionals to compensate for any area parents may have difficulty. Parents' support needs are also accounted for and delivered to the extent to which available services allow. Where services do not reflect parents' needs, due to issues such as eligibility or lack of appropriate services, participants work imaginatively and seemingly harder than they would for others, to ensure the needs of these parents are met to the best of their ability. In these situations, without the extra work of CSWs and sometimes in spite of it, parents with the capacity to improve might ultimately fall through the gaps with their needs unmet due to the lack of appropriate services. However, these efforts can only

be successful where parents reciprocate and respond as needed to the supports provided. For this, participants motivate parents to take up services and monitor their progress to make informed decisions that promote children's best interests.

Support for PWID is additionally limited by external constraints unrelated to parents and participants. Participants often described how they were often particularly ill-equipped to work with PWID, lacking expertise and specialist resources, suffering from finance and labour constraints, and curbed by government-mandated time-limits for assessment. Where specialist resources and system constraints might be addressed by increased in funding training, the issue of time remains problematic. The time-limits are imposed and enforced to minimise the time spent by children in poor conditions, however, it is clear from the participants that PWID require more time than others to be properly engaged and make the necessary changes dictated by child safeguarding procedures. Where there is an objective, universal benchmark designed to promote children's fundamental interests by bodies and professionals whose sole role is to cater for children's needs, justifying allowances for parents is complicated. However, the issue remains that among all parents, those with ID appear to be at a distinct disadvantage. Extra time is needed to ensure information is communicated effectively, for the correct assessments and supports to be implemented, for the type of long-term support often needed, and for parents to make progress within the confines their disability allows. Without these, parents are deprived of a fair chance of their children remaining in their care compared to other parents, though their children must also be allowed the same chance as other children for their wellbeing to be promoted.

CHAPTER 7

Discussion

7.1 Chapter overview

In this chapter, the last of this thesis, the methods and findings from the data analyses are summarised. The findings are discussed in the context of the existing literature and the similarities and differences are considered. The contribution of this research to the wider understanding of how children's social workers (CSWs) make decisions when working with cases concerning families headed by parents with intellectual disabilities (PWID) are discussed. The implications of the findings in light of what is already understood in this field are examined.

The policy recommendations that have been drawn from the findings are laid out and possible avenues for future research are suggested. The methodology is discussed and the shortcomings of the overall mixed methods study design are considered.

7.2 Summary of study methods and findings

This study used extensive literature review and consultation to inform three forms of data collection and analyses. The products of each of these components jointly contributed to answering the research question, "How do children's social workers assess cases concerning the children of parents with intellectual disability?" This required a study design that permitted enquiry into the decision-making mechanisms of CSWs, both in terms of how they conceptualised intellectual disability (ID) within a parenting and safeguarding context as well as the health and social care systems where they make these assessments.

7.2.1 *Serious case review analysis*

First, secondary analysis of 33 serious case reviews was carried out using the Framework Method. This was performed as an exploratory exercise, to inform the subsequent data collection and analysis but also to gain insight into the climate in

which CSWs work and the cases with whom they have contact. Descriptive accounts of families were developed and an understanding was established of the role CSWs played among the other professionals involved with the families with whom they work. The reviews themselves were examined to determine the extent to which parental intellectual disability (PID) was considered a pertinent factor to the cases by the reviewers.

Findings

The findings from the SCR analysis elucidated on the actual environment in which CSWs work and make decisions.

Families

The families about whom the reviews were written presented as complex cases, often with numerous vulnerabilities as well as being known to have, or being suspected to have, ID. Due to the multiplicity of stressors each family and specific family members faced, they often had multi-professional and multi-service supports. Involvement with each individual service was subject to frequent change but the overall service involvement tended to begin during parents' own childhoods and extend into adulthood and their own parenthood. The complicated presentation of ID and parents' willingness to disclose the ID-related difficulties they experienced meant it was often laden with nuance. Its emergence was often missed and its significance was lost among the range of competing factors. Professionals frequently failed to give PID due regard in terms of the impact it could potentially have on individuals' capacity to be meaningfully involved and supported to make the changes necessary to safeguard their children.

The services involved with families were often operating under significant strain due to their own system issues, which to a degree compromised their ability to work with families and each other as they should. Effective multi-agency working was often undermined by poor communication and information-sharing between professionals. Agencies often worked in isolation from each other and in a blinkered and restrictively

prescriptive manner, rather than viewing families and individual relatives holistically and considering the interrelated nature of their issues. The referral systems, eligibility criteria, and funding all served as substantial obstacles to securing the appropriate specialised services. Once parents did receive specialist services, the professionals with whom they engaged often failed to consider their needs in the wider context of their being parents. Where it was not possible to procure the necessary services, or there were limited attempts to do so, professionals working for the children would, at times, make up for gaps in provision. This resulted in these professionals becoming overstretched or their attention being diverted from the needs of the children in question. Focus on children's needs was often distracted by the prominence and urgency of parents' needs.

Children's social workers and other services

Understanding and assessment of PID beyond superficial and presumptive evaluations were limited in the cases examined. Professionals frequently worked with little reference to parents' histories, particularly those relating to ID and, as such, this information could not be used to inform the approach they adopted. It was often unclear from the reviews the adjustments and efforts made to meet the specific needs of people with ID, such as providing Easy Read material, using simplified language, or checking for informed consent.

A significant observation was that CSWs were potentially just one of several agency professionals involved with families. In the case of very young children in particular, their roles were largely minimal, if at all. CSWs' involvement relied upon referrals made by other agencies and depended on their tendency to do so. For a range of reasons, concerns noted by professionals were sometimes not shared with children's social care or escalated during group meetings. Where they were involved, CSWs were often lacking in experience, supervision, were rapidly assigned and reassigned, and over-burdened. They also were involved insofar as they would assess needs, arrange

services, and monitor progress, but would do so prescriptively and with an emphasis on working on a short-term basis.

Each of the cases included in this analysis serve as an example of professional practice with PWID. In terms of examining how PID impacted on assessments made and the approach used to safeguard children overall, there were few instances where this information made a tangible impact on practice. In many cases, indicators of PID were dimmed by the presence of more glaring elements and cases proceeded with professionals missing a fundamental step. As far as CSWs are concerned, it is misleading to consider their role in isolation rather than among the other services with whom they work. They certainly must be equipped and enabled within their roles to assess parents appropriately and procure the necessary services in order to ensure the best interests of children. However, they do not perform their role in a vacuum and it is equally important for others involved to be sensitive and able to meet the needs of families.

Reviews

The reviews themselves approached the issues of PID in various ways. While some earmarked PID as an issue for investigation from the outset, others did not, and there was little mention or examination of how it affected service interaction and provision. Some recognised how practices could be improved to better suit the needs of PWID and their families. While it is not always necessary for PID to be a key issue of inquiry and for there to be PID-related recommendations and action plans, its absence from some reviews is notable. When PID is not considered, there is no way for Local Safeguarding Children Boards (LSCBs) to know whether agencies made assessments that incorporated the ID-related needs of families, removing the opportunity to learn and make changes to ensure these needs are acknowledged.

7.2.2 *Questionnaire-based experiment*

The second part of data collection and analyses was in the form of a questionnaire-based experiment (QBE) involving 191 CSWs employed by six local authorities in England. An internet-based questionnaire was developed using Qualtrics survey software, informed by a factorial survey design. The participants were asked to assess nine hypothetical child safeguarding vignettes depicting a fictional seven-year-old child and his parents. Components of the vignettes were randomly manipulated to capture how changes in these particular factors affected the CSWs' assessments. Two factors were subject to manipulation, the parents' ID status – whether they had ID or not, and the safeguarding scenario. By performing generalised ordinal logistical regression on the QBE data, it could be determined how disclosing PID affected assessments across the range of scenarios.

Findings

The analysis from the QBE illustrated how CSWs' assessments of the vignettes depended on the information that had been disclosed. The case scenarios depicted a range of child-safeguarding situations, some of which were considered to be more risky than others, and parents' ID status was randomly included as an additional item of information. When presented with scenarios considered to be less risky, the PID disclosure was found to contribute significantly to a higher assessment score – the participants considered the situation to demonstrate the family's greater support need. However, when presented with scenarios that were considered more risky, the additional PID disclosure was found to not make a significant contribution to a higher score. The participants did not consider the situation with the additional PID disclosure necessarily relevant to the family's overall support need.

These findings demonstrate that the risk associated with PID is not fixed but instead relative to the situation in which it is encountered. The effect of the PID disclosure in situations considered to be indicative of a lower support need compared to the effect in situations indicative of greater needs gives insight into how PID is understood. Firstly,

the assessment of greater need is not necessarily negative or demonstrative of willingness to remove children from their parents' care. It instead demonstrates the recognition of a need for further assessment and the possible provision of support. That this effect is not consistent across the scenarios is notable. This is because ascertaining support needs related to PID would be required regardless of the particular situation, but perhaps even more so in cases indicative of greater need. It is unclear from the QBE the extent to which PID contributed to participants' decision-making when confronted with cases that without the disclosure were considered to be objectively risky.

7.2.3 *Focus group discussions*

The third part of data collection and analysis was a series of three focus group discussions each held with five-six CSWs employed in a county council. During these discussions, the groups were presented with the nine vignettes used in the QBE, each including the PID disclosure. Participants were asked to discuss how they would assess each case in practice. The vignettes were presented open-endedly and were used as springboard tools to facilitate further discussion. Participants were encouraged to draw on and share their own experiences, openly express their opinions, and develop their ideas as the discussions progressed. The FGD data was thematically analysed using the constant comparison method as outlined by grounded theory.

Findings

The data collected from the FGDs turned out to be rich and diverse. The themes developed demonstrated the complexity of CSWs' decision-making processes and the sheer number of contributing components. There are several elements that simultaneously act upon CSWs as they assess situations. These relate to the systems in which they work – the services and skills available, the resources and time constraints, as well as their own professional capacities. Within an individual's professional capacity there were aspects that counted towards participants'

assessments of parents with ID in particular, but also how they would work with parents overall.

Participants appeared to approach the issue of PID in a way that used assessment and tended to be guided by the needs as they arose, rather than follow a formulaic pattern reserved for PWID. They tended to work prompted by families' cues and situated their assessments in families' contexts. Participants appeared to view families sympathetically, and were emotionally invested in their work with both the children and parents.

Their decision-making appeared to rest on a series of balances. Despite the principle that children should remain with their parents wherever possible, the apparent conflict between the needs of parents and the wellbeing of children pulled participants in several directions. Their actions are dictated by the instinct to act rapidly to quickly secure children's best interests while trying to allow parents sufficient time to make changes. In addition to this, scrutiny of their professional practice presented a source of potential tension – the need to build a strong case. Facing pressure from public opinion and courts, they would strive to work as quickly as they could for children while still working to gradually build as strong a case as they could, and still trying to remain objective.

It seemed that a major part of participants' assessments was down to their ability to provide the services that parents would require. This would often depend on whether the services and skills were available to provide to parents, or CSWs' ability to provide the necessary supports, informally, in their absence. In this respect, at times when cases result in children being removed from their parents care, this might be suggestive of an inability to locate appropriate support for parents rather than a concrete failure on the parents' part. However, there were also other challenges such as the degree to which parents and families engage with services provided, or the

extent of their ability to retain the skills and use the supports provided, and whether they were able to address professionals' concerns about their children.

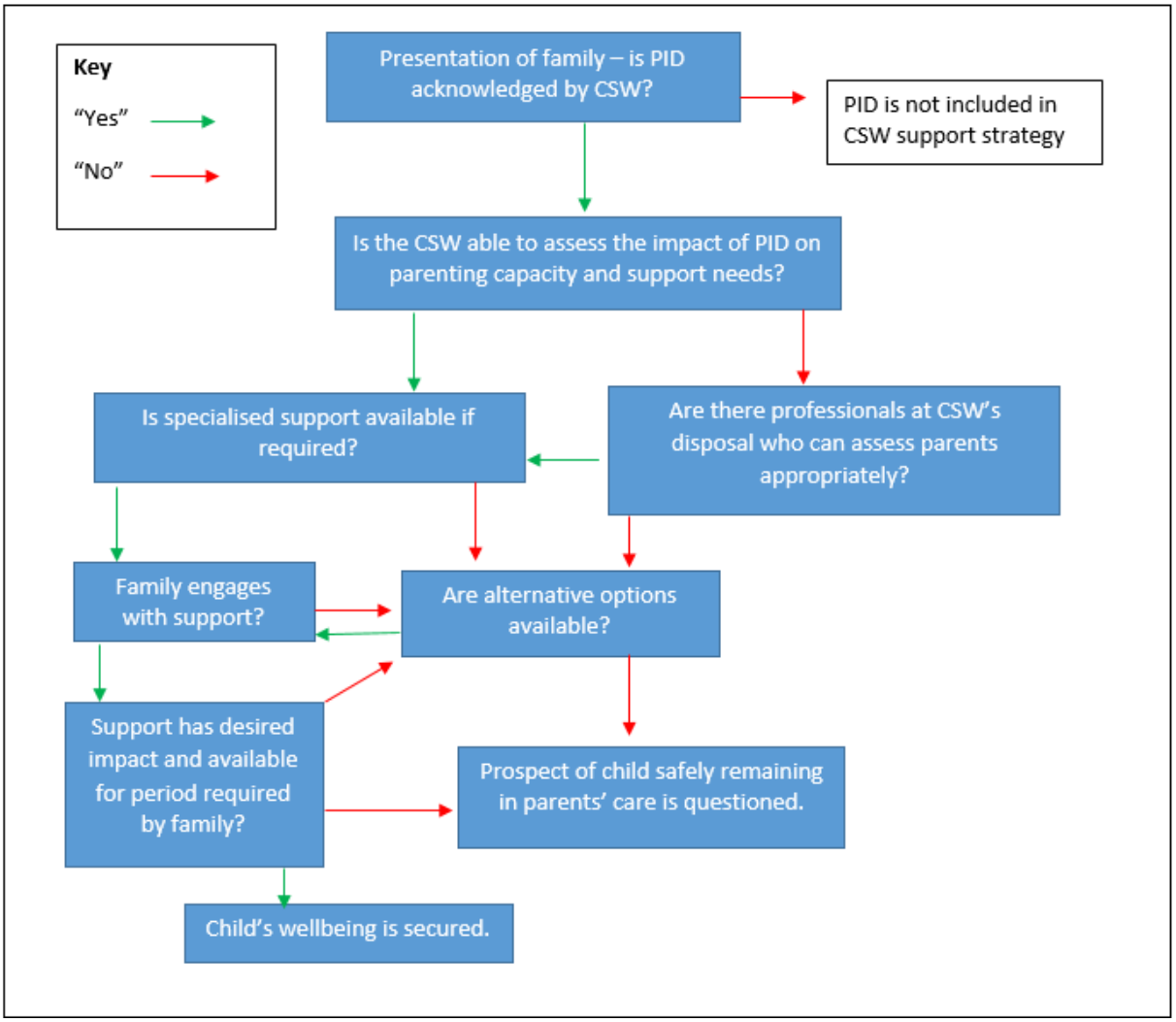
7.2.4 *Conclusion*

The research aim was to find how CSWs assessed the cases concerning families headed by parents with intellectual disability. Based on the findings of this study, it can be concluded that there is no fixed way in which CSWs go about making these assessments. They take place across a range of interactions and are updated and revised throughout.

Firstly, CSWs' involvement with families is not definite, and often there are other professionals involved with families in various capacities. Whether they do start working with families is determined by a referral process that depends on the decisions of other professionals and whether they have assessed a case to meet a certain threshold of concern. The success of the referral once it is made and how the CSWs in question assess families once they have contact also affects the degree of CSWs' involvement. Where CSWs are not involved, decisions relating to PID are left to the professionals who are involved.

Once CSWs do become involved with families, the figure below loosely demonstrates the chain of events that take place during the assessment process. By simplifying the various stages of assessment and intervention, the figure illustrates the junctures at which successful service provision can either be compromised or secured. It can be undermined by CSWs' failure to recognise the presentation of PID; availability of assessment means and individuals with necessary training; availability and range of specialised services; family willingness to engage; and efficacy of the supports. The illustration depicts a single interaction with children's social care which may be subject to repetition as the final three outcomes [that the child's wellbeing is secured; the prospect of child remaining safely in parents' care is questioned; and, PID is not included in CSW support strategy] do not remove the possibility that the child and their

family will not either remain in receipt of CSW assistance or return to their attention in future. In fact, the FGDs and SCRs demonstrate how in many cases, case closure may only indicate that child wellbeing in an immediate sense rather than as a long-term guarantee of safety. The figure additionally depicts how PID management from the initial contact depends upon the professionals, their respective skillsets and resources. Without uniformity of training, experience and means, the standard of professional intervention for PWID would be subject to chance.



The findings from the SCR and QBE analyses demonstrated how the features that present alongside PID upon contact with professionals impact upon the way the issues related to PID are prioritised. When a family presents as being chaotic with a number of vulnerabilities that result in a complex picture, the visibility of PID among these

various attributes appears to decrease. Whether PID is registered and prioritised by professionals dictates whether it is included in the assessment and support strategy that follows. There is a possibility that the outcome of cases have very little to do with the PID factor, as it may not have been included in decision-making at all. In these cases, the impact of its absence is unclear but there is a possibility that there may have been issues related to PID that remained unaddressed as a result. This could possibly have a detrimental effect on whether parents were able to make the changes necessary for their children to remain safely in their care. The visibility of PID is not the only determinant at this stage, but also whether the CSW is aware and sensitive to its indicators.

The findings from the FGDs and SCRs suggest that the next issue is the extent to which CSWs themselves or professionals with whom they have contact are able to assess parenting capacity in the context of PID. In the absence of these, the needs of parents cannot be fully understood and possible support options cannot be considered and explored. When parenting capacity can be ascertained and support needs are identified, the issue arises of whether the provision of necessary supports is viable. Due to reasons such as CSWs' awareness, funding, eligibility, availability, support for parents cannot be guaranteed. Without these, alternative options must be explored and the FGDs demonstrated how using resourcefulness, a patchwork of services can be sewn together to meet the same needs. Also, the network of agencies must be able to jointly work, communicate effectively and concertedly ensure children's wellbeing.

As services and supports are made available to families, their efficacy is partly determined by how parents and families engage with them. There can be some substantial obstacles to effective parental and familial engagement and these are met with how services respond. This depends on the level of obligation to which parents and families are held to meet the stipulations of support plans whereby they are

required to take up certain services and work with various professionals. The obligation to take up services varies across agencies but ultimately, where child-safeguarding is concerned, when efforts are not made by parents to improve their own ability to safely parent, these count against parents' cases for their children to remain in their care.

Beyond engagement is the question of whether the supports are having the desired effect and children's wellbeing is being supported as a result of their families' efforts. Throughout this process, in order to monitor families' progress effectively, CSWs must ensure that they maintain contact and meaningfully track developments. They must also remain objective when judging how families proceed and constantly keep in mind the wellbeing of the children concerned. For all of these things to be accommodated, there must be continuity in the professionals involved. When CSWs are reassigned, those picking up cases must be able to acquaint themselves with families, their backgrounds and their goals. There must also be a robust supervision and management system under which informed and considered decisions may be made. The SCRs and FGDs illustrated how there are numerous challenges to each of these.

While supervision and management is required in the immediacy, there must be some oversight of the systems overall. The SCR findings illustrated that the impact of PID upon the approaches taken by professionals, their subsequent practices, and the ultimate path of cases are investigated inconsistently. This limits the prospect of making changes in light of any shortcomings in these areas.

7.3 Strengths and weaknesses of overall study

This study uses qualitative and quantitative methods in the form of FGD and SCR analyses for the former, and a questionnaire-based experiment for the latter. The findings from each of these components were used to inform and build an account of how CSWs make decisions about cases concerning the children of PWID. Mixed methods can be defined as "research in which the investigator collects and analyses

data, integrates the findings and draws inferences using both qualitative and quantitative … methods in a single study" (Tashakorri and Cresswell, 2007, p. 4). The way in which the quantitative and qualitative elements are integrated to form a "mixed methods study" is subject to debate. For some, mixed methods is simply the collection and analysis of both types of data whereas for others, a complete integration of the two approaches is required (Doyle et al, 2009).

This study does not attempt to triangulate its qualitative and quantitative findings, rather each sits alongside each other. Triangulation "allows for greater validity in a study by seeking corroboration between quantitative and qualitative data" (Doyle, Brady and Byrne, 2009, p. 178) whereby "data are transformed either by quantifying qualitative data or by qualifying quantitative results" (Doyle, Brady and Byrne, 2009, p. 180).

This is because each of the three components aimed to approach the research question from different perspectives and had different aims. The SCR analyses sought to give a descriptive account of families, provide insight into the roles of CSWs and how PID was incorporated into their approaches, and the extent to which PID featured in SCRs. The QBE aimed to ascertain the impact PID disclosure had upon CSWs' assessments and how the particular scenarios interacted with this effect. The FGDs aimed to investigate how participants assessed each hypothetical scenario and use these vignettes as a springboard for discussion to gain insight into their wider understanding of PID and their experiences. Each of these provided broad and rich results which, alone and considered together, allowed the wider research question to be answered. The final conclusions are not drawn from an all-encompassing, over-arching model that incorporates the three sets of findings into a set of quantifiable results, but are instead an amalgamation of them.

The strengths and weaknesses of the individual components of the research have been discussed at length in their respective chapters. Each of these contributes to the

overall strengths and limitations of the research in its entirety. However, by using these three methods, the study has captured a more complete picture of how CSWs assess cases concerning PWID. Each of the methods "offsets" the weaknesses of the others, allowing the construction of stronger conclusions (Cresswell et al., 2003; Bryman, 2006; Doyle, Brady and Byrne, 2009).

7.4 Implications of findings

7.4.1 *Location of study within existing research*

There is already an academic interest in the topic of parenting by individuals with ID and their interaction with protective services in relation to their children. The existing studies appear to indicate that PWID are over-represented in terms of the parents whose children are subject to child protection procedures and ultimately removed from their parents' care. PWID are considered to be at risk of having their children removed.

It is not known how many parents there are living in England who have ID but people with ID represent approximately 2% of the general population in England (Holland, 2011). Despite this, of the parents about whom children's services have concerns, 12.8% of the mothers and 6.8% of fathers are known to have "learning difficulties" (Masson et al., 2008). Studies examining child protection procedure (Booth & Booth, 1996; McConnell and Llewellyn, 2000; Wates, 2002; Llewellyn, McConnell and Ferronato, 2003; Booth, Booth and McConnell, 2005) and the experiences of PWID (Booth and Booth, 2004; Baum and Burns, 2007; Gould and Dodd, 2014) suggest case outcomes and parents' negative experiences may be due to discrimination by practitioners. Fear of discrimination has been cited as why PWID are wary of engaging with parental support services (Gould and Dodd, 2014).

Booth, Booth and McConnell (2005) investigated how social services and courts in England handle child protection cases involving parents with ID. They found that children of PWID were more likely to be subject to freeing orders than children of other

parents. These children were also more likely to be placed out-of-home and outside of their kinship network. The conclusions drawn from such research often state how the parents are treated more harshly than other parents on the basis of their disability. That PID was being scapegoated was a concern and that "the problems giving rise to the professionals' concern and leading them to feel that the situation as such was irredeemable were directly related to … intellectual disability" (Booth, Booth and McConnell, 2005, p. 15). Unexamined prejudices against those with any form of disability have been cited as cause for the over-representation of children of people with disabilities in the looked-after system (Wates, 2002). These are sentiments that are echoed throughout the international literature (Hayman, 1990; Taylor et al. 1991; Watkins 1995; Levesque 1996; Keyzer, Carney and Tait, 1997; Bray, 1999; McConnell and Llewellyn 2000, 2002; Swain, French and Cameron, 2003).

That discrimination is the basis for this seemingly differential treatment is challenged by this study. From all three phases of analysis, it is clear that rather than a widely-held negative view of parents with ID, the defining factor that determines the path and outcome of cases appears to be the other factors that are present. These appear to divert attention from PID and any related difficulties and result is that in cases where there are more overt issues, PID is largely overlooked. When placed with additional vulnerabilities, PID and the associated support needs appear to be side-lined in favour of need that appear more pressing. Rather than an active, more negative form of discrimination as is suggested by the wider literature, this study illustrates a pattern of accidental discrimination stemming from difficulties with the presentation of PID.

There are studies that contradict the view that PWID are negatively regarded by professionals working with children, one of which is study of child protection service worker decision-making in the United States of America (Proctor and Azar, 2013). This study, upon whose methods the QBE component built upon, used vignettes to investigate the effect PID disclosure had upon workers' "emotional reactions,

attributions and decisions about risk to the child, whether to remove the child and workers' general willingness to help the parent" (Proctor and Azar, 2013, 1104). While they found that perceived increased risk to children was significantly associated with PID disclosure, so was workers' willingness to help. Also, lower feelings of anger, higher ratings of pity, and greater willingness to help were also observed for cases with PID. The FGD data supplemented these findings illustrating that when PID is known or suspected, the cases that ensue can evoke a series of emotional responses that can impact upon the course of families' service interaction. CSWs empathise strongly with parents and will them to succeed, often working with them creatively and resourcefully for such long periods of time that their objectivity is undermined and children are left in poor conditions for too long.

In addition to the emotional aspects of their work, CSWs are subject to a range of internal, external and systemic forces during their work with families headed by PWID. The extent to which services systems, and the individuals within them are equipped to meet the needs of PWID appears to be subject to great variation. The participants in the FGDs frequently described the difficulties acquiring the necessary skills, knowledge, and resources to work appropriately with PWID. This takes places within a climate of scrutiny and time constraints, while still striving to ensure that the children in question and their wellbeing remain at the centre of their work. The capacity of systems to handle PID and appropriately support PWID and their families is not a new question. Azar and Read (2009) have demonstrated the gap between professionals' and systems' capability to meet these needs and the demand, and the effect of failing to address this shortfall. That systems are seemingly ill-equipped to cope with the needs of PWID specifically is problematic.

This raises questions of which professionals should be accountable for the specific needs within families that relate to PID and fill the gap. An issue that frequently arose in the FGDs and in the SCRs was that parental support was often problematic. The

professionals involved with children must prioritise children's direct needs and while these are often entangled with those of their parents, their training and purpose is such that they often cannot meet the needs of PWID entirely. While issues relating to adults' services persist, such as funding, eligibility, engagement, and patchy availability, parents' needs will remain unmet in some cases.

This highlights a fundamental fissure within this question, that in finding an answer it must be acknowledged that the needs and rights of two vulnerable groups are at play. Individuals with ID and children are two groups to whom certain obligations of protection and provision are held. The subject of parenting and intellectual disability is highly emotive and the needs of these two groups are often placed on opposing sides. Poor outcomes for children are perceived to be tied to the perceived shortcomings of parents and as such, support for one can be considered to be detrimental to the support required for the other. The field of research also appears to take this shape and a cleft emerges, separating investigation into two "sides" – one considering the needs, experiences, and interests of parents, and the other catering for those of children. The development and design of this study was informed and directed by the research and there appeared to be a shortage of studies investigating the services supporting children. Specifically, the particular experiences of children's services professionals and the climate in which they work is under-investigated, while parents' experiences of being subject to child protection procedure and parenthood more generally is more so (Booth and Booth, 1995; Aunos, Goupil and Feldman, 2005; Booth and Booth, 2005; Baum and Burns, 2007; MacIntyre and Stewart, 2011; Mayes and Llewellyn, 2012; Gould and Dodd, 2014). This study aimed to fill a gap in the research by bridging the two sides and drawing upon the insights and experiences of CSWs to better understand their work with PWID.

There are two studies that have been conducted in England, specifically examining social services practitioners working with PWID and their views. The first, by Cleaver

and Nicholson (2007, 2008), explored assessment, parental involvement, and children's outcomes and found that social workers worked in partnership with PWID. Social workers felt ID was an obstacle to parent's involvement and children were placed away from home after substantial service input failed to bring about the required change. There was no evidence parental ID in itself was the reason children were removed. The welfare of a significant proportion of the children in the sample was not being promoted and they were continuing to live in unacceptable situations. The findings from the FGDs mirror these conclusions and add further explanations for how these outcomes come about.

The second study examining six family centre workers working with PWIDs found "an underlying perception that parents with learning difficulties [ID] have limited capacity to change" and suggested that this could negatively impact upon the assessment process and outcomes (Jones, 2013, p. 177). PWID are wary of engaging with parental support services due to fear of discrimination (Gould & Dodd, 2014) but perceived parental "non-cooperation" has been found to be a predictor for the removal of children (McConnell et al., 2011). This study provides clarity on how parental engagement and cooperation impacts upon CSWs' decision-making. Parental engagement is explored at length and is taken as a marker by CSWs for willingness to address and recognition of children's needs. It is only upon service uptake that the efficacy of the supports provided can be ascertained, through assessment and monitoring of families' progress. In these circumstances, these processes are how children's wellbeing is ensured.

7.4.2 *Considerations for future policy*

7.4.2.1 *Identification of PID by CSWs*

The findings from this study demonstrated how when PID presents alongside other more seemingly demanding factors, its significance is downplayed or overlooked. When this takes place, the danger is that the issues relating to ID and the

considerations that ensure elements of children's social care interaction like communication, effective engagement, and appropriate support are included in care strategies, are lost. In terms of efforts made to meaningfully engage parents in the wellbeing of their children, when attempts are not made to address support needs relating to PID that potentially undermine parenting ability, it cannot be said that all means of attempting to do so have been exhausted. Also, CSWs are best equipped to support families when they are aware of all of the elements that are at play in a case and the extent to which each of these components impacts upon parenting capacity and their ability to ensure their children's wellbeing.

This can be addressed by ensuring that CSWs are firstly aware of the potential relevance PID has to parenting capacity and any subsequent support measures installed. Information on the ID status of parents can be found in their histories, whether they had a statement of Special Education Need, had attended a school for individuals with special needs, whether they have a diagnosis of ID or receive any support or benefits on this basis. CSWs should be supported and facilitated within their roles to draw on available information or that which is communicated by other professionals, and incorporate this information into their strategies. CSWs should be encouraged to ask questions of parents when seen to be necessary in order to tease out information relating to ID.

The descriptive accounts of families from the SCR analysis illustrated the diversity of the families affected by PID. The multifaceted nature of the stressors and vulnerabilities experienced by families where PID is known or suspected demonstrates that these families do not fit neatly in one box. Instead, potentially any CSW working within any area of children's social care could encounter cases where families are headed by PWID. The amorphous manner in which PID may present itself within families means that all CSWs must be aware and sensitive to its indicators and have a sense of how to proceed with this information.

7.4.2.2 *Support for PWID*

The FGDs illustrated that there is great variation in the degree of comfort and confidence CSWs have in terms of working with PWID and meeting their needs. There were differences in case experience, training, general knowledge of PWID and the supports available, and inconsistency in the resources available to professionals in order to assess and work with parents appropriately. This indicates a need for uniformity to ensure that all CSWs are able to work with PWID to secure the best interests of the children concerned.

The question of systems' capacity to identify and support PWID also arises. CSWs often represent one of a plethora of agencies working with families. The degree to which these systems can communicate effectively, share relevant information and work in combination to ensure the needs of parents are met must be explored. Each of the agencies engaged with families is there to meet a specific need and their joint efforts weave together to support families, with each covering their specific area. Each individual must be facilitated to effectively perform their roles and be able to rely on the availability and provision of the various other areas. For example, CSWs should be able to rely on the professionals from areas of social care better equipped to support parents so that they are able to focus on the immediate needs of children. A considerable issue that arose from the SCR and FGD analyses were the inherent difficulties in securing specialised assessments and supports for parents. When these services are absent, either due to poor parental engagement, lack of availability, funding or eligibility issues, the professionals already involved are left to fill the gaps, lessening their focus on their own roles and forcing them to work in areas for which they are not trained.

At times, it is not an issue of the relevant supports being available but whether they exist. A finding from the FGDs was that there appeared to be a gap as far as PWID were concerned, where there was a lack of services for individuals with ID to be

supported in their capacity as parents. There appears to be a missing area beneath the Venn Diagram overlap between adults with ID and the children to whom they were parents. People with ID becoming parents appears to challenge the current system of social care as many services appear unprepared and unclear of how to proceed. During the FGDs, participants reported how services working under significant strain were not able to give the time required to fathom how to proceed with families, making specialised assessments a rarity and joint action nearly impossible because of agencies feeling unable to take on additional responsibilities.

7.4.2.3 *Opportunities to learn*

The findings from the SCR analysis illustrated how the approach to considering how lessons might be learned from cases concerning the children of PWID is inconsistent across LSCBs. While not all cases concerning PWIDs can be assumed to have been affected by PID and how professionals worked with PID in mind, there should be some uniformity in ascertaining whether this is or is not the case. Without this, possible avenues for learning from gaps and shortcomings in practice from cases are lost. Based on the findings from the other areas of this study, the approach taken by CSWs to assess, understand, and work with PWID is highly inconsistent. Such inconsistency necessitates a system of review that wholly accounts for and is sensitive to potential failings and issues with practice and services. It cannot be assumed that parents with ID, in their capacity as people with ID, have had their needs met and understood, and that all possible lessons have already been learned.

7.5 Recommendations for future research

A key issue demonstrated by this study is the inconsistency in how parenting by individuals with ID is approached. This relates to several areas including to the training received by CSWs, the availability of services and supports, and the handling of cases by LSCB reviewers. Before concrete proposals for policy can be made, the

particularities of each of these things must be established. This could be done by auditing both the training received by CSWs and the overview reports of SCRs. Mapping out the services for PWID available throughout England, will permit insight into how these can be improved, strengthened, and provide services more widely, and allow identification of gaps in services. Monitoring these will enable researchers and policy-makers to draw informed conclusions about the capacity of the systems inhabited by families to appropriately meet their needs. In doing so, the capacity of systems to support PWID can be better understood and the prospects of families can be improved.

7.5.1 *Obstacles to evidence-based policy in children's social care*

During the process of planning and collecting data for the fulfilment of this thesis, significant difficulties were encountered in sampling and recruiting CSWs. The volume of these difficulties were such that they may present obstacles to future evidence-based policy (EBP) in children's social care. EBP is an approach where "professionals use the best evidence possible, i.e., the most appropriate information available, to make … decisions" (McKibbon, 1998, p. 396) and is usually informed by research. The use of EBP in social work is subject to debate (Black, 2001; Webb, 2001; Grol and Wensing, 2004) but for subjects such as as parents with ID in England, limited research is a weakness when beginning a dialogue on policy and planning.

There were substantial problems encountered while recruiting children's services to participate in the QBE component. Of the 23 services approached to participate, six agreed to do so. Those who replied and were not able to participate cited a range of reasons why this was the case. Often, the reason for opting to not take part was the burden already faced by the service and their being unable to justify the additional burden of participating in research. For the services that did participate, recruitment to the study was not straightforward and the final response rate was low. Despite the

efforts made by all of those involved, for some of the children's services there was limited improvement in recruitment throughout the data collection period. Similar issues were found during recruitment for the FGDs. The result of these was that data collection took far longer than had been initially expected and the resulting data was subject to limitations.

The utility of research hinges on its applicability and where there are doubts about representativeness due to limited service participation and internal recruitment, the use of the research becomes questionable. Also, these issues could serve as a significant enough obstacle to deter future research. This is unfortunate as it was clear from the FGDs that children's social care houses a seemingly untapped reserve of experienced, knowledgeable, and enthusiastic professionals, whose wealth of expertise should be capitalised upon.

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Appendix 1: ADCS approval letter

ADCS
Leading Children's Services

Ameeta Retzer
National Perinatal Epidemiology Unit, Nuffield Department of Population Health, University of Oxford

National Perinatal Epidemiology Unit, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF

By email

3 March 2014

Dear Ameeta,

Request for ADCS research approval – University of Oxford - Children's social workers' (CSW) assessments of parents with intellectual disabilities (ID) in England

ADCS ref: RGE140128

I write on behalf of Sue Wald, Chair of the ADCS Research Group regarding your request for research approval for the above named project.

The Research Group has considered your request and given its approval believing that the results of the project will be useful to local authorities. We would be grateful if when contacting local authorities you would quote the reference above.

The group is satisfied with the various responses you have provided regarding the queries raised. It would also be appreciated if you could advise us if the scenarios do indeed change post-testing.

The Group's encouragement to respond to the survey will be communicated to ADCS members in local authorities in England in the next edition of the ADCS weekly e-bulletin which is produced and circulated on Friday afternoons. A list of approved research projects can be found on the ADCS website. The Research Group wishes you well with the project.

As mentioned in the ADCS Guidelines for Research Approvals, please send the Research Group a copy of the full report and the summary of your main findings when the research is complete.

If you have any queries about this feedback, please contact me in the first instance.

Yours sincerely

Ga[redacted], **on behalf of S[redacted] Chair of the ADCS Research Group**

Appendix 1b: Medical Sciences Inter Diversional Research Ethics Committee approval letter

MEDICAL SCIENCES INTER DIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, University of Oxford

University Offices, Wellington Square, Oxford, OX1 2JD
Tel: +44(0)1865 616577 Fax: +44(0)1865 280467
ethics@medsci.ox.ac.uk http://www.medsci.ox.ac.uk

CONFIDENTIAL

Ref: MSD-IDREC-C1-2014-024

Mrs A. Retzer
85 Monmouth Drive
Sutton Coldfield
B73 6JH

6th March 2014

Dear Ameeta

CUREC checklist

I am writing to acknowledge receipt of your CUREC-1 form for your project: **Children's social workers' assessments of cases concerning parents with intellectual disabilities**

On the basis of the information you have provided this has now been approved by the Medical Sciences IDREC **subject to:**

a) **your following the BPS guidelines for online research;**

b) **it is your responsibility to comply with the requirements for administering any tests or questionnaires and if in doubt to contact the publisher of those tests or questionnaires.**

The reference number for this project is **MSD-IDREC-C1-2014-024** and is valid for a period of **9** months from the CUREC 1 approval date, **5th March 2014**. Please may I remind you that your project may be reviewed at some stage during an annual audit of projects.

Amendments

Should you at some stage alter some of the techniques or procedures then you should first undertake a checklist (CUREC-1) to see whether these changes alter the ethics of the research. If these remain the same then the committee will require notification of the changes to lodge with the project. If they do not remain the same then you may need to complete a CUREC-2 form and undergo further scrutiny by the committee.

Please do not hesitate to contact me if you have any queries about this.

Yours sincerely

Gi[redacted]
Research Ethics Co-ordinator, Medical Sciences

Appendix 2: SCR inclusion and progress chart

Case	Local Authority	Included ?	Notes	Overview Report?	Read?	In Excel?
Child I (2015)	Lambeth	Y	2 parents with ID, vulnerable and isolated family	Y	Y	Y
Child D (2014)	Unknown	Y	Previously looked-after young mother with history of involvement and engagement – shook 7 w/o daughter	Y	Y	Y
Family A (2014)	Southampton	N	Travellers – no parental ID – just illiteracy	-	-	-
SCR CN10 (2014)	Devon	Y	Stepfather with mild ID – mother failed to protect	Y	Y	Y
Child W3 (2014)	Walsall	N	Children w ID	-	-	-
Child S (2014)	Surrey	Y	Serious injury of 2 m/o boy – MWID – elder half siblings subject to CPP – alcohol abuse and domestic v	Y	Y	Y
Child I & M (2014)	Southampton	Y	Death of 2 y/o boy and his 4y/o half-brother – failure to assess parenting capacity	Y	Y	Y
Child G (2013)	Wirral	N	Death of 17 y/o girl – no children	-	-	-
Adults A, B, C (2013)	Rochdale	N	Historic abuse case – parents did not have ID	-	-	-
Young People 1,2,3,4,5,6 (2013)	Rochdale	N	Parents did not have ID	-	-	-
Young Person 7 (2013)	Rochdale	N	Parents did not have ID	-	-	-
Emma	Wakefield and	Y	Mother with	Y	Y	Y

(2013)	District		suspected ID, father moderate – child died at 7 weeks			
Child 1 (2013)	Bolton	Y	Pakistani family – isolated mother, father w ID. Child died as an "immobile infant"	Y	Y	Y
Child R & Q (2013)	Rochdale	N	Parent doesn't have ID, children did.	-	-	-
Maisie Harrison (2013)	Northamptonshire	Y	Parents both with ID, multiple vulnerabilities, complex issues – PID not considered, even in SCR. Baby cot death, 4 weeks	Y	Y	Y
		Pre-2010, publication of Overview Report not required, Executive Summaries available				
Baby Kathy (2012)	Southend on Sea	Y	Father with ID, mother w multiple difficulties – 8 w/o baby died. Poor communication	N – follow up with NSPCC or Southend – EMAILED SOUTHEND – not subject to publishing requirements so exec summary only available – RECEIVED EXSUM	Y	Y
Child R (2012)	Bridgend	N	Suicide of 13 y/o boy. Parents	-	-	-

			w/o ID			
Child B (2012)	Luton	Y	Injury of 9m/o girl – mother and father w multiple vulnerabilities – M w ID	N – Follow up with NSPCC or Luton – EMAILED LUTON – RECEIVED EXSUM	Y	Y
Child H (2012)	Leicestershire and Rutland	Y	9 w/o child sofa-co-sleep death. Parental ID	N – Requested from L&R, will check with NSPCC – neither exec summary or Overview Rep available – emailed for exec sum – RECEIVED	Y	Y
Child U (2012)	Leeds	N	17y/o boy – child has ID themselves	-	-	-
Child S (2011)	Rotherham	Y	Murder of 17 y/o MWID – needs not properly assessed	Y	Y	Y
Child K (2011)	Tameside	Y	Baby w parents who both have ID – issues w assessment	N	Y	Y
Child D and Child B (2011)	Bromley	Y	2 brothers taken into care after 1 was injured – MWID	N	Y	Y
Child T and Child R (2011)	London Borough and Barking and Dagenham	N	Child w LD, mother w MH issues	-	-	-
Children C and D (2011)	Vale of Glamorgan	N	Abuse by man w ID, not father but fostered by the family	-	-	-

Child X (2011)	Sunderland	N	Child had ID, mother and stepfather had substance and MH issues	-	-	-
Baby M (2010)	London Borough of Barking and Dagenham	Y	Death of 6w/o girl – parental and familial ID	N	Y	Y
Child Y (2010)	Leicestershire and Rutland	Y	Non-acc injury to child – MWID, father w history of criminal activity	Need to email to request Exec Sum – EMAILED – RECEIVED	Y	Y
Child BN (2010)	Nottinghamshire	N	Child w ID and disability – abuse and neglect	-	-	-
5 children in a family (2010)	Kirklees	Y	Abduction of 3rd child by MWID – all siblings neglected	N	Y	Y
SCR of Young Person (2009)	Cornwall and the Isles of Scilly	N	Adolescent woman w ID – needs not understood/met	-	-	-
Baby F (2009)	Hampshire	Y	6w/o child, M and StepF w ID – child injured – poor C&A work	N – requesting both from LCSB – in the post – OUTSTANDING – received – hard copy	Y	Y
Child HB (2009)	Herefordshire	N	Child aged 7y/o died following surgery – Child w ID	-	-	-
Child R (2009)	Hertfordshire	Y	Child injured, MWID, ambivalence towards pregnancy	Requested ExSum – XXXXX S - RECEIVED	Y	Y
Brooke (2009)	Kent	Y?	AWLD in keywords – Non-accidental	N	Y	Y

			injuries, MWMH			
Child T (2009)	Lancashire	Y?	Death of child 1y/o – mother may have ID	Requested ExSum - RECEIVED	Y	Y
Young woman KK (2009)	Lewisham	N	Young woman who may have ID – had one child. Woman herself was neglected and abused. Not included as KK was not a parent, though may have been pregnant. Gives insights into sex education and sexuality w YPWID	Requested ExSum - XXXXX checking with XXXXX – will email her again – OUTSTANDING – emailed 26Aug – received 19Dec	-	-
K Family (2009)	Lewisham	N	Case related to the above, KK sexually abused and exploited by parents – parents were not learning disabled	>>? XXXXX checking with XXXXX – will email her again – OUTSTANDING – emailed 26Aug - received 19Dec	-	-
Child A (2009)	Newham	Y	Death of 2m/o – assault and neglect, MWID	N - RECIEVED	Y	Y
Case No.9 (2009)	Birmingham	Y	Chronic neglect, possible death by malnutrition, 1/both parents have ID	N - RECIEVED	Y	Y
Child A (2009)	Torbay	Y	Serious injuries 8w/o boy, parents w multiple vulnerabilities and ID	N	Y	Y
Child M (2008)	Camden	N	Child has ID and other disabilities	-	-	-

Child A (2008)	Durham	Y	Child aged 5m/o died, both parents w ID – lack of supervision	TRYINGGGG - OUTSTANDING	-	-
Young child, 11 w/o (2008)	Kirklees	Y	Injury to 11 w/o child, PWID. Issues w assessments and discharge at birth	Requested ExSum, XXXXXXM - RECEIVED	Y	Y
Child B (2008)	Surrey	Y	Death of 3.5y/o child – chaotic family, multiple vulnerabilities, MWID	N	Y	Y
Child F (2008)	Somerset	Y	Serious injury of 9w/o, MWID, father w issues	N	Y	Y
Child E (2008)	Somerset	Y	Death of 3w/o, both PWID – providing support to new parents w ID	N	Y	Y
Child J (2008)	Stockport	N	Overdose by 16y/o girl w ID – she had no children	-	-	-
Jenny (2007)	Nottingham	N	16 y/o woman went missing, no children	-	-	-
Child B06 (2007)	Bury	N	Child w ID etc, not a parent	-	-	-
Child RD (2007)	Stockport	N	Child w ID etc, not a parent	-	-	-
Child A06 (2006)	Bury	Y	Death of 6m/o child, physical abuse and neglect, 1/both PWID	N	Y	Y
Family B (2006)	Cambridgeshire	Y	Family w MWID and 2/3children w ID. Abuse and neglect, failure to protect – adult men	Requested ExSum from website – update from XXXX D – getting it from archive – OUTSTAN	Y	Y

				DING – to be posted		
Family C (2006)	Cambridgeshire	Y	5 children – neglect and harm, MWID with multiple male partners. Support needs overshadowed signs of abuse	Requested ExSum from website – update from XXXX D – getting it from archive – OUTSTANDING – to be posted	Y	Y
Child E (2006)	Camden	Y	Death of 2m/o child, mother w multiple vulnerabilities, w ID – over-positive view of capacity	N	Y – same as Newham	Y
Child [1] (2006)	Coventry	N	Child w ID, not a parent	-	-	-
6 w/o baby boy (2005)	Staffordshire	Y	Death of 6w/o baby, teenage parents both w ID- limited ExSum, no details of ID	N	Y	Y

Appendix 2b: SCR thematic framework

Families	**Service**	**Review**
Child – characteristics and descriptors	Services for parents – support, housing, ID specific services, etc.	Questions posed from the outset of review – Is PID mentioned as an item for investigation?
Parents – mother, father – characteristics and descriptors	Services for children – schools, nurseries, children's social workers (CSWs), etc.	PID mentioned in recommendations
Grandparents and wider family circle – characteristics and descriptors	Services for families – midwifery, health visiting, etc.	
Home circumstances, living situation		
Service engagement – attending appointments, self-reporting, help-seeking behaviours, avoidance behaviours		
Identification of PID		
➢ Family characteristics	➢ Role of CSWs among these agencies	➢ Weight ascribed to PID in review

Appendix 2c: Table of the ages of the children included in the SCR analyses

Serious case review	Age of child at event
Child I (Lambeth, 2015)	19 months
Child D (LSCB unknown, 2014)	7 weeks
CN10 (Devon, 2014)	13-17 years
Child S (Surrey, 2014)	2 months
Child I&M (Southampton, 2014)	2 years, 4 years
Emma (Wakefield, 2013)	7 weeks
Child 1 (Bolton, 2013)	-
Maisie Harrison (Northamptonshire, 2013)	4 weeks
Baby Kathy (Southend on Sea, 2012)	8 weeks
Child B (Luton, 2012)	9 months
Child H (Leicestershire, 2012)	9 weeks
Child S (Rotherham, 2011)	17 years
Child K (Tameside, 2011)	<1 year
Child D&B (Bromley, 2011)	5 years, 6 years
Baby M (Barking and Dagenham, 2010)	6 weeks
Child Y (Leicestershire, 2010)	<2years
“5 children in a family” (Kirklees, 2010)	-
Baby F (Hampshire, 2009)	6 weeks
Child R (Hertfordshire, 2009)	<3years
Brooke (Kent, 2009)	<4weeks
Child T (Lancashire, 2009)	1 year
Child A (Newham, 2009)	2 months
Case No.9 (Birmingham, 2009)	-
Child A (Torbay, 2009)	8 weeks
Young Child (Kirklees, 2008)	11 weeks
Child B (Surrey, 2008)	3.5 years
Child F (Somerset, 2008)	9 weeks
Child E (Somerset, 2008)	3 weeks
Child A (Bury, 2006)	6 months
Family B (Cambridgeshire, 2006)	15 years
Family C (Cambridgeshire, 2006)	<1 year, 3years, 5years, 11years, 13years
Child E (Camden, 2006)	2 months
“6 week old boy” (Staffordshire, 2005)	6 weeks

Appendix 2d: Table of SCR characteristics

#	Serious case review	PID noted at start of review	PID noted in "Learning Points" or "Findings"	PID mentioned in recommendations	PID mentioned in "Action Plan"
1	Child I (Lambeth, 2015)	X	X	x	x
2	Child D (LSCB unknown, 2014)	X	X	x	o
3	CN10 (Devon, 2014)	O	O	o	o
4	Child S (Surrey, 2014)	O	X	o	o
5	Child I&M (Southampton, 2014)	O	X	x	x
6	Emma (Wakefield, 2013)	X	X	x	x
7	Child 1 (Bolton, 2013)	X	X	x	o
8	Maisie Harrison (Northamptonshire, 2013)	O	X	o	o
9	Baby Kathy (Southend on Sea, 2012)	O	O	x	o
10	Child B (Luton, 2012)	O	O	o	o
11	Child H (Leicestershire, 2012)	O	O	o	o
12	Child S (Rotherham, 2011)	X	X	x	o
13	Child K (Tameside, 2011)	X	X	x	x
14	Child D&B (Bromley, 2011)	O	O	o	o
15	Baby M (Barking and Dagenham, 2010)	O	X	x	o
16	Child Y (Leicestershire, 2010)	O	O	o	o
17	"5 children in a family" (Kirklees, 2010)	O	X	x	o
18	Baby F (Hampshire, 2009)	X	X	x	x
19	Child R (Hertfordshire, 2009)	O	X	x	o
20	Brooke (Kent, 2009)	O	O	o	o
21	Child T (Lancashire, 2009)	O	O	x	o
22	Child A (Newham, 2009)	O	X	x	o
23	Case No.9 (Birmingham, 2009)	X	X	x	x
24	Child A (Torbay, 2009)	O	X	x	o
25	Child A (Durham, 2008)	-	-	-	-
26	Young Child (Kirklees, 2008)	X	X	x	o
27	Child B (Surrey, 2008)	O	O	x	o
28	Child F (Somerset, 2008)	O	o	o	o
29	Child E (Somerset, 2008)	X	x	x	o
30	Child A (Bury, 2006)	O	o	o	o
31	Family B (Cambridgeshire, 2006)	O	x	x	o
32	Family C (Cambridgeshire, 2006)	O	x	x	o
33	Child E (Camden, 2006)	O	x	x	o
34	"6 week old boy" (Staffordshire, 2005)	O	o	o	o
	Key: **X – presence of characteristic** **O – absence of characteristic**				

Appendix 3: Development of scenarios

Identification of *one or more risk factors does not of itself determine that a child is suffering or is likely to suffer significant harm*. It indicates need for further assessment.

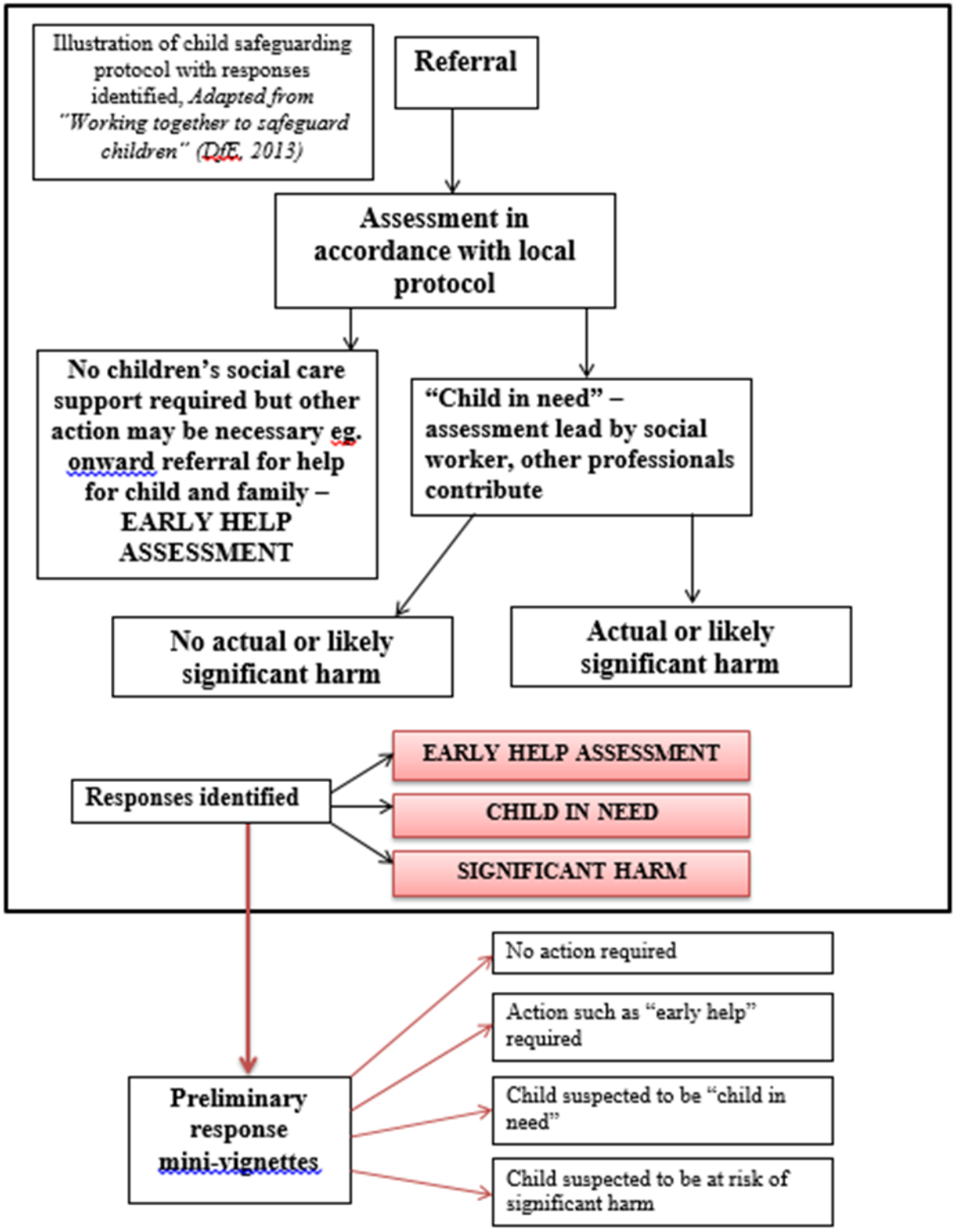
CAFCASS risk factors	**Detail**
Past, present, and/or likely harm to child (including unborn)?	Including: physical abuse, emotional abuse, sexual abuse, neglect
Vulnerability factors of child, which may increase risk?	e.g. disability; not being a child of the family; behavioural difficulties; uncertain immigration status; family breakdown associated with high conflict where the child is "unseen", "unheard" or caught up in the adult battle; unborn children
Child putting self and/or others at risk?	e.g. substance abuse; sexually harmful behaviour; past/present and/or likely future suicide attempts; self-harm; involvement in community-based violence such as gang, group and knife crime
Children in specific circumstances	e.g. being a victim of bullying; sexual exploitation; child trafficking; faith-based concerns, e.g. child possession, honour-based violence, forced marriage (of child)
Hazardous environment	e.g. unsupervised access to dangerous dogs, drugs, busy road
Domestic violence	Including: violence between siblings; a child witnessing the violence; with other partners (either in the past or currently); pre-separation; post-separation; linking to contact; escalation; forced marriage (of the parents); threats/ fears of child abduction
Vulnerability factors relating to adults?	Including: previous/current mental health problems; adult learning difficulties [ID]; drug/alcohol abuse; past, current and/or likely future suicide attempts/threats/self-harm
Other social exclusion factors?	e.g. poverty, racism, homelessness, sudden change e.g. redundancy, bankruptcy
Presence of a person?	Within the family/household/immediate network who represents a risk to children.

Appendix 3b: Development of scenarios

Proctor (2011) vignettes – Are CAFCASS (2012) risk factors present? Y/N

Proctor vignettes → **CAFCASS Guidelines ↓**	#1 Two parents live with their child in an old house. Two windows in the room the child plays are broken and the glass has jagged edges. The child has cut his hand, requiring three stitches.	#2 Two parents make no effort to keep their child clean. The child's hair is matted with bits of old food.	#3 Two parents regularly leave their child alone outside the house during the day until almost dark. Neighbours have spotted the child wandering 5 blocks from home.	#4 Two parents have not taken their child to a dentist. The child has difficulty eating.	#5 Two parents always insist that their child clean his plate, which they keep full of food. Doctors have warned that the child's health will suffer if he continues to eat so much.
Past, present, and/or likely harm to child (including unborn)?	Y (neglect)	Y (neglect)	Y (neglect)	Y (neglect)	Y (neglect)
Vulnerability factors of child, which may increase risk?	N	N	N	Y (difficulty eatng?)	N
Child putting self and/or others at risk?	N	N	N	N	N
Children in specific circumstances	N	? Possible – bullying?	N	N	N
Hazardous environment	Y (broken glass)	N	Y	N	N
Domestic violence	N	N	N	N	N
Vulnerability factors relating to adults?	N	N	N	N	N
Other social exclusion factors?	N	N	N	N	N
Presence of a person?	N	N	N	N	N

Appendix 4: Development of assessment options



Appendix 4b: Table of the two versions of the questionnaire

Scenario [and label]	Version 1	Version 2
2 windows in the room where the child plays are broken and the glass has jagged edges. The child has cut his hand, requiring 3 stitches ["glass"]	ID disclosed	ID not disclosed
The parents have been arguing a lot for the past few months and have been quite distracted. The child has not been getting help with his homework from his parents and often has to prepare his own meals ["argue"]	ID disclosed	ID not disclosed
The child has met some older children who are known to be part of a violent gang. The child is spending less time with his old friends and more time with these older children ["gang"]	ID disclosed	ID not disclosed
The parents are known to have spoken about the child getting married when he is older, to someone they choose and the child may not know. If such a marriage were proposed, the child may not have a choice ["marriage"]	ID disclosed	ID not disclosed
The parents have recently adopted a dog from an animal rescue and the child often plays with the dog unsupervised ["dog"]	ID not disclosed	ID disclosed
The child has been in a number of physical fights with his sister. Most recently the child has a cut on his lip and a bruise on his head. The child has been injured as a result of these fights in the past ["sister"]	ID not disclosed	ID disclosed
The child's mother has self-harmed in the past and is now saying she is feeling depressed and suicidal. The child is aware that his mother feels this way ["depression"]	ID not disclosed	ID disclosed
The child's father has recently lost his job and the child's mother does not work. There is a possibility that the family will not be able to pay their rent as the father's employment was the main source of income ["unemployed"]	ID not disclosed	ID disclosed
The child's maternal uncle has committed an offence that has meant he is now designated a "risk to children". This uncle has regular and sometimes unsupervised contact with the child ["uncle"]	ID not disclosed	ID disclosed

Appendix 5: Sample letter to children's service directors

Ms G
Director of Children's Services
CSC House
CSC Street
CSC Department
City
Postcode

Dear Ms G,

My name is Ameeta Retzer and I am a doctoral candidate working at the National Perinatal Epidemiology Unit in the University of Oxford. I am carrying out a study examining how children's social workers assess risk when considering cases concerning parents with intellectual disabilities. The purpose of the research is to better understand these parents' interactions with children's social services with a view to support positive practice and make recommendations to address any issues.

Following the email sent on the 7th of March, 2014, I would like to formally invite X Children's services to participate in the research.

I am distributing a questionnaire to be completed by children's social workers working in 23 children's services departments in England. These 23 services have been chosen to get the most representative sample of children's social workers, and collect the highest quality data. The questionnaire will open in May and will close on the 1st of August and takes between 20-30 minutes to complete. The questionnaire is electronic and can be completed at questionnaire any time within the May-August period.

The Association of Children's Services Directors have given this research their approval (ADCS ref: RGE140128) and the Medical Sciences Inter-Divisional Research Ethics Committee (University of Oxford) have given their permission for the research to go ahead.

If you have any questions or need any clarifications, please do not hesitate to contact me, by email (ameeta.retzer@wolfson.ox.ac.uk) or by phone (01865 617 822).

I look forward to hearing from you.

Best wishes,

Ameeta Retzer

National Perinatal Epidemiology Unit
Nuffield Department of Population Health
University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF
T +44 (0)1865 289700 F +44 (0)1865 289701 www.npeu.ox.ac.uk

Appendix 6: QBE recruitment email to CSWs

Hello, my name is Ameeta Retzer. I am a third year doctoral (PhD) student at the University of Oxford.

I am carrying out research and **I would like to invite you to participate in a questionnaire**.

I have developed an online questionnaire that calls upon your experience as a children's social worker to see how you would assess child safeguarding cases where the child's parents have intellectual disabilities. A person is considered to have an intellectual disability when they have difficulty understanding new or complex information and learning new things; are less able to cope independently; and experience this during childhood with permanent effect.

This research is so we can better understand these cases from the perspective of children's social workers. To do this, I need to recruit as many children's social workers from across England as possible and from the fullest variety of backgrounds to complete the questionnaire. This is where I need your help. There has not yet been any work on this subject in England and your opinions on these cases are crucial to understanding this subject better.

The questionnaires are completely confidential and anonymised, and you will be sent a link directing you to the website where the questionnaire is located.

If you would like some more information, please contact me at ameeta.retzer@wolfson.ox.ac.uk. This research is approved by the Association of Directors of Children's Services (ADCS ref: RGE140128) and your local authority has given their permission for you to take part. The Central University Research Ethics Committee at the University of Oxford has also given their approval (ref: MSD-IDREC-C1-2014-024).

Thank you so much for your time.

Contact: ameeta.retzer@wolfson.ox.ac.uk, National Perinatal Epidemiology Unit, Nuffield Department for Population Health, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF.

Appendix 7: CSW questionnaire

Block 6

Hello, my name is Ameeta Retzer

I am a third year doctoral (PhD) student at the University of Oxford in the Nuffield Department of Population Health. I can be contacted at ameeta.retzer@wolfson.ox.ac.uk, National Perinatal Epidemiology Unit, Nuffield Department for Population Health, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF.

I would like to invite you to participate in a questionnaire.

However, before we begin I would like to give you some information. If you would like to take part in this questionnaire after reading the information in the pages below, click "yes" and you will be directed to a consent form. After completing the consent form you will be able to complete the questionnaire. If you choose not to take part, simply click "no", and you will be directed away from the questionnaire. Reading the following information and completing the questionnaire will take approximately 20-30 minutes. This research is approved by the Association of Directors of Children's Services (ADCS ref: RGE140128) and your local authority has given their permission for you to take part.

If you choose to complete this questionnaire, please do not do so more than once.

What is the project?

I am working on a project that aims to find out how children's social workers respond to child safeguarding cases where the child in question has parents with intellectual disabilities. A person is considered to have an intellectual disability when they display three specific characteristics. Firstly, they have difficulty understanding new or complex information and learning new things. Secondly, they are less able to cope independently. Thirdly, they experience this during childhood with permanent effect. This may mean they require more assistance than others in learning a task and adapting to changes in routine.

In England, people with intellectual disabilities are encouraged to live in the same way as people without intellectual disabilities - this may mean having jobs, going to college or having children etc. People with intellectual disabilities may need support to do these things so it is important that they access services and professionals that can help. This includes help with parenting.

In this project I hope to see how cases involving children of parents with intellectual disabilities are assessed in a range of different child safeguarding situations. I am gathering information in two ways, by holding focus group discussions with children's social workers to discuss cases in detail and by distributing a questionnaire. The questionnaire is the part that I would like you to take part in.

Why do I need your help?

The subject of "parents with intellectual disabilities" has until now been a fairly under-researched area. Research has focused largely on the experiences of parents, but to get a fuller understanding of this subject, it is important to consider the views of the professionals who work with families. I have drawn up nine child safeguarding scenarios that depict different cases that involve a child whose parents have intellectual disabilities. I would like to call upon your unique knowledge and experience because your input will provide insight into how these cases are understood. With your help, this questionnaire can collect the best quality information so that we can really understand this subject and get an idea of whether things can be improved, and if so, how improvements can be made. This means asking you, if you choose to participate, to answer the questions as honestly as possible.

What to expect from the questionnaire?

The questionnaire will take approximately fifteen minutes to complete. It includes some questions about your background (eg. your age group, gender), your professional history (eg. your qualifications, length of your social work career) and your personal experience of disability. You will not be asked for your name or any information from which you could be personally identified - your participation is completely anonymous.

Next, you will be presented with nine short case descriptions. Some of the cases describe families where the parents have intellectual disabilities and the remaining cases have parents who no do not have intellectual disabilities. You

will be asked to read through the case descriptions and choose from the answers provided the one that best describes your professional impression of each case.

Is participation voluntary?

Please feel free to ask any questions about the study before you decide whether to participate. I can be contacted using the email address listed at the top of this page. Participation is completely voluntary and you may withdraw from the study at any time with no reason necessary, or choose not to take part at all.

The questionnaire is open from the 1st of May until the 1st of August 2014 and you may take part at any point within this period.

Has the study been ethically approved?

This project has been reviewed and approved by the University of Oxford Central University Research Ethics Committee.

What happens to the information collected from the questionnaire?

The information you provide will not be shared with anyone else and will be stored in password protected data storage drives. You will be assigned a unique identifying code and any information related to your identity will be deleted before the information from the discussions is used. Your identity will not be disclosed in any reports, publications or conferences.

The University of Oxford is committed to the dissemination of its research for the benefit of society and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

If you agree to participate in this project, the research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published with open access, which means it will be freely available on the internet. The work is likely to be discussed in academic meetings and published in peer-review journals.

Your local authority will also receive a personalised, confidential and anonymised mini-report about the research findings, as well as an offer for me to present the research findings in person.

Are there any risks or benefits?

Apart from setting aside time to complete the questionnaire there are no risks to you for taking part in the project. However, the benefit of your time and input is your invaluable contribution to a field of research that aims to improve the interactions with services that are necessary to support parents and their children.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the relevant researcher (Ameeta Retzer, 01865 617822) or their supervisors (Dr Ron Gray, 01865 289446 or Dr Jane Kaye, 01865 287898), where applicable, who will do his/her best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner).

Now that you have read the above information, would you like to take part in this questionnaire?

- ○ Yes, I want to take part in this questionnaire
- ○ No, I do not want to take part in this questionnaire

Background questions and consent

The statements below are to ensure that you are giving your full consent to take part in this questionnaire. Please answer, " I agree to participate", if these statements apply to you and you wish to complete the questionnaire.

I confirm that I have read and understood the participant information.

I have had the opportunity to ask questions about the study and I have received satisfactory answers to questions, and any additional details requested.

I understand that I may withdraw from completing this questionnaire.

I understand that this project has been reviewed by, and has received ethical clearance through, the University of Oxford Central University Research Ethics Committee.

I understand the information I provide will be seen only by the researcher and will be stored in password-protected data storage drive, and my identity will be deleted and replaced with a unique identifying code before analysis takes place.

I understand that my identity will not be disclosed, published or presented in reports, papers or conferences by the researcher.

I understand that this study will be written up as a thesis and if successfully submitted, will be deposited both in the print and online archives of the University of Oxford, and will be accessible through the internet.

I understand how to raise a concern and make a complaint about this study.

Based on the above statements, do you consent to participating in this questionnaire? If you click, "Yes, I consent to participate", you will be immediately directed to the questionnaire.

- ○ Yes, I consent to participate

In the following section you will be asked some questions about your personal and professional background.

Which local authority do you belong to?

Which age group do you fit into?

- ○ 20-29 years
- ○ 30-39 years
- ○ 40-49 years
- ○ 50-59 years
- ○ Over 60 years
- ○ Prefer not to say

What is your gender?

- Male
- Female
- Prefer not to say

Please select the item that best describes your ethnic background.

What is your marital status?

- Married
- In a relationship
- Single
- Widowed/Divorced/Separated
- Prefer not to say

Do you have any children?

- Yes
- No
- Prefer not to say

Professional Background

Which of these qualifications do you have? Please select all that apply.

- Diploma in social work (DipSW), alongside either a DipHE/BA/BSc or MA/MSc/PgDip
- Certificate of Qualification in Social Work (CQSW)
- Certificate in Social Services (CSS)
- Undergraduate or Postgraduate degree in Social Work (BA, BSc, MA, PgDip) recognised by one of the UK Care Councils
- Any other UK social work qualification recognised by the GSCC as eligible for inclusion on the part of the Social Care Register for social workers
- Any other non-UK social work qualification recognised by the GCSS as eligible for inclusion on the part of the Social Care Register for social workers
- Teaching or education professional qualification (eg. B Ed, PGCE)
- Registered nurse qualification (eg. RN, RGN)
- Professional qualification in occupational therapy or other profession allied to medicine
- Level 4, Level 5 or Level NVQ qualification in early years, social or health care

Any other qualification

Do you have any of the following qualifications? Please select all that apply.

- "Top up" degree or postgraduate professional qualification in social work
- Post-qualifying award in social work
- Other undergraduate or postgraduate degree in a subject other than social work
- Other recognised diploma (eg. diploma in counselling recognised by the British Association for Counselling and Psychotherapy [BACP])

Altogether, for how many years have you practised as a qualified social worker?

For how many years have you worked primarily in direct children's social care?

For how many years have you worked primarily in direct adult social care?

What is your job title?

Which of the following client groups do you work with?

- Child protection
- "Looked after" children
- Care leavers
- Family support/prevention
- Child and adolescent mental health
- Children with special educational needs
- Children with complex health needs
- Young carers

Young people's substance misuse service

- [ ] Asylum seekers/refugees
- [ ] Foster carers

Experiences of disability

In the following section you will be asked about your own experience of disability.

Do you have any of the following conditions? Please select any that apply.

- [ ] Blindness
- [ ] Deafness/severe hearing impairment
- [ ] A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
- [ ] Intellectual disability
- [ ] A psychological or emotional condition
- [ ] Chronic illness
- [ ] Other, please specify
- [ ] None of the above
- [ ] Don't know
- [ ] Prefer not to say

Do you know anyone who has a disability? Please select any that apply.

- [ ] Spouse/partner
- [ ] Member of immediate family
- [ ] Other relative
- [ ] Friend
- [ ] Neighbour
- [ ] Acquaintance
- [ ] Colleague/work contact
- [ ] Other
- [ ] Not sure/don't know
- [ ] Prefer not to say

What type (or types) of disability does the person (or people) you know have? Please select all that apply.

- [ ] Blindness
- [ ] Deafness/severe hearing impairment

- [ ] A condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting or carrying
- [ ] Intellectual disability
- [ ] A psychological or emotional condition
- [ ] Chronic illness
- [ ] Other, please specify
- [ ] None of the above
- [ ] Don't know
- [ ] Prefer not to say

Case descriptions

Now I would like to call upon your professional knowledge. In the next section you will see nine short descriptions of unconnected cases where the safety of a child is in question. Please carefully read through the case descriptions and select the statement that best describes how you assess the case. Some of the scenarios describe families where the parents are suspected to have intellectual disabilities. For the other families described where intellectual disability is not mentioned, you can assume that the parents do not have intellectual disabilities.

Block 4

A seven year old child is living with his parents. Both of the parents are suspected to have intellectual disabilities. Two windows in the room where the child plays are broken and the glass has jagged edges. The child has cut his hand, requiring three stitches.

- ( ) I think this child's situation does not require any intervention
- ( ) I think this child and his family need an "early help" intervention
- ( ) I think this child may be "in need"
- ( ) I think this child may be at risk of "significant harm"

A seven year old child is living with his parents. Both of the parents are suspected to have intellectual disabilities. The parents have been arguing a lot for the past few months and have been quite distracted. The child has not been getting help with his homework from his parents and often has to prepare his own meals.

- ( ) I think this child's situation does not require any intervention
- ( ) I think that this child and his family need an "early help" intervention
- ( ) I think this child may be "in need"
- ( ) I think this child is at risk of "significant harm"

A seven year old child is living with his parents. Both of the parents are suspected to have intellectual disabilities. The child has met some older children who are known to be part of a violent gang. The child is spending less time with his old friends and more time with these older children.

- ( ) I think this child's situation does not require any intervention
- ( ) I think this child and his family need an "early help" intervention

- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. Both of the parents are suspected to have intellectual disabilities. The parents are known to have spoken about the child getting married when he is older, to someone they choose and the child may not know. If such a marriage were proposed, the child may not have a choice.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The parents have recently adopted a dog from an animal rescue and the child often plays with the dog, unsupervised.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The child has been in a number of physical fights with his elder sister. Most recently, the child has a cut on his lip and a bruise on his head. The child has been injured as a result of these fights in the past.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The child's mother has self-harmed in the past and is now saying that she is feeling depressed and suicidal. The child is aware that his mother feels this way.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The child's father has been recently lost his job and the child's mother does not work. There is a possibility that the family will not be able to pay their rent as the father's employment was the main source of income.

- I think this child's situation does not require any intervention

- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The child's maternal uncle has committed an offence that has meant he is now designated as a "risk to children". This uncle has regular, and sometimes unsupervised, contact with the child.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

Block 5

A seven year old child is living with his parents. Two windows in the room where the child plays are broken and the glass has jagged edges. The child has cut his hand, requiring three stitches.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The parents have been arguing a lot for the past few months and have been quite distracted. The child has not been getting help with his homework from his parents and often has to prepare his own meals.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The child has met some older children who are known to be part of a violent gang. The child is spending less time with his old friends and more time with these older children.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. The parents are known to have spoken about the child getting married when he is older, to someone they choose and the child may not know. If such a marriage were proposed,

the child may not have a choice.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. Both parents are suspected to have intellectual disabilities. The parents have recently adopted a dog from an animal rescue and the child often plays with the dog, unsupervised.

- i think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. Both parents are suspected to have intellectual disabilities. The child has been in a number of physical fights with his elder sister. Most recently, the child has a cut on his lip and a bruise to his head. The child has been injured as a result of these fights in the past.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. Both parents are suspected to have intellectual disabilities. The child's mother has self-harmed in the past and is now saying that she is feeling depressed and suicidal. The child is aware that his mother feels this way.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. Both parents are suspected to have intellectual disabilities. The child's father has been recently lost his job and the child's mother does not work. There is a possibility that the family will not be able to pay their rent as the father's employment was the main source of income.

- I think this child's situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

A seven year old child is living with his parents. Both parents are suspected to have intellectual disabilities. The child's maternal uncle has committed an offence that has meant he is now designated as a "risk to children". This uncle has regular, and sometimes unsupervised, contact with the child.

- I think this child' situation does not require any intervention
- I think this child and his family need an "early help" intervention
- I think this child may be "in need"
- I think this child is at risk of "significant harm"

Appendix 8: Table of QBE participant characteristics

Characteristic	**Number of participants (n=191)**
Gender	
Male	21 (10.99)
Female	167 (87.43)
Prefer not to say	3 (1.57)
Age	
20-29	25 (13.09)
30-39	59 (30.89)
40-49	53 (27.75)
50-59	44 (23.04)
Over 60	8 (4.19)
Prefer not to say	2 (1.05)
Marital status	
Married	95 (49.74)
In a relationship	52 (27.23)
Single	19 (9.95)
Widowed/divorced/separated	18 (9.42)
Prefer not to say	7 (3.66)
Has children	
Yes	146 (76.44)
No	42 (21.99)
Prefer not to say	3 (1.57)
Ethnicity	
White	178 (93.19)
Mixed race	4 (2.09)
Asian/Asian British	1 (0.52)
Black/Black British	3 (1.57)
Arab/Other	2(1.04)
Prefer not to say	3 (1.57)

Number of qualifications	2.05 (1-6)
Social worker career (months)	103.19 (0-480)
Job title	
Service manager	2 (1.05)
Team manager	31 (16.23)
Senior social worker	48 (25.13)
Social worker	99 (51.83)
Alongside staff	10 (5.24)
Prefer not to say	1 (0.52)
Children's social care career (months)	123.82 (0-468)
Adult social care career (months)	10.09 (0-360)
Total number of client groups	3.96 (1-11)
Number of participants' disabilities	
None	162 (84.82)
One	22 (11.52)
Two	7 (3.66)
Number of people with disability known to participant	1.48 (0-7)
Total number of disabilities of known people	1.45 (0-7)

Appendix 9: Table of QBE explanatory variables

Characteristic	No ID (n=862)	ID (n=857)
Children's service		
1	196	191
2	142	146
3	14	13
4	238	239
5	54	54
6	214	209
Prefer not to say	4	5
Age		
20-29	111	114
30-39	271	260
40-49	238	239
50-59	197	199
Over 60	35	37
Prefer not to say	10	8
Gender		
Male	94	95
Female	755	748
Prefer not to say	13	14
Ethnicity*		
White	803	799
Mixed race	17	19
Asian/Asian British	5	4
Black/Black British	15	12
Arab/Other	9	9
Marital status		
Married	432	423
In a relationship	234	234
Single/widowed/separated	84	87
Prefer not to say	27	27
Has children		
Yes	662	652
No	187	191
Prefer not to say	13	14
Total qualifications		
1	294	300
2	335	331
3	145	143
4	75	69
5	4	5
6	9	9
Job title		
Service manager	9	9
Team manager	143	136
Senior social worker	216	216

Social worker	444	447
Alongside staff	46	44
Participant's disability		
0	738	720
1	94	104
2	30	33

Appendix 9b: Table illustrating the spread of the assessments across vignette categories

Vignette	**Assessment**			
Unemployed	No risk	Early help	In need	Significant harm
PID disclosed (n=93)	11	68	14	0
PID undisclosed (n=98)	35	52	11	0
Uncle	No risk	Early help	In need	Significant harm
PID disclosed (n=93)	0	2	8	83
PID undisclosed (n=98)	0	1	9	88
Sister	No risk	Early help	In need	Significant harm
PID disclosed (n=93)	1	24	27	41
PID undisclosed (n=98)	2	46	30	20
Marriage	No risk	Early help	In need	Significant harm
PID disclosed (n=98)	18	40	23	17
PID undisclosed (n=93)	24	24	28	17
Glass	No risk	Early help	In need	Significant harm
PID disclosed (n=98)	0	18	39	41
PID undisclosed (n=93)	4	23	29	37
Gang	No risk	Early help	In need	Significant harm
PID disclosed (n=98)	1	39	38	20
PID undisclosed (n=93)	3	34	29	27
Dog	No risk	Early help	In need	Significant harm
PID disclosed (n=93)	49	33	8	3
PID	67	27	4	0

undisclosed (n=98)				
Depression	No risk	Early help	In need	Significant harm
PID disclosed (n=93)	0	19	48	26
PID undisclosed (n=98)	0	23	51	24
Argue	No risk	Early help	In need	Significant harm
PID disclosed (n=98)	0	42	48	8
PID undisclosed (n=93)	0	33	52	8

Appendix 10: FGD recruitment email to CSWs

Hello, my name is Ameeta Retzer. I am a third year doctoral (PhD) student at the University of Oxford in the Nuffield Department of Population Health. I can be contacted at ameeta.retzer@wolfson.ox.ac.uk, National Perinatal Epidemiology Unit, Nuffield Department for Population Health, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF.

I am carrying out research that looks at how children's social workers assess child safeguarding cases where the child's parents have intellectual disabilities and **I would like to invite you to participate in a focus group discussion**. Working with hypothetical cases, I would like to hear about your views and thoughts, whether you have experience of working with these parents, and how you would assess these situations.

A person is considered to have an intellectual disability when they have difficulty understanding new or complex information and learning new things; are less able to cope independently; and experiences this during childhood with permanent effect. The purpose of this research is to better understand these cases from the perspective of children's social workers, identify any issues and make recommendations for how things may be improved.

If you would like some more information, please contact me at ameeta.retzer@wolfson.ox.ac.uk.

Thank you so much for your time and I hope to hear from you soon.

Appendix 11: FGD participant information sheet

CHILDREN'S SOCIAL WORKERS' ASSESSMENTS OF CASES CONCERNING PARENTS WITH INTELLECTUAL DISABILITIES, NUFFIELD DEPARTMENT OF POPULATION HEALTH, UNIVERSITY OF OXFORD

FOCUS GROUP DISCUSSION PARTICIPANT INFORMATION SHEET

Hello, my name is Ameeta Retzer.

I am a third year doctoral (PhD) student at the University of Oxford in the Nuffield Department of Population Health. I can be contacted at ameeta.retzer@wolfson.ox.ac.uk, National Perinatal Epidemiology Unit, Nuffield Department for Population Health, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF.

I would like to invite you to participate in a focus group discussion.

What is the project?

I am working on a project that aims to find out how children's social workers assess child safeguarding cases where the child in question has parents with intellectual disabilities. A person is considered to have an intellectual disability when they have difficulty understanding new or complex information and learning new things; are less able to cope independently; and experiences this during childhood with permanent effect. This may mean they require more assistance than others in learning a task and adapting to changes in routine.

In England, people with intellectual disabilities are encouraged to live in the same way as people without intellectual disabilities - this may mean having jobs, going to college or having children etc. People with intellectual disabilities may need support to do these things so it is important that they access services that can help, this includes help with parenting.

In this project I hope to see how cases involving children of parents with intellectual disabilities are assessed in a range of different child safeguarding situations. I am gathering information in two ways, by holding focus group discussions with children's social workers to discuss cases in detail and by distributing a questionnaire. I would like you to take part in the focus group discussion.

Why do I need your help?

The subject of "parents with intellectual disabilities" has been a fairly under-researched area until now. Existing research has focused largely on the experiences of parents but to get a fuller understanding of this subject, it is important to consider the views of the professionals who work with families. I have drawn up child safeguarding scenarios that depict different cases that involve a child whose parents have intellectual disabilities. I would like to call upon your knowledge and experience to discuss how you would assess these cases in practice. By doing this, I can see how assessments differ from case to case.

What will happen in the group discussion?

The focus group discussion will take place at one of three sites – A/B/C, depending on which you are affiliated with. If you choose to take part in this study, you would be participating in one discussion session which I will be facilitating. There will be five children's social workers participating in the session, which should last for between one and two hours. During the discussion I will present you with pre-prepared scenarios, one at a time, and I'd like you to discuss your thoughts on them. I would like to hear your views on the issues that arise from each case, how you would approach such a case in practice and what you think the response should be to each case. By the end of the session, each of the scenarios will have been discussed in detail by you and the others participating in the group. The sessions will be recorded in order to capture all that is said during the session.

Is participation voluntary?

Please feel free to ask any questions about the study before you decide whether to participate. Participation is completely voluntary and you may refuse to answer certain questions, withdraw from the study at any time and with no reason necessary, or choose not to take part at all.

Has the study been approved?

This project has been reviewed and approved by the University of Oxford Central University Research Ethics Committee.

What happens to the information collected for and during the discussion?

The information you provide and is gathered from the session will not be shared with anyone else and will be stored in password protected data storage drives. You will be assigned a unique identifying code and any information related to your identity will be deleted before the information from the discussions is used. Your identity will not be disclosed in any reports, publications or conferences. There is also a declaration in the consent form signed before joining the study stating that participants will not disclose the identities of participants taking part in the discussion or the topics discussed, after the session takes place.

The University of Oxford is committed to the dissemination of its research for the benefit of society and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

If you agree to participate in this project, the research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published with open access, which means it will be freely available on the internet. The work is likely to be discussed in academic meetings and published in peer-review journals.

Are there any risks or benefits?

Apart from setting aside approximately one hour to take part in the discussion there are no risks to you for taking part in the project. However, the benefit of your time and input is your invaluable contribution to a field of research that aims to improve the interactions with services that are necessary to support parents and their children. Your local authority has given their permission for you to take part in this research.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to me (Ameeta Retzer, 01865 617822) or my supervisors (Dr Ron Gray, 01865 289446 or Dr Jane Kaye, 01865 287898), where applicable, who will do his/her best to answer your query. I will acknowledge your concern within 10 working days and give you an indication of how I intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner.

Appendix 12: FGD participant consent form

CHILDREN'S SOCIAL WORKERS' ASSESSMENTS OF CASES CONCERNING PARENTS WITH INTELLECTUAL DISABILITIES, NUFFIELD DEPARTMENT OF POPULATION HEALTH, UNIVERSITY OF OXFORD

CONSENT FORM FOR PARTICIPATING IN DISCUSSIONS

The following declaration is to state consent to participate in the study conducted by Ameeta Retzer (Contact: ameeta.retzer@wolfson.ox.ac.uk, third year doctoral (PhD) student, National Perinatal Epidemiology Unit, Nuffield Department for Population Health, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF).

The study involves designing and distributing a questionnaire to examine how children's social workers respond to child safeguarding cases where the child's parents have intellectual disabilities. Discussions are being held to gather information on the views, thoughts and experiences of children's social workers.

Please confirm the following by ticking the boxes on the right:

1. I confirm that I have read and understood the participant information sheet. ☐
2. I have had the opportunity to ask questions about the study and I have received satisfactory answers to questions, and any additional details requested. ☐
3. I understand that I may withdraw from this study at any time by advising the researcher of this decision. ☐
4. I understand that this project has been reviewed by, and has received ethical clearance through, the University of Oxford Central University Research Ethics Committee. ☐
5. I understand the information I provide will be seen only by the researcher and will be stored in password-protected data storage drive, and my identity will be deleted and replaced with a unique identifying code before analysis takes place. ☐
6. I understand that my identity will not be disclosed, published or presented in reports, papers or conferences by the researcher. ☐
7. I understand that this study will be written up as a thesis and if successfully submitted, will be deposited both in the print and online archives of the University of Oxford, and will be accessible through the internet. ☐
8. I understand how to raise a concern and make a complaint about this study. ☐
9. To protect the privacy of myself and others, I shall not disclose the identities of others participating in this discussion or the issues discussed. ☐
10. **I agree to participate in this study.** ☐

----------	----------	----------
Signature of participant	Date	Name of participant
----------	----------	----------
Signature of researcher	Date	Name of participant

Appendix 13: FGD participant background information form

CHILDREN'S SOCIAL WORKERS' ASSESSMENTS OF CASES CONCERNING PARENTS WITH INTELLECTUAL DISABILITIES, NUFFIELD DEPARTMENT OF POPULATION HEALTH, UNIVERSITY OF OXFORD

FOCUS GROUP DISCUSSION PARTCIPANT BACKGROUND INFORMATION FORM

1. In which County Council site do you normally work?

……

2. Which age group do you fit into?

20-29 years ☐
30-39 years ☐
40-49 years ☐
50-59 years ☐
Over 60 years ☐
Prefer not to say ☐

3. What is your gender?

Male ☐
Female ☐
Prefer not to say ☐

4. Please tick the box that best describes your ethnic background:

a. White	**b. Mixed**	**c. Asian or Asian British**
English/Welsh/ Scottish/ Northern Irish/ British ☐ Irish ☐ Gypsy or Irish traveller ☐ Any other white background ☐	White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Any other mixed/ multiple heritage background ☐	Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Any other Asian background
d. Black or Black British	**e. Other ethnic group**	
Caribbean ☐ African ☐ Any other Black/African/ Caribbean background ☐	Arab ☐ Any other ethnic group ☐	

5. Altogether, how many years have you practised as a qualified social worker?

……

6. How many years have you worked primarily in children's social care?

……

7. How many years have you worked primarily in adult social care?

……

8. Which of the following client groups do you work with?

Child protection ☐

'Looked after' children ☐

Care leavers ☐

Family support/prevention ☐

Child and adolescent mental health ☐

Children with special educational needs ☐

Children with complex health needs ☐

Young carers ☐

Young people's substance misuse service ☐

Asylum seekers/refugees ☐

Foster carers ☐

9. What is your job title?

……

10. Do you consider yourself to have personal experience of disability? If so, would you like to briefly elaborate?

……

……

Appendix 14: Preliminary codes and themes from FGDs

Code number	Initial code	Themes
1	Engagement	"Communication", "Tactics, opportunism, resourcefulness", "Fostering long-term working relationships and long-term dependence", "Families engagement", "Parents' choice to take up services/support", "Effective and Appropriate Engagement", "Parents feeling patronised",
2	Theories about LD	"Parents' learned mechanisms", "Parents can be impressionable", "Parents' rigidity of thought and handing new information", "Social disadvantage experienced by PWID", "Parents' social isolation", "Parents fearful/embarrassed/intimidated when they do not understand", "How information should be given", "Absence of parenting models", "Not being able to cope", "ID can be used as an excuse",
3	Statements about how parent's ID is understood/assessed	"Ambivalence about whether ID would factor into decision-making", "What are parents able and not able to do? Assumptions? Teaching?", "Difficulties presented by parents' pace", "The nature of the disability", "Vulnerabilities of parents", "Wary of how other people may interpret disability", "Possible minimising of parents' difficulties/optimism", "making concessions/more lenient due to the possible disability", "What are 'normal' standards of parenting", "Parents are fearful/apprehensive about doing something wrong"
4	Time and resource pressure	"Tendency to de-escalate/close", "Quick pace of children's social work", "Giving too much time to parents", "Time needed to assess/familiarise

		with families and their needs”, “Interactions with PWID taking longer”, “Families needing to have long-term support/service provision” “Is parenting sufficient even with long-term support” “Parents needing time to develop working relationships”, “Worker-heavy support”, “Time needed to adapt to a parents’ learning needs”, “Lack/issues/expense of resources”, “Regional variation in resources”,
5	Services and support	“Diagnosis is key to accessing services and support/difficulties”, “Families let down because of lack of appropriate services”, “Variability in access to services”, “Creative service provision for those outside thresholds/when there aren’t appropriate services”, “Service provision from non-social care services”, “Universal services support for children besides parents”, “Misunderstandings with other professionals/services”, “Scepticism about adults’ services”, “Trusting/delegating to other professionals/services”, “Using family networks”, “Parents involved in support choices”, “What would work/works…”, “Educating parents”
6	Children of parents with ID	“Children vulnerable to being overlooked”, “High expectations for young carers”, “Question of how much children can take on as young carers/effect”, “Keeping the child’s needs central/taking cues from the child”, “Parents considering their children’s interests”, “Tension between children’s and parents’ needs”, “Children needing guidance and support from those other than their parents”, “Children worried about their parents”, “Children’s needs surpassing the abilities of their parents”,

		"Removing children is not the goal", "Children are vulnerable", "Children are likely to be removed/be subject to CPP", "Equipping the child"
7	Interacting with other services/professionals	"Using existing professional relationships/resourcefulness", "Building and maintaining relationships", "Seeking and using specialist resources and knowledge"
8	Assessment process and SW skills	"Current service involvement and support needs", "Noting positives", "Trying to understand what parents can and cannot do/engage parents about their parenting", "Labels", "Logistical/practical difficulties with ID assessment", "Concerns /behaviours may be unrelated to ID", "What is 'normal'?", "Cautious", "Differences/shortage in knowledge/experience/expertise", "Working on parents' understanding/supporting parents is key to building a strong case for the courts", "Time required to build strong cases", "Assessing, monitoring, and reassessing", "Remaining objective as time goes on", "Undiagnosed ID not being the first thing to come to mind when getting a new case"
9	Emotional impact on SWs	"Exasperation with non-ID parents", "Frustration with lack of expertise/resources", "Difficulties working with ASC", "Working with difficult to engage families", "Information-seeking behaviours and concern", "Being pleased when there is progress with parents/families", "Going the extra mile", "Empathising with parents", "Rooting for parents", "Regretting how things can turn out for

		families”, “Empathising with the child”, “Job pressure”, “Feeling scrutinised”, “Feeling compelled to advocate for the parents”, “Emotional strain”

Appendix 15: FGD coding framework

Initial topic area	Number	Code	Example quote
Engagement	1	Communication	P12 C – "… I would try paraphrasing things, put things in different ways to try and get her to understand why I was worried about her son …"
	2	Tactics, opportunism, resourcefulness	P10 C – "well you've got to be creative about it! Find out where they go so you might turn up, you know they visit someone on a regular basis you turn up there, say, oh, just kind of popped in to see you. Or I've tried to arrange a visit when someone else [another professional is visiting]"
	3	Fostering long-term working relationships and long-term dependence	P12 C – "But because I had been working with her for four or 5 years, she actually by the end of it, would talk to me …"
	4	Families' engagement	P10 C – "so we don't want you involved, we don't want anything to do with you, we want to live our lives how we want to live, we don't want the help thank you, so you've got to take into account that as well"
	5	Parents' choice to take up services/support	P6 B – "quite often adults services support is more voluntary so they've got to be on board with that as well, haven't they?"
	6	Effective and Appropriate Engagement	P49 C – "so you're not forever, not saying, you're trying to get parents to take responsibility. It's not about just having money to throw at a family; it's about helping them use what is available in the community."
	7	Parents feeling patronised	P70 B – "… like if I go out to one of my parents who I, who I think, they've got a level of … a level of learning difficulty, and then I'm making that assessment without, because they haven't got a social worker in the learning disability team, and then I go, what's your reading and writing like? And they then, I then get their back up massively because they think, you cheeky patronising so and so. It's really difficult, it's really hard and that ..."

Theories about LD	8	Parents' learned mechanisms	P10 C – "[on parents avoiding SW visits by hiding] … that's about the learned behaviour, I mean you can learn even with ID you can learn strategies for yourself about how you're going to manage situations"
	9	Parents can be impressionable	P8 C – " '… did they hear someone say it, because you know, people tend to pick up stuff don't they, so maybe they know someone who has done it and they thought oh, that's what we're going to do because that's what they should do' '… the vulnerability of these people, people with intellectual disabilities'"
	10	Parents' rigidity of thought and handing new information	P27 A – "sometimes their understanding is quite black and white, isn't it …? He's found not guilty so he's not guilty and that's that …"
	11	Social disadvantage experienced by PWID	P22 C – " 'parents who have learning disabilities and how they do struggle on a lot of levels in terms of being more disadvantaged in terms of work opportunities , income, children's outcomes and stuff … so we're just trying to support her as best as we can really, but erm, but its mixing with all the other bits and pieces …' 'so nothing ever as simple as it is on a piece of paper'"
	12	Parents' social isolation	P30 C – "one of the other things with parents with learning disabilities, or adults generally, and young adults, because they are so isolated …"
	13	Parents fearful/embarrassed/intimidated when they do not understand	P69 B – " 'I ask people if they understand but, like Katie said, like, just to get rid of me, because I go on a bit, they might just go yeah …' 'well, yeah, maybe they're just embarrassed to say that …'"
	14	How information should be given	P31 C – " 'some of them don't like to be overloaded w information, some need information to the nth degree' 'some need it visually, some need it in written form, you know'"

	15	Absence of parenting models	P62 B – "… but it's not the whole picture, there's also a lack of motivation, really poor parenting when they were growing up so they've not learned to parent, and there's lots of other factors…"
	16	Not being able to cope	P34 C – "will she engage with the different workers, and she engaged with some but not all of them, but then she can't cope with too much …"
	17	ID can be used as an excuse	P3 B – " 'actually checking that they do have, erm, problems, I've had a family that erm, … the doctors wrote all over the place the parents have learning disabilities and they didn't, so I guess, checking those facts as well, …making sure that they really do have a ….' 'because there are different levels of this... Of difficulties' 'whether it is a level that is actually affecting the parenting …' 'and whether that is just being used as an excuse…'"
How parents' ID is understood/assessed	18	Ambivalence about whether ID would factor into decision-making	P21 c – "just this whole thing about the intellectual impairment, I don't know how much it fits, automatically with my decision-making, any of this would be the same for any parents really, so I don't …"
	19	What are parents able and not able to do? Assumptions? Teaching?	*P7 c - "*with that information coming in you might go and have a conversation with the parents about it, what do they mean, their understanding about it, and you know, come to what their thinking is, so you know, you could help them maybe look at things differently … look at it from different angles"
	20	Difficulties presented by parents' pace	P13 c – "she's got borderline learning disability and when pressure starts being put on her, she starts shutting down in accessing, in accessing our service"
	21	The nature of the disability	P25 c – "because that's what you've got to be thinking about,

			it's not a year or two, its long term(emphasis) ..."
	22	Vulnerabilities of parents	P26 A – "but, but they're I think it's just even more vulnerable to being groomed by perpetrators …: they are such nice people who have been to see me … and they said that they'll take jimmy out for a walk …"
	23	Wary of how other people may interpret disability	P4 B – "... because lots of neighbours and things will say, that, oh, they can't cope, you know, but actually when you look into it, that they're better able to cope than people realise"
	24	Possible minimising of parents' difficulties/optimism	P57 B – "… if that's the case parents need to be able to manage that situation before it escalates … if you get the parents the right help, removing that victim child out of the household is the last thing you'd want to do …"
	25	Making concessions/more lenient due to the possible disability	P25 A – "[engaging wider family to] pick up whether they are going to excuse behaviour because of any disabilities …"
	26	What are 'normal' standards of parenting	P46 B – "[line between healthy and unhealthy] because everyone's entitled to a good old argument every now and then, its healthy ... but you know … if that's long term, if that's chronic …"
	27	Parents are fearful/apprehensive about doing something wrong	P20 B – "We had a lady who was terrified that the … that the feeding thing ended up being a massive issue … She wouldn't feed him any solid food, would she, she was too nervous … she wouldn't, she wouldn't do it, … it actually ended up being really sad, all of her children ended up being removed"
Time and resource pressure	28	Tendency to de-escalate/close	P1 C – "it would be a very, sort of, quick assessment of the situation, then if parents responded by, doing something … Then it could well be, become closed"
	29	Quick pace of children's social work	P4 C– "… the nature of the game, it's the nature of the funding and you don't just keep people open,

			they arrange it, they assess them, they sort out what they need, they provide the need and they close the case"
	30	Giving too much time to parents	P23 c – "you do bend over backwards to try and give them a chance but actually, sometimes that's too long, we actually should have been a … harder"
	31	Time needed to assess/familiarise with families and their needs	P5 C – "it's not until you get to know the families and you begin to unpick some of the behaviours and some of the difficulties that they have that you realise that actually there's something else, erm, going on for them"
	32	Interactions with PWID taking longer"	P31 C – "and they are all saying, you know, you need to work with them for a longer period of time as well, and there's the time factor as well"
	33	Families needing to have long-term support/service provision	P12 C – "if you're working with parents w learning needs, you know, intellectual, learning, whatever, it can take years … I worked for a lady with a learning disability whose son also had a learning disability … I've worked with them for about 5 6 years? ... Had lots of services going in there … so all those sorts of things, sometimes it's a long term relationship for adults w learning needs that becomes more productive, but when you're going in, having to do the hard-line stuff … it's not easy."
	34	Is parenting sufficient even with long-term support	P40 C – "two learning disabled parents … we put in huge amount of support, erm, with keeping the house tidy … but its reached a point now where the, they cannot, with all the guidance and support that they've been given keep the house at a reasonable standard, so it is about to go to child protection …"
	35	Parents needing time to develop working relationships	P18 C – "[in a case where a mother had several children removed and for the final one,] I suppose what helped us through

			all of that was the fact that I actually knew mom already"
	36	Worker-heavy support	P23 B– "… she was in an assessment centre and then she came to the supported living, and back then while we were in the supported living there was a lot of support …"
	37	Time needed to adapt to a parents' learning needs	P4 A – "… you maybe need to do some extra work if I was feeling that they weren't grasping the reasons behind that …"
	38	Lack/issues/expense of resources	P35 C – " 'it is about resources as well' 'it is yeah, resources are tight and people are working really, really hard, and they think, I can't take another one'"
	39	Regional variation in resources	P14 A – "[about working with Mencap workers in another LA] 'well we go out with Mencap worker who did all that for us ...' 'You're very lucky …!' 'We don't have that here, we are the resource … !'"
Services and support	40	Diagnosis is key to accessing services and support/difficulties	P29 A – "my experience of adult services is that, you know, if you are deemed to be eligible then yes, they will provide a service …"
	41	Families let down because of lack of appropriate services	P28 A – "… that sort of situation where she wasn't going to meet the threshold for adult services by no means but equally … just really struggled, erm … to understand how to protect her children…"
	42	Variability in access to services	P3 C – "not all adults I would say, have an allocated worker … erm, so you know, they might well be out there with, with no services whatsoever"
	43	Creative service provision for those outside thresholds/when there aren't appropriate services	P30 C – "we are in quite a lucky situation because we have the care services for the child so we are looking at modelling with the care worker for this mother …"
	44	Service provision from non-social care services	P4 C – "they've got hours agreed so she has a service through a voluntary charity organisation, so she has that, but she actually is now closed to adult services"
	45	Universal services support for children besides	P22 A – "… I suppose if they're pre-school then that's really

		parents	important and I suppose it would involve nurseries and … in that … wouldn't they, a lot of them would … hopefully they would help stimulate the child … and children's centres …"
	46	Misunderstandings with other professionals/services	P41 B – " 'don't you often get, erm, that it's a "social issue" rather than a mental health issue …' 'dear me, all, yeah, they'd say … she did that, and … because she had … a learning disability … you know in some way, rather than it being specifically a mental health …'"
	47	Scepticism about adults' services	P16 B – "'there isn't much collaboration between children and adults services, is there ... you know,' 'really?' 'not at all …?' 'not in my opinion'"
	48	Trusting/delegating to other professionals/services	P35 B – "ask if she's been in touch with her GP… and I guess if she was really at risk then, you'd get someone ... a GP or a medical person to actually go out there"
	49	Using family networks	P25 C – "… use the extended family to see who is around, who could give support, what support can they give and is it realistic? Because sometimes families can do that …"
	50	Parents involved in support choices	P21 C – "… mum got a lot of services in her own way and actually helped support the decision-making for the future of the child …"
	51	What would work/works…	P53 B – "that's where … early intervention, from a young age to help them with boundaries and stuff like that, so ... they don't come to our attention at 7 when it's in a crisis, but to, when we think it might be an issue …"
	52	Educating parents	P41 B – "that's really important isn't it, it's kind of the teaching side of it to mom, of the impact of what your behaviour has on your child"
Children of parents with ID	53	Children vulnerable to being overlooked	P22 C – " 'and we have to keep the focus on the child' 'yep, the child's needs' 'and it's very easy to

			get sort of tied up, with, yes the parents do need the support but even with that, can … Are they good enough parents to the children, are the children suffering from neglect' 'children's lives are just so short'"
	54	High expectations for young carers	P27 C – " 'but he is having food, he's making his own meals' 'well, yes, he's making his own meals, but the fact that the concern is that he's making his own meals' 'but if he was a young carer he'd be making doing that, it would be acceptable for him to do that'"
	55	Question of how much children can take on as young carers/effect	P7 A – " 'the sister could have easily taken over the parenting role of this young boy … and erm ... and … obviously doing her best but not having a sense of …' '… she's trying to do the best she can. I suppose it's, I guess it's trying to establish that really'"
	56	Keeping the child's needs central/taking cues from the child	P24 C– "you make a record of that, so you can see … that this is happening again, there's no changes, and the impact of that on the child's development"
	57	Parents considering their children's interests	P6 A – "telling mom what to do, mom can't cope, so mum is then also contacting the local authority, you know, you've got to … you've got to take him away, or take her away because this isn't ... this isn't working"
	58	Tension between children's and parents' needs	P36 C – "… so they may have this disability but you, you have to weigh up they can responsibly support their children and look after their children and keep them safe …"
	59	Children needing guidance and support from those other than their parents	P51 B – " 'if they[parents] can't do it, ring other family members or other people that can help them, to support them to do it…' 'find other things for him to do, find other … you know … a cub group, or something ... to get him meeting other people his age …'"
	60	Children worried about their parents	P8 C – "[have someone to talk to when …] Like mum mentioned

			this, what do, what does that mean, can you help me with that, to help them, you know have a voice about the situation …"
	61	Children's needs surpassing the abilities of their parents	P22 A – "the children … are really under-stimulated and they are very flat … developmentally, and not on track, it's the fact that she's not seeing that, is she, she's not seeing that her children are flat and under-stimulated ..."
	62	Removing children is not the goal	P58 B – " 'if you get the parents the right help, removing that victim child out of the household is the last thing you'd want to do …' 'you'll want to keep the children together!'"
	63	Children are vulnerable	P53 C – "my experience with a couple of cases is parents who have got learning needs you get some kind of predatory people out there, kind of prey on these parents, to get to the children, you know, sex offenders or whatever and they've actually groomed the parents to get to the child …"
	64	Children are likely to be removed/be subject to CPP	P6 A – "… a family that I've worked with where at certain points, we've now seen all the children coming into care at a certain age …"
	65	Equipping the child	P41 B – "I worked with a 10 y/o who lived with her mom … her mom had self-harmed for all of her life, and she'd had so much input from mental health services, and for years and years and years, and there was no change so … it wasn't going to change, the focus then was trying to make sure the child was protected and safe and emotionally sort of, had counselling and that sort of thing"
Interacting with other services/professionals	66	Using existing professional relationships/resourcefulness	P14 B – "[working in the children's disability team] we have the connections with adults' services already, yeah so for us in a specialist team'"
	67	Building and maintaining relationships	P15 B – " 'it's another area, you see, and the connections are not,

			even with us, how many years have we been trying to do … [two of the participants] work in building relationships with adult services and even that, even though it's a full time job for you, is ... its … it's tricky' 'well, well, yeah, and I wouldn't say we're still a hundred percent clear, ourselves …'"
	68	Seeking and using specialist resources and knowledge	P15 C– "You've obviously managed to do something with colour coding, it would be quite interesting to sort of share …"
Assessment process and SW skills	69	Current service involvement and support needs	P20 C – "talking to schools, talking to the GP, is she accessing support, do they have support in place, wider family members, those sorts of things really …"
	70	Noting positives	P16 A – "he may well be getting himself up but that's, he didn't get himself up at the age of 4 or 5 when he started school, someone has initiated him actually going to school, and they obviously, they probably see some importance, you know, for the child to go to school."
	71	Trying to understand what parents can and cannot do/engage parents about their parenting	P46 C– " 'it would depend on the parents, we would tend on a conversation with the parents, you know, and what their reaction was and you know, were they aware of it, were they …' 'what did they try to do ...?'"
	72	Labels	P67 B – "the parent, the parent with the learning difficulty, disability, intellectual disability …"
	73	Logistical/practical difficulties with ID assessment	P32 A – "[time] impacts on practice and it impacts on the families greatly, I think, erm, having worked in disability for so long and seeing how those things do impact and you can't get the proper assessments done in those timescales at all. So therefore you're scrimping on them and you're not actually getting what you need at the end of it."
	74	Concerns /behaviours may be unrelated to ID	P3 C – "this child has cut his hand, he's been telling us for weeks that

			the window not be repaired, but there is nothing wrong with mom and dad's intellectual abilities, they just can't be bothered. So it might be … so you see … its very much … its quite subjective"
	75	What is 'normal'?	P16 A – "loads of families do that, if they get a hot meal at school, that's their hot meal for the day so then after school they then make them a sandwich … whether that right or not right …"
	76	Cautious	P15 A – "we're thinking, you know, worst case scenario, but actually, a lot of parents don't do homework with children …"
	77	Differences/shortage in knowledge/experience/expertise	P8 B – "she's probably getting a dis-service from us, because we don't know how to make sure that she understands what is expected of her because this isn't our expertise … we are entering a child protection arena that potentially with the right support may have been avoided"
	78	Working on parents' understanding/supporting parents is key to building a strong case for the courts	P15 A – "when you're in court, and there's being asked questions about what has been to ensure that that person has actually understood and if it hasn't been demonstrated effectively enough then you go back to point A again.."
	79	Time required to build strong cases	P24 C – "you just sort of think, well, should I have taken the decision … earlier than I did, but it about evidence a lot of the time as well, isn't it? It's about having clear evidence, having significant evidence"
	80	Assessing, monitoring, and reassessing	P24 C – " 'but these little things …' 'add up …' 'they add up, and just have to keep making a record of it, and you know, keep an eye on it, and evidence in …'"
	81	Remaining objective as time goes on	P36 C – "it's really hard sometimes … especially if you've been working with somebody for quite a while, well actually you're going to have to turn around and say, well look, we can't do this

			anymore, and we are going to have to take this particular route"
	82	Undiagnosed ID not being the first thing to come to mind when getting a new case	P69 B – "[after being involved with mother since pre-birth] baby is now 6months, it was only two months ago that it became apparent that the mom couldn't read or write, because … no one had thought to ask her, … because it's not automatically something you would ask necessarily …"
Emotional impact on SWs	83	Exasperation with non-ID parents	P3 C – "he's been telling us for weeks that the window not be repaired, but there is nothing wrong with mom and dad's intellectual abilities, they just can't be bothered."
	84	Frustration with lack of expertise/resources	P15 C– "… we had all the computers changed, and we said very clearly to our IT please can you make sure this goes onto a computer? ... No. So we are a bit resource-less aren't we …?"
	85	Difficulties working with ASC	P18 B – "sometimes it's like as if you're working against each other … and [ASC] gave her the impression that she should [do one thing], but then I was telling her completely the opposite and this poor woman was stuck in the middle of all of that"
	86	Emotional impact of working with difficult to engage families	P13 A – "you can explain all of that and you get that level of understanding and you think, ahh, I think we've cracked it now, you know, and you, you put a contract in place, or whatever it might be to do very attainable tasks and then, you realise halfway down the line that actually, they haven't really understood …"
	87	Information-seeking behaviours and concern	P22 C – "there isn't anything specifically from this identifiable learning disability that's sort of available for her, and you know, I've been discussing it with her at length with [a colleague] and with my manager and you know in my supervision, she said we have to be the experts ourselves on this, in terms of trying to help support

			this mom …"
	88	Being pleased when there is progress with parents/families	P68 B – "[about a case where a mother successfully fought the decision for her child to be placed out of county, with the support of an advocate] 'Interestingly now … she gives us a really hard time now, which is great to see …' 'you've empowered her … !' '[laughs] which is great to see'"
	89	Going the extra mile	P21 B – "we did masses of work around it … we did basically a progression of so ... made the solid foods go from ... erm ... literally liquid to small chunks, oh we did loads, so we did it slowly over time and worked through work sheets, what you could choke on and what you couldn't, all sorts."
	90	Empathising with parents	P11 B – "[on a mother who is very open about disclosing her problems] the bigger picture is the lack of support where somebody else might ring their own mom or a friend to say ohh, I'm so frustrated with my husband that he was drinking and I told him not to drink … she has to tell a professional because she's, you know, sees that as a friend maybe"
	91	Rooting for parents	P23C– "it can be really sad and heart-wrenching but there are times when these parents, they cannot, they can't do anything, as much as you'd love them, to, they just can't, and they, and the sad thing is that often they don't understand that they can't, and that's really traumatic."
	92	Regretting how things can turn out for families	P31 A – "we need to be really careful about timeframes for people with learning difficulties… we push because of these timeframes and we don't always get it right then for that family, and you think well actually, if I had another 6 weeks with them we might actually get there and you know, prevent certain things from

			happening, erm, but we don't always have that time frame for us to do that now."
	93	Empathising with the child	P48 C– "It's a hard thing, because they wouldn't have parents to give them support with school or homework or, erm ... All those things that they need, discussing friendships and things, it's quite a lonely place"
	94	Job pressure	P19 B – "[a specialist colleague] will help but obviously she is massively hard-pressed, well we've all got our own things to be dealing with …"
	95	Feeling scrutinised	P37 C – "I saw a social worker getting roasted in court once…I think the mother had learning needs and they hadn't addressed it and tried to work with her, so in the court I went for my first visit to see how social worker was in court and that's what I saw and I thought Oh my god, they were really …"
	96	Feeling compelled to advocate for the parents	P34 A – " 'what is very important within all of this, if parents do have an intellectual impairment, it is able being able to give those parents a voice … being able to understand and being able to be a part of that process and not isolated and not just walked all over because, you know …' 'that would be the easy way about it …' 'yeah.'"
	97	Emotional strain	P35 B – "it's so you can cope, if it is the worst case scenario, so when you go home at night you've already ... you've almost prepared yourself, prepared yourself potentially for the worst case scenario. It's like our own coping strategy isn't it …? We all have a very dark sense of humour as well, I think, to [cope] …"

Appendix 16: FGD codes and sub-themes

Sub-theme	Source	Code
Social disadvantage	Theories about PWID	Social disadvantage experienced by PWID
Social disadvantage	Theories about PWID	Parents' social isolation
Social disadvantage	Theories about PWID	Absence of parenting models
Social disadvantage	Services and Support	Educating parents
Parents' vulnerabilities	Theories about PWID	Parents can be impressionable
Parents' vulnerabilities	How PWID are understood	Vulnerabilities of parents
Parents' vulnerabilities	Theories about PWID	Not being able to cope
Engaging with parents	Engagement	Communication
Engaging with parents	Engagement	Tactics, opportunism, resourcefulness
Engaging with parents	Engagement	Families' engagement
Engaging with parents	Theories about PWID	Parents' rigidity of thought and handling new information
Engaging with parents	Theories about PWID	How information should be given
Engaging with parents	How PWID are understood	Parents are fearful/apprehensive about doing something wrong
Engaging with parents	Services and Support	Parents involved in support choices
Engaging with parents	Emotional impact on SW	Emotional impact of working with difficult to engage families
Working with ID	Engagement	Parents feeling patronised
Working with ID	Theories about PWID	Parents' learned mechanisms
Working with ID	Theories about PWID	Parents fearful/embarrassed/intimidated when they do not understand
Working with ID	How PWID are understood	The nature of the disability
Working with ID	Assessment	Undiagnosed ID not being the first thing to come to mind when getting a new case
Working with ID	Assessment	Labels/diagnoses
Working with ID	Emotional impact on SW	Exasperation with non-ID parents
Wariness of discrimination	Theories about PWID	ID can be used as an excuse
Wariness of discrimination	How PWID are understood	Ambivalence about whether ID would factor into decision-making
Wariness of discrimination	How PWID are understood	Wary of how other people may interpret disability
Wariness of discrimination	How PWID are understood	Possible minimising of parents' difficulties/optimism

Wariness of discrimination	How PWID are understood	Making concessions/more lenient due to the possible disability
What is normal?	How PWID are understood	What are 'normal' standards of parenting
What is normal?	Assessment	Concerns /behaviours may be unrelated to ID
What is normal?	Assessment	What is 'normal'?
Assumptions?	How PWID are understood	What are parents able and not able to do? Assumptions? Teaching?
Assessing	Assessment	Current service involvement and support needs
Assessing	Assessment	Noting positives
Assessing	Assessment	Trying to understand what parents can and cannot do/engage parents about their parenting
Assessing	Assessment	Cautious
Assessing	Assessment	Assessing, monitoring, and reassessing
Time	How PWID are understood	Difficulties presented by parents' pace
Time	Time and resource pressures	Tendency to de-escalate/close
Time	Time and resource pressures	Quick pace of children's social work
Time	Time and resource pressures	Time needed to assess/familiarise with families and their needs
Time	Time and resource pressures	Interactions with PWID taking longer"
Time	Times and resource pressures	Parents needing time to develop working relationships
Time	Assessment	Logistical/practical difficulties with ID assessment
Time	Time and resource pressures	Time needed to adapt to a parents' learning needs
Long-term support	Time and resource pressures	Families needing to have long-term support/service provision
Long-term support	Time and resource pressures	Is parenting sufficient even with long-term support
Long-term support	Time and resource pressures	Worker-heavy support
Long-term support	Engagement	Fostering long-term working relationships and long-term dependence
Long-term support	Engagement	Effective and Appropriate Engagement
Accessing services	Services and support	Diagnosis is key to accessing services and support/difficulties

Accessing services	Services and support	Variability in access to services
Accessing services	Services and support	Creative service provision for those outside thresholds/when there aren't appropriate services
Using other services	Services and support	Service provision from non-social care services
Using other services	Services and support	Universal services support for children besides parents
Using other services	Services and support	Misunderstandings with other professionals/services
Using other services	Services and support	Trusting/delegating to other professionals/services
Using other services	Interaction with other services and professionals	Building and maintaining relationships
Using other services	Interaction with other services and professionals	Using existing professional relationships/resourcefulness
ASC problems	Services and support	Scepticism about adults' services
ASC problems	Engagement	Parents' choice to take up services/support
ASC problems	Emotional impact	Difficulties working with ASC
Specialist expertise	Interaction with other services and professionals	Seeking and using specialist resources and knowledge
Specialist expertise	Assessment	Differences/shortage in knowledge/experience/expertise
Specialist expertise	Emotional impact	Information-seeking behaviours and concern
Specialist expertise	Emotional impact	Frustration with lack of expertise/resources
Specialist expertise	Services and support	Families let down because of lack of appropriate services
Resources	Time and resource pressure	Lack/issues/expense of resources
Resources	Time and resource pressure	Regional variation in resources
Resources	Emotional impact	Job pressure
Resources	Services and support	What would work/works…
Children's vulnerability/parents' needs	CoPWID	Children vulnerable to being overlooked

Children's vulnerability/parents' needs	CoPWID	High expectations for young carers
Children's vulnerability/parents' needs	CoPWID	Question of how much children can take on as young carers/effect
Children's vulnerability/parents' needs	CoPWID	Keeping the child's needs central/taking cues from the child
Children's vulnerability/parents' needs	CoPWID	Parents considering their children's interests
Children's vulnerability/parents' needs	CoPWID	Tension between children's and parents' needs
Children's vulnerability/parents' needs	CoPWID	Children worried about their parents
Children's vulnerability/parents' needs	CoPWID	Children's needs surpassing the abilities of their parents
Children's vulnerability/parents' needs	CoPWID	Children are vulnerable
Children's vulnerability/parents' needs	CoPWID	Children are likely to be removed/be subject to CPP
Children's vulnerability/parents' needs	Emotional impact	Empathising with the child
Supporting children with their parents	Services and support	Using family networks
Supporting children with their parents	CoPWID	Children needing guidance and support from those other than their parents
Supporting children with their parents	CoPWID	Equipping the child
Supporting children with their parents	CoPWID	Removing children is not the goal
Sympathy towards parents	Time and resource pressure	Giving too much time to parents
Sympathy towards parents	Assessment	Remaining objective as time goes on
Sympathy towards parents	Emotional impact	Going the extra mile
Sympathy towards parents	Emotional impact	Empathising with parents
Sympathy towards parents	Emotional impact	Rooting for parents
Sympathy towards parents	Emotional impact	Feeling compelled to advocate for the parents

Scrutiny	Assessment	Working on parents' understanding/supporting parents is key to building a strong case for the courts
Scrutiny	Assessment	Time required to build strong cases
Scrutiny	Emotional impact	Feeling scrutinised
Emotional impact	Emotional impact	Being pleased when there is progress with parents/families
Emotional impact	Emotional impact	Regretting how things can turn out for families
Emotional impact	Emotional impact	Emotional strain

Appendix 17: FGD themes and sub-themes

Theme	Sub-theme
Perceptions of parents with Intellectual Disability	Social disadvantage; Parents' vulnerabilities; Engaging with parents; Working with ID
Assessment	Wariness of discrimination; What is normal?; Assumptions?; Assessing
Time	Time; Long-term support
Providing support	Accessing services; Using other services; ASC problems; Specialist expertise; Resources; Suggested recommendations
Children's needs	Children's vulnerability/parents' needs; Supporting children with their parents
Emotional impact on SWs	Sympathy towards parents; Scrutiny; Emotional impact