

**A Fragmented System: Understanding Child Protection Decisions for Canadian Parents
with Intellectual Disabilities**

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Thesis submitted to the University of Ottawa in partial fulfillment of the requirement for
the Doctor of Philosophy in Experimental Psychology

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ACKNOWLEDGEMENTS

Completing this thesis has been amongst my most significant and enriching academic endeavours. It would not have been possible without the guidance, support, and encouragement I received from many people along the way. First and foremost, I would like to express my deepest gratitude to my supervisor, Dr. Virginie Cobigo. Your insightful mentorship, consistent guidance, and unwavering support have been instrumental in shaping my academic growth. You have encouraged me to think critically, remain focused, and pushed me to achieve my best. Thank you for believing in me and for being a constant source of motivation.

I would also like to extend my sincere thanks to the members of my thesis advisory committee, Dr. Laura Pacheco, Dr. John Sylvestre, Dr. Cristina Atance and Dr. Irene Vitoroulis. Your thoughtful feedback, and valuable advice have greatly improved the quality of this work. I am grateful for the time and encouragement you provided in helping me succeed.

I am deeply indebted to the co-researcher for her dedication and commitment to this research and for contributing the invaluable expertise of her lived experience. I am also immensely grateful to the parents who participated in this research with trust and openness, sharing their highly personal stories so others may learn from their experiences. I am also thankful to the workers who took part and shared their challenges and successes in the child protection system.

I am thankful to several research assistants for supporting my thesis completion, especially Niima Er-raji, Emily Cliché and Melanie Beres. I would also like to extend thanks to my PhD colleagues, whose camaraderie and support made the challenging moments bearable and the successes more enjoyable.

I would like to acknowledge the Social Sciences and Humanities Research Council for awarding me a doctoral fellowship, which enabled me to undertake and complete this research. I would also like to extend special thanks to organizations that supported recruitment for my research and to Open Collaboration for Cognitive Accessibility for support with inclusive methods and accessibility.

On a personal note, I would like to express my heartfelt thanks to my family for their unrelenting support throughout my academic journey. To my parents, Mubashra Tahir and Tahir Ahmed, your belief in my abilities and your encouragement have been a constant source of strength. To my parents-in-law, Sadiqa Nasir and Abdul Shakoor, thank you for your patience, understanding and support as I completed this academic journey.

I am profoundly grateful to my partner, Ata-ul Munim, who was the first to believe in me and encourage me to undertake this amazing journey. Thank you for your endless patience, love, and understanding as I completed my studies. You have been my anchor and kept me grounded during the most stressful times. I am incredibly fortunate to have you by my side.

Lastly and most importantly, I dedicate this thesis to my son, Aydin Zayyan. You have been the greatest source of happiness and blessings since you were born. Experiencing motherhood and watching you grow has been the ultimate privilege and gift. It has shaped my parenting research in integral ways. You have transformed me as a person and inspired me to do better in every domain of life. Thank you for being at the centre of every joy in my world!

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GENERAL ABSTRACT

Parents with intellectual disabilities are disproportionately represented in child protection investigations in Canada and around the world. In some cases, children are removed from mothers with intellectual disabilities soon after birth. Research has shown that parents' intellectual disability status often plays a role in child protection decisions. However, there is limited research on what specific conditions or factors impact the final decision to remove child custody or reunify a family headed by parents with intellectual disabilities. In an effort to comprehensively examine the conditions that influence child protection decisions involving Canadian parents with intellectual disabilities, this dissertation undertook three qualitative studies: 1) content analysis of published court cases in Ontario; 2) semi-structured interviews with child protection workers from local agencies in Ontario; and 3) semi-structured interviews with parents with intellectual disabilities in Ontario and Manitoba. The first study examined how child protection decisions were made at family court and how the COVID-19 pandemic impacted child protection decision-making for parents with intellectual disabilities in 10 published Ontario court cases. The findings of this study contributed to the extant literature showing judicial reliance on parents' intellectual disability to permanently remove child custody. Furthermore, this study highlighted cognitive accessibility challenges and inconsistent use of "evidence-based" practices in the child protection system. The second study captured the perspectives of 11 child protection workers supporting parents with intellectual disabilities in Ontario through semi-structured interviews. The findings of this study revealed the immense need for disability-specific trainings for child protection workers and the need for collaboration across developmental service agencies and child protection agencies. This study also had a promising finding regarding child protection workers not relying solely on parents' intellectual disability

status in their decision-making and taking intersecting factors into consideration. The third study used an inclusive research design and included 13 parents with intellectual disabilities in Ontario and Manitoba. Their perspectives were analyzed in collaboration with a co-researcher with lived experience. The findings of this study showed the importance of informal social supports and the need for continuity of formal social supports. Some parents named the child protection agency itself as an instrumental support and reported having positive relationships with their workers, in contrast with some previous research. The overall findings of the three studies are discussed using the *Inequities Contextual Framework* by Powell et al. (2024) to demonstrate that barriers at the contextual and institutional levels heavily influence outcomes for families headed by parents with intellectual disabilities. The implications for service system changes are also discussed.

CHAPTER 1: GENERAL INTRODUCTION

Research Overview

Although the eugenics movement ended half a century ago along with deinstitutionalization (Kempton & Kahn, 1990), prejudice and biased attitudes toward persons with intellectual disabilities exercising their right to friendship, sexuality and parenthood have continued into the 21st century (Aunos & Feldman, 2002; Pajot et al., 2015; McConnell & Phelan, 2022; Sigurjonsdottir & Rice, 2023). Most countries, including Canada, have ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (United Nations, 2006; Council of Canadian with Disabilities, 2010), which clearly states the right of persons with intellectual disabilities to become parents and build a family. Statistics around the world show that persons with intellectual disabilities are exercising this right in increasing numbers (e.g., Brown et al. 2018). Despite the modern-day trend toward inclusivity, fairness and justice, negative attitudes toward parents with disabilities continue to persist (McConnell et al., 2021b). The news of a baby born to a mother with intellectual disability is often considered “a mistake never to be repeated rather than a celebration” (International Association for the Scientific Study of Intellectual and Developmental Disabilities; IASSIDD, 2008).

Who are Parents with Intellectual Disabilities?

Historically, intellectual disability was defined only in terms of intellectual functioning and a score below the range of 70-75 on standardized Intelligence Quotient (IQ) tests led to a diagnosis of intellectual disability (DSM-5, 2013). However, this conceptualization of disability as an individual problem within the medical model has led to decades of stigma and discrimination for persons with intellectual disabilities (Guevara, 2021; Mander, 2022). An IQ score alone is no longer considered sufficient for a diagnosis of intellectual disability and a

complete assessment involving adaptive functioning must be carried out for diagnosis. The American Association of Intellectual and Developmental Disabilities (AAIDD) provides a more comprehensive definition of intellectual disability, aligned with the social model of disability, as follows:

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 22. (AAIDD, 2024)

In addition to intellectual functioning, persons with intellectual disabilities have challenges in adaptive functioning, including conceptual skills (e.g., math concepts and language), social skills (e.g., interpersonal skills and social problem-solving) and practical skills (e.g., schedules and routines). The 12th AAIDD manual requires the consideration of a person's social and contextual setting as well as cultural and linguistic diversity as key elements in the assessment of intellectual disabilities. It also makes clear its stance that limitations co-exist with strengths and the purpose of evaluating limitations is to develop a "profile of needed supports" that can help to improve the quality of life of persons with intellectual disabilities (Schalock et al., 2021).

Based on a recent position paper by the Parenting Special Interest Research Group at IASSIDD, most parents with intellectual disabilities have mild cognitive limitations (IASSIDD, 2008). However, the reality is that many parents with intellectual disabilities are in the hidden majority, who may not be formally diagnosed with an intellectual disability and may or may not be receiving support services for their cognitive and adaptive challenges. Sometimes, parents with intellectual disabilities are only identified in child welfare when a problem arises with their parenting (IASSIDD, 2008).

Throughout this dissertation, the term ‘parents with intellectual disabilities’ will be used to refer to parents who are either formally diagnosed or self-identify as having an intellectual disability or a developmental disability. Parents with intellectual disabilities without a diagnosis who are receiving services from developmental service agencies (e.g., Developmental Services Ontario; DSO) will also be included in this terminology.

Prevalence of Parents with Intellectual Disabilities

According to the Canadian Disability Survey (StatCan, 2017), 22.3% of Canadian citizens live with some type of disability. Of the total adult population, 1% have a diagnosis of developmental disability (StatCan, 2017; Lin et al., 2014), which adds up to 375,900 persons with developmental disabilities in total. Brown et al. (2016) completed a population-based study of fertility rates in women with and without intellectual disabilities and found 430 births to women with intellectual disabilities in a single year and the fertility rate was 20.3 live births per 1000 women. This statistic can be understood as almost 1000 children born to women with intellectual disabilities every 2 years. It should be noted that there are no statistics available on fathers with intellectual disabilities in Canada.

Although there are currently no firm estimates on the prevalence of parents with intellectual disabilities in the Canadian population (other than fertility rates found by Brown et al. 2016), the Canadian Community Health Survey (Statistics Canada, 2011) implies that parents with intellectual disabilities comprise a little over 1% of the Canadian population (McConnell et al., 2020). While this percentage may seem small, this means over 700,000 people in a population context. As mentioned previously, many parents with intellectual disabilities may not have a formal diagnosis of intellectual disability but may be in receipt of adult developmental services. Although formal prevalence estimates are difficult to make in this population due to

lack of consensus on terminology and parents not being identified (IASSIDD, 2008), researchers around the world have identified that amongst the total adult population, there are 0.4% of parents with intellectual disabilities in Australia (Man et al., 2017), 1% in Norway (Tossebro et al., 2017) and 1.4% in Germany (Pixa-Kettner, 2008). Overall, most countries have reported a prevalence rate of approximately 1% of the nation's population being parents with intellectual disabilities. These statistics indicate that people with intellectual disabilities form a sizable part of our society, and it is crucial to explore their experiences and address their needs, as they continue to navigate their life stages while exercising their right to become parents and build families.

Involvement in Child Protection

Parents with intellectual disabilities have been overrepresented in child protection investigations around the world, including Canada, for several decades (e.g., Booth & Booth 2004; Booth & Booth, 2005; Booth et al., 2005, McConnell et al. 2011, McConnell et al., 2021; Laliberte et al., 2024). International studies have reported that up to 50% of parents with intellectual disabilities have their children removed from the home and placed out-of-home (Gillberg & Geijer-Karlsson, 1983; Larson, Lakin, Anderson, & Kwak, 2001; Llewellyn, McConnell, & Ferronato, 2003; Van Hove & en Wellens, 1995). An analysis of the Canadian Incidence Study (CIS-2003) found that 10% of all child maltreatment investigations in Canada involved parents with intellectual disabilities, which translates to over 22,000 children who had parents with intellectual disabilities undergoing investigation in 2003 (McConnell et al., 2008a; McConnell, et al., 2011). McConnell et al. (2011) found that child maltreatment investigations for parents with intellectual disabilities continued more frequently (61%) after initial report, compared to parents without intellectual disabilities (46%) in Canada. These investigations also

ended in out-of-home placements more frequently than parents without intellectual disabilities. Files of parents with intellectual disabilities were kept open even when claims of child maltreatment were not substantiated, meaning no evidence of maltreatment was found (McConnell et al. 2008; McConnell et al. 2011). These findings were replicated and corroborated by McConnell et al. (2021) using CIS core data from 2008, in which the authors additionally identified a 16% rate of involvement for parents with intellectual disabilities who had infants during the year 2008. Booth et al. (2005) found that parents with intellectual disabilities were almost 4 times more likely to have their children permanently removed from their home than parents without intellectual disabilities. In a recent Canadian study, Brown et al. (2018) found that almost 6% of newborns born to women with intellectual disabilities were discharged to child protection services compared to only 0.2% of newborns of women without intellectual disabilities, although the reasons surrounding why the newborns were discharged to protective custody are not known in this study. These are staggering numbers for parents with intellectual disabilities in child protection, considering that the prevalence of intellectual disabilities in the adult population is estimated to be 1% (Lin et al. 2014).

McConnell et al. (2011) conducted an analysis on 1,243 child maltreatment investigations in Canada and found that parents having intellectual disabilities was a strong predictor of court action even after controlling for other factors such as socioeconomic status, child characteristics and other parent characteristics. They also found that cases were more likely to be kept open despite absence of child maltreatment if the parent was perceived to be noncooperative with caseworkers or if they had few social (informal) supports. Furthermore, child neglect was found to be the most commonly reported concern (rather than other types of child maltreatment, such as physical or emotional abuse), a finding that has been corroborated by recent studies (Slayter &

Jensen, 2019). The likelihood of court action significantly decreased if referrals to parenting intervention programs were made. Lastly, McConnell et al. (2011) interestingly found that the characteristics of the child protection workers also predicted the outcome of the investigations. For example, child protection workers with lighter caseloads and less experience were more likely to substantiate child maltreatment claims. Studies examining the experiences of child protection workers involved in investigations with parents with intellectual disabilities are limited.

McConnell et al. (2021) further corroborated previous studies in an examination of 15,980 Canadian cases that revealed 6.3% of all child protection investigations involved parents with intellectual disabilities and they were up to four times more likely to result in child removal and court action. Similar to McConnell et al. (2011), intellectual disability status in parents was significantly more predictive of court action as well as cases remaining open for longer, after controlling for other parent characteristics (e.g., mental health problems), child characteristics and socioeconomic factors. When parents were found to have intellectual disabilities, the case was treated differently, and factors that would be weighed heavily in other cases such as history of prior involvement with child welfare agencies and nature of the child maltreatment concern, did not influence outcomes as much as intellectual disability status. McConnell et al. (2021) also found that Canadian parents with intellectual disabilities were not referred to suitable parenting programs that were tailored towards supporting parents with intellectual disabilities as often as they are in the United States of America (USA; Slayter & Jensen, 2019; Pacheco et al., 2022b).

Studies in the USA have found similar overrepresentation of parents with intellectual disabilities in child protection investigations and have also demonstrated that the child protection system is ill-equipped to deal with parents with intellectual disabilities (Laliberte, 2013;

Laliberte et al. 2017; Laliberte et al., 2024). Part of the overrepresentation of parents with intellectual disabilities may be explained by a lack of appropriate services for parents with intellectual disabilities as well as the inherent bias of caseworkers, judges and other professionals involved. In a study by Proctor and Azar (2013), 212 caseworkers were presented with vignettes about parents with and without intellectual disabilities and asked to provide ratings and emotional reactions. The status of intellectual disability was more likely to result in feelings of pity, sympathy and willingness to help the parents. This demonstrates that caseworkers may make differential decisions in cases of parents with intellectual disabilities compared to parents without intellectual disabilities, which may lead to the disparities seen in outcomes of child protection investigations. Callow et al. (2017) found that appeal courts upheld 81% of decisions to terminate parental rights of parents with intellectual disabilities, and a diagnosis of intellectual disabilities was often cited as a primary reason for this decision.

Sociodemographic Context of Parents with Intellectual Disabilities

Parents with intellectual disabilities are often impacted by a myriad of contextual factors that influence their parenting ability. It can be difficult to parse out the impact of intellectual disability alone on parenting capacity beyond other social factors. They are more likely than parents without intellectual disabilities to be single parents, face poor socioeconomic conditions, have unstable housing, have multiple children as well as struggle with substance abuse (Feldman & Walton-Allen, 2002; Aunos et al., 2008; O’Keefe & O’Hara, 2008; Heyman et al. 2023). Furthermore, parents with intellectual disabilities are likely to be socially isolated and have low social support, as well as participate less in their community (Baum & Burns, 2007; Darbyshire & Kroese, 2012; Llewellyn & McConnell, 2002; McGaw, Ball & Clark, 2002). Poor mental health and experiences of trauma can also contribute to parenting struggles and influence the

capacity of parents with intellectual disabilities to provide adequate care for their children (Llewellyn et al., 2002; Forslund et al. 2022). Brown et al. (2022) found that although mothers with intellectual disabilities experience high rates of mental stress, supports for these mothers only revolve around parenting skills and support providers may not consider the unique mental health needs of this group.

Wade et al. (2011) demonstrated that perceived social support can significantly impact parenting style and positive parenting practices. Social support continues to be identified as an integral factor in successful parenting for parents with intellectual disabilities (Potvin et al, 2016; Koolen et al., 2020). Moreover, availability and access to resources can act as a buffer to the hardships experienced by parents with intellectual disabilities, such as financial support (Meppelder et al., 2015). Other social factors such as personal history may also influence caregiving ability. For example, McConnell et al. (2022) found that 81% of parents with intellectual disabilities ($N=91$) experienced some form of childhood abuse or adversity and those parents that recalled having a more positive childhood experience were more likely to have better social supports and form positive connections with their own children. Zijlstra et al. (2024) demonstrated that risk factors beyond intellectual disability (such as relational problems, substance abuse, physical illness and psychiatric problems) begin impacting expectant parents with intellectual disabilities and involvement with child protection even before the child is born.

Parenting Interventions for Parents with Intellectual Disabilities

Research on parenting interventions for parents with intellectual disabilities has been ongoing since the mid-1980s, when initial outcome studies on parenting interventions were published (e.g., Feldman et al. 1985; Tymchuk et al. 1987; Feldman et al. 1989). These interventions are generally aimed at increasing parenting skills to effectively reduce contact and

involvement with child protection services. A recent scoping review on preventive parenting interventions for parents with intellectual disabilities identified six interventions aimed at increasing good enough parenting during the first 1001 days of parenthood, including expectant parenthood starting in pregnancy (Zijlstra et al., 2023). They found that positive family outcomes were noted even when only partial components of “good enough parenting” (Zijlstra, 2012) were addressed. Zijlstra et al. (2023) highlighted the importance of taking an ecological perspective and addressing the conditions in society in addition to conditions within the family to achieve major impact.

In addition to the scoping review outlined above, three systematic reviews have been conducted on parenting intervention studies involving parents with intellectual disabilities (Feldman, 1994; Wade et al. 2008; Wilson et al. 2013). All three systematic reviews concluded that parents with intellectual disabilities benefit from skill training interventions aimed at improving specific parenting skills and practices, particularly using behavioural teaching methods during early childhood. Several studies have shown that parents with intellectual disabilities can improve basic childcare skills, increase sensitivity toward their infants, improve parent-child interactions and implement more positive parenting practices with their young children, such as delivering effective instructions and acknowledging children’s positive actions (e.g., Feldman et al. 1999; Feldman & Case, 1999; Llewellyn et al. 2003; Feldman, 2004; Mildon et al. 2008; Phaneuf & McIntyre, 2007; Glazemakers & Deboutte, 2013; Tahir et al. 2015). Parenting programs often must be adapted and individualized (e.g., individual sessions rather than group learning, repeated practice of skills, home-based learning and inclusion of audiovisual aids in lieu of reading materials) for parents with intellectual disabilities so they can successfully learn and/or improve parenting skills (Feldman, 1994; Wade et al. 2008; Wilson et al. 2013).

Although earlier research has included small sample sizes and may lack generalization and maintenance data, participants made significant gains in specific parenting behaviours. For example, in an early study by Feldman and Case (1999), 10 parents with intellectual disabilities were taught to implement child safety skills in a home-based program (e.g., identifying illness, preventing burns), using self-directed teaching materials (pictorial checklists and audiotapes with instructions) and significant gains were found in 9 out of 10 parents and 10 out of 11 skills. These gains were maintained at a 6-month follow-up assessment. Mildon et al. (2008) carried out an intensive home-based program with 24 parents who had intellectual disabilities, which began with an assessment of the contextual fit for each parent and designing a tailored parenting intervention. The intervention included three modules: 1) home safety, 2) parent-child interaction and 3) positive behaviour support strategies to teach appropriate discipline methods. Results showed that participants had increased scores of parental self-efficacy, reported fewer disruptive behaviours at home and had improved home environments.

In recent years, video feedback interventions have gathered strong support via randomized controlled trials (RCTs) of parenting interventions for parents with intellectual disabilities (Hamby et al., 2019). For examples, Hodes and colleagues (2017) carried out an RCT on the Video-Feedback Intervention to Promote Positive Parenting and Sensitive Discipline (VIPP-SD; Juffer et al. 2008), which is a manualized intervention with roots in attachment theory (Ainsworth, 1978). The intervention involves videotaping parent-child interactions and pausing at specific moments to provide specific feedback, and praise and practice parental sensitivity. The RCT consisted of 85 parents with intellectual disabilities, with an experimental condition (VIPP-SD; $n=43$) and a control condition (traditional parenting program; $n=42$). The results

showed that parents within the experimental condition had significantly higher rates of parental sensitivity and reduced parenting stress, leading to a modest but significant effect size ($d=0.46$).

Overall, parenting interventions are more successful when they are contextually relevant and offer the specific type of support parents with intellectual disabilities need based on socioeconomic factors (Wade et al. 2008; Wilson et al. 2013; Zijlstra et al. 2023). Wade et al. (2008) found that parents who had less social support, unhelpful partners, a higher number of children and maternal depression were less likely to benefit from parent education interventions. Parents with intellectual disabilities have shown to benefit considerably from social support interventions, and often have better outcomes when surrounded by a support network (e.g., McConnell et al. 2009).

In child protection cases, parents with intellectual disabilities are often not referred to individualized parenting programs; court-mandated programs are usually not well-suited for persons with intellectual disabilities (McConnell, Llewellyn, & Ferronato, 2002; Booth & Booth, 2004; Azar, Maggie, & Proctor, 2013; Pacheco et al. 2022b). Based on challenges with attention, memory and literacy, combined with social disadvantages, group-based interventions in lecture format are not likely to significantly improve parenting skills of parents with intellectual disabilities. In fact, referrals to traditional parenting programs may make parents with intellectual disabilities seem uncooperative or irresponsible. Although identification of intellectual disabilities should create pathways for parents with intellectual disabilities to access specialized services and supports, it paradoxically limits their access to parenting supports since they are often presumed to be incapable of increasing their parenting capacity (MacIntyre, Stewart, & McGregor, 2019).

Decision-Making in Child Protection

Decision-making in child protection has historically been a complex subject, lacking consensus and standardized procedures. Child protection workers must often grapple with the seemingly inherent contradiction between the needs of the child and the needs of the parent (child safety vs. family preservation). Most jurisdictions around the world place the safety and interests of the child at the center of the child investigation process. In doing so, there may be an overestimation of the risk of harm to the child to err on the side of caution. The term “good enough parenting” has been used to describe the minimal level of care and support that a parent needs to provide a child to grow into healthy productive member of society (Choate & Engstrom, 2014; Budd and Holdsworth, 1996). In the absence of standardized assessments in child welfare, *clinical judgement* remains the primary method by which decisions are made in child protection cases (Choate & Engstrom, 2014). However, clinical judgement can vary dramatically even within the same jurisdiction, based on educational background, years of experience, level of expertise and personal attitudes of child protection workers.

In this dissertation, the local Ontario child protection system will serve as a context for the studies conducted, albeit many similarities exist in other provincial jurisdictions across Canada and other countries. Family court decisions in Ontario are governed by the *Child and Family Services Act* (2017), which provides detailed definitions of who is “a child in need of protection” as well as guidelines for action needed to be taken by Children’s Aid Societies when a child is deemed to be in need of protection. The Ontario Association of Children’s Aid Societies (2020) defines child neglect as:

“..fail[ing] to provide basic needs such as adequate food, sleep, safety, education, clothing or medical treatment. It also includes leaving a child alone or failing to provide adequate supervision. If the caregiver is unable to provide the child with basic needs due

to financial inability, it is not considered neglect, unless relief has been offered and refused.”

In Ontario, child protection workers are expected to follow the Child Protection Standards (2016) and follow the assessment guidelines provided in the Ontario Child Protection Tools Manual (2016) and the Eligibility Spectrum (OACAS, 2021) when assessing risk of harm. Some of the formalized government guidelines contain discriminatory language surrounding parents with disabilities (including intellectual disability) within specific rating scales. For example, in the Eligibility Spectrum (OACAS, 2021), a child is experiencing “moderately severe” risk of harm when a caregiver has the following “problems”:

“Caregiver Has Problem Causing Risk That the Child Is Likely To Be Harmed

It is alleged/verified that caregiver has a problem created by a physical, mental/emotional, or behavioural condition that threatens to interfere with their childcaring ability (or that has already caused some erratic child-care quality). Examples are chronic physical illnesses, physical disabilities, mental or emotional illnesses, substance abuse, criminal activity, **intellectual disability**.”

Furthermore, the same document provides examples of situations which demonstrate how intellectual functioning may reduce parenting capacity:

“...a parent with limited intellectual functioning who is unable to perceive when the child is ill or a first-time parent whose family of origin was neglectful and/or abusive and does not view neglect or abuse as wrong.”

In the absence of legislation akin to the American with Disabilities Act and a ruling in the USA mandating protection of the rights of parents with disabilities (US Department of Justice, 2008), Canadian caseworkers and legal professionals are faced with several ambiguities in child protection decision-making. With formal guidelines such as the Eligibility Spectrum (OACAS, 2021), it is up to the child protection workers to parse out inherently biased recommendations, such as assuming that a parent will not be able to identify their child’s illness if they have an intellectual disability, to make objective decisions. This may be a challenging task for newly

trained child protection workers who may unwittingly perpetuate the stigma faced by parents with intellectual disabilities and make decisions based on assumptions of child maltreatment rather than actual parenting capacity and parenting skills.

Parenting Capacity Assessments with Parents with Intellectual Disabilities

Although research has demonstrated that IQ alone does not predict parenting capacity (Tymchuk, 1992), the diagnosis of intellectual disability and IQ scores continue to be used in parenting capacity assessments ordered by courts (Callow et al. 2016; Aunos and Pacheco, 2021). Often when a parent with intellectual disabilities is involved in a child protection investigation, it is immediately assumed that they are incompetent parents and the appropriate assessments may not even be pursued to substantiate claims of child maltreatment (Feldman & Aunos, 2010; Mayes & Llewellyn, 2012; Aunos and Pacheco, 2021).

Researchers have agreed that parenting capacity assessments should include data from multiple objective sources, should not be an IQ evaluation (APA, 2010) and should include direct behavioural observations of parent-child interactions (Feldman & Aunos, 2010). Feldman and Aunos (2010) recommend carrying out a contextualized parenting capacity assessment rather than relying solely on a psychological evaluation or intelligence testing. They highlight the following interactional factors as key determinants of parenting capacity: social factors; parent history; life crises; parental health; family characteristics; social support and services; child's heredity and early experiences; parenting skills; and child and family outcomes. The authors recommend using the *Impediments and Supports Checklist* (Feldman, 2002; Feldman & Aunos, 2010) to determine the precise type and level of supports needed by families who have parents with intellectual disabilities.

Aunos and Pacheco (2021) recruited 8 mothers with intellectual disabilities who received specialized parenting services to participate in a study evaluating parenting capacity assessments in Quebec, Canada. The participants shared their parenting capacity assessment reports and other case records. The authors found that child protection workers often concluded that parents with intellectual disabilities did not possess the capacity to provide adequate parenting compared to assessors from specialized developmental support agencies or intellectual disabilities support agencies.

Ableism in Child Protection

Based on extant literature, ableist attitudes are entrenched within child protection processes and decisions across the globe (Powell, 2023; Spencer et al. 2023; Pacheco et al. 2024). Ableism can be broadly defined as “stereotyping, prejudice, discrimination, and social oppression toward people with disabilities” (Bogart & Dunn, 2019). This can be seen in court cases analyses and legal perspectives in the field. For example, Sigurjonsdottir and Rice (2017) conducted a study on 56 national published court cases in Iceland between 2002-2014 to conduct an analysis using a ground theory approach. They found that court professionals tended to assume that parents with intellectual disabilities would have worse parenting skills over time and regardless of intervention, they continue to have intellectual disability and that precludes them from ever becoming capable parents (Sigurjonsdottir & Rice, 2017). In Canada, Pacheco et al. (2024) conducted an extensive discourse analysis of how intellectual disability is socially constructed using 10 public court records in Quebec, Canada. Their findings revealed that mothers with intellectual disabilities are often portrayed as being “irreversibly vulnerable” in a system that expects or even requires people to be *able* in a static and constant manner.

The lack of adequate legal support and accessibility for parents with intellectual disabilities also highlights ableist attitudes and prevalent bias. In the United Kingdom, Booth and Booth (2005) interviewed parents with intellectual disabilities and their partners from 20 households. Most parents reported being mystified by legal procedures and court proceedings, not having adequate legal support, feeling severely anxious and depressed after an investigation began and even deciding on sterilization to avoid future pregnancies. In a study by Albert & Powell (2020), an attorney explained the lack of understanding of the needs of parents with intellectual disabilities as such:

“You’re saying that someone has an intellectual disability such that you don’t think they’re able to safely parent their kid but then you just hand them a packet with an eight-page form with a whole bunch of fine print on it and expect them to fill it out and then say they’re not cooperative or noncompliant when they don’t do it.”

Albert and Powell (2020) recommended increasing resources not only for parents with disabilities but also resources for the child welfare system to increase knowledge and training on providing individualized support tailored to the needs of the parents. Atkin and Kroese (2022) found that parents with intellectual disabilities significantly benefited from having independent advocates supporting them to understand legal procedures and navigate the child protection process in the midst of being socially isolated and feeling powerless.

Theoretical Frameworks

Few theoretical or conceptual models have been proposed to understand factors that influence parenting with intellectual disabilities or the lived experience of parents. The first model described here is the *Interactional Model of Parenting* (Aunos & Feldman, 2002) which was an early attempt at identifying specific sociodemographic factors beyond parental disability that may impact parenting ability. Drawing on ecological, interactional and transactional approaches, such as Bronfenbrenner’s (1992) ecological systems theory, Aunos & Feldman

(2002) developed the interactional model of parenting which depicts the complex linkages between parenting, social factors and child/family outcomes. This model highlights specific risk and resilience factors that influence the parenting ability of parents with intellectual disabilities. As previously outlined, parents with intellectual disabilities are affected by factors that likely influence all parents (including parents' history, parents' health, child characteristics, social support and more); however, they also experience factors such as discrimination and stigmatization, which complicates their social context further because parental disability may get conflated with parenting skills. In this interactional model, parenting ability is conceptualized not as a static trait, but as a dynamic and changing attribute that is impacted by variables such as support, services, health, child outcomes and family characteristics (Aunos & Feldman, 2002; Feldman & Aunos, 2010). A revised version of this model has recently been empirically validated (Feldman et al. 2020).

Although an insightful theoretical model that proposes relationships between factors at an individual level for parents with intellectual disabilities, it does not provide an understanding of the systemic barriers that may impact parenting with intellectual disabilities. Given the reality that parents with intellectual disabilities have experienced disproportionate contact with child protection services through the years (e.g., Laliberte et al. 2024), a top-down conceptual approach is needed for a deeper understanding of challenges experienced by this group of parents.

The *Inequities Conceptual Framework* proposed by Powell et al. (2024) presents a way to identify and analyze barriers impacting parents with intellectual disabilities using a top-down approach (see Figure 6.1). The framework is tiered and proposes three levels of factors impacting inequities experienced by parents with intellectual disabilities. These are presented in order from

distal to proximal in relation to inequities experienced by parents: 1) contextual, 2) institutional and 3) individual. Factors at the contextual level include 1a) societal attitudes, 1b) state and federal laws and policies, and 1c) availability of formal supports and services. Factors at the institutional level are grouped into agency-systemic factors and human decision-making factors. Agency-systemic factors include 2a) institutional ableism, 2b) training for staff about disability, 2c) relationship with disability community, 2d) accessibility, and 2e) parenting assessments. Human decision-making factors include 2f) bias, 2g) lack of disability-cultural competence and humility, and 2h) inconsistent decision-making. Individual factors are separated into parent and family characteristics and interactions with the child welfare system. Parent and family characteristics include 3a) disability type, 3b) sociodemographic characteristics, and 3c) social supports), while interactions with the child welfare system include 3d) prior involvement and 3e) out-of-home placement.

The individual and institutional levels are nested within the contextual level to suggest that the contextual level impacts the institutional and individual levels in an instrumental way. Interactions between specific factors at each level or between levels are not proposed within the model but briefly discussed by Powell et al. (2024). Although this conceptual model was created for USA child welfare system, the inequities experienced by parents with intellectual disabilities are global (e.g., McConnell et al. 2021). The inequities suggested in the model include 1) overrepresentation within the child welfare system, 2) high rates of termination of parental rights, 3) inadequate services and supports, and 3) denial of services and supports.

Research Gaps

Overall, the overrepresentation of parents with intellectual disabilities in child protection is well-documented (e.g., McConnell et al., 2021; Lima et al. 2022; Laliberte et al., 2024).

However, the factors or conditions that influence child protection decisions in specific cases in the current Canadian child protection system are not yet well-understood using qualitative methods. Qualitative research on child protection involvement of parents with intellectual disabilities can help us achieve a more thorough and in-depth understanding (Maxwell, 2021) of the conditions that influence custody decisions made in the Canadian child protection system (at the worker's level and at family courts) and capture the complexities not possible to examine in population-based studies depicting persistent overrepresentation of parents with intellectual disabilities in child protection over the decades (e.g., Gillberg & Geijer-Karlsson, 1983; McConnell et al. 2008; McConnell et al. 2021; Laliberte et al. 2024). There are few qualitative studies that have comprehensively explored the following three perspectives: 1) family court judges, 2) child protection workers, and 3) parents with intellectual disabilities.

In terms of court documents, only a handful of studies have examined actual court records to investigate custody and placement decisions made regarding children of parents with intellectual disabilities (Callow et al. 2017; Sigurjonsdottir & Rice, 2017; Aunos & Pacheco, 2020; Pacheco et al. 2024), with qualitative studies using court documents being even fewer (Sigurjonsdottir & Rice, 2017; Pacheco et al. 2024). Most recently, Pacheco et al. (2024) examined how narratives of intellectual disability are socially constructed through qualitative analysis of 10 published court cases in Quebec, Canada. No such analysis has been conducted in Ontario to date. In addition, there are currently no studies examining how court proceedings carried out during the COVID-19 pandemic impacted cases involving parents with intellectual disabilities. This is important to examine given research findings that adults with intellectual disabilities were cut off from essential supports and were socially isolated during the pandemic

(e.g., Lake et al. 2021; Doody & Keenan, 2021) and the documented importance of social supports for parents with intellectual disabilities (e.g., Koolen et a. 2021).

It should be noted that recent studies have made significant contributions in understanding the perspectives of social workers supporting parents with intellectual disabilities. For example, Strnadova et al. (2017) conducted a survey with 329 Australian social workers, a majority of whom were engaged in child protection work. They found that most workers did not have sufficient knowledge and training in intellectual disability and almost half of them believed that women with intellectual disabilities who become pregnant should get an abortion. In Canada, Pacheco et al. (2022a) interviewed 39 key workers doing disability-related social work with parents with disabilities, who identified a lack of tools and trainings for social workers to increase disability competency. They also identified having heavy caseloads, the need for collaboration between agencies, as well as the importance of building a good working relationship with parents. Most relevant is Norlin and Randell's (2022) study involving four focus groups with 12 child protection workers in Sweden. They found that although child protection workers found it more difficult to assess "good enough parenting" in cases involving parents with intellectual disabilities, their focus when assessing capacity was not on the disability but rather the whole social context surrounding the parent. No similar study examining the nuances of child protection workers' experiences have been conducted in Ontario, Canada. There continues to be a gap in understanding the practical nuances of the experiences of child protection workers, which are likely sensitive to regional policy and practice variations and must be studied accordingly.

There are also research gaps in capturing the lived experience of Canadian parents with intellectual disabilities using inclusive research designs. Walmsley et al. (2018) offered a revised

definition of inclusive research which emphasizes the need to champion the lived experience of co-researchers with disabilities and to empower them to make decisions that impact their own lives. Some studies have examined the lived experience of parents undergoing child protection investigations and their feelings of bewilderment and confusion, as well as lack of appropriate access to supports and services (e.g., Booth and Booth, 2004; 2005; Sheerin and Keenan, 2013; Atkin and Kroese, 2022). Stefansdottir et al. (2023)'s case study revealed that for one couple with intellectual disabilities, the support of family members, advocates, and social service workers was crucial to positive family outcomes. A total of four inclusive research studies were found centered on parents with intellectual disabilities that were conducted in collaboration with co-researchers with intellectual disabilities (Theodore et al. 2018; Strnadova et al. 2019; Collings et al. 2019; Franklin et al. 2021). They explored different types of social supports available to parents, the importance of structured peer supports, recognition of the need for professional services and resources amidst pervasive assumptions about lack of parenting capacity, and the desire of parents with intellectual disabilities to engage in family planning. However, none of these inclusive studies directly examined the lived experience of parents within child protection investigations, particularly in a Canadian context. It is essential to capture the lived experience of Canadian parents with intellectual disabilities and understand these experiences in collaboration with a co-researcher with similar lived experience.

In sum, what we **already know** is:

- Parents with intellectual disabilities have a higher-than-usual rate of child protection investigations and the child protection workers' decision is highly valued in family court (McConnell et al. 2021).

- Parents with intellectual disabilities are often involved in complex social situations, such as single parenthood, poor or unstable housing, low income, substance abuse and intimate partner violence, which can adversely impact parenting skills and ability (Darbyshire & Kroese, 2012; Powell & Parish, 2017; Wickstrom et al. 2017; Tarasoff et al. 2020; Hammarlund et al. 2023).
- We know that mothers with intellectual disabilities often lose custody of their children immediately after birth, a period that is crucial for parent-child bonding and immediate removal of newborns can result in maternal suicide and child developmental problems (Brown et al. 2018).

What we **do not yet have full understanding of** is:

- How much does intellectual disability still play a role in court judges' analysis and final custody decisions in child protection cases today?
- How much does intellectual disability play a role in child protection workers' decisions and what are other social and contextual factors that may influence workers' decisions (which we know are highly valued in court)? Although the Ontario government has restructured child welfare work and published formalized tools to guide decision-making (e.g., Eligibility Spectrum; OACAS, 2021), it is unclear to what extent these are used by child protection workers in decision-making.
- What do parents with intellectual disabilities think about their involvement in child protection, the information they receive regarding the process and the challenges they experience as they navigate their cases?

If ableism and prejudice toward adults with intellectual disabilities becoming parents continues to underlie child protection decisions, it has serious implications for the health and well-being of

this growing group of families who experience perpetually unmet needs. It is imperative that we understand the specifics of the conditions that impact custody decisions to prevent unnecessary parent-child separation that can be damaging for both parents with intellectual disabilities and their children, while ensuring that children's rights and safety are protected. Therefore, in the present dissertation, we aimed to utilize a qualitative study design across three studies (described below) to obtain a comprehensive understanding of child protection cases involving parents with intellectual disabilities.

Dissertation Objectives

The purpose of this dissertation was to qualitatively examine the conditions that impacted the final child custody decisions made in cases involving parents with intellectual disabilities, completed in three phases. Specific objectives for each study are outlined below:

Study 1 Objectives

- The objective of Study 1 (reported in Chapter 3) was to describe and examine specific parent characteristics and other social conditions or contextual factors as described by the family court judge that contributed to final custody decisions for parents with intellectual disabilities, within published family court proceedings in Ontario, Canada.

Study 2 Objectives

- The objective of Study 2 (reported in Chapter 4) was to describe how child protection workers make decisions regarding custody decisions in cases involving parents with intellectual disabilities. We aimed to examine the sources of information they used to inform their decision-making and the challenges they experienced when making decisions. In this study, the primary objective was to investigate how heavily intellectual

disability status weighed in child protection workers' decision to remove the child from the parent or make efforts toward reunifying the family.

Study 3 Objectives

- The objective of Study 3 (reported in Chapter 5) was to obtain the perspective of parents with intellectual disabilities in an accessible and inclusive study to ensure that parent voices are heard in our analysis of what influences child protection decisions. Another aim of this study was to involve a co-researcher with intellectual disabilities who had lived experience as a parent to support development of research tools and collaborate on data collection and data analysis (described in detail in Chapter 5). We aimed to examine how information regarding the child protection process is conveyed to parents with intellectual disabilities, and whether they understand the information given to them and the decisions made for their families.

Research Question

The overarching research question posed for the three studies in this dissertation was: **What influences child custody decisions regarding which parents with intellectual disabilities keep custody of their children and which parents with intellectual disabilities do not?**

CHAPTER 2: AN OVERVIEW OF DATA ANALYSIS METHODS

The purpose of this chapter is to provide a description of the data analysis methods utilized in each of the three studies included in this dissertation. The objective of Study 1 was to select a sample of published child protection records in Ontario, Canada, to examine what individual and contextual factors were considered during custody decision-making by family court judges in cases involving one or more parents with intellectual disabilities. The Study 2 objectives included examining the perspectives of child protection workers, the factors that influenced their decision-making and the challenges they experienced in investigating families headed by parents with intellectual disabilities. The aim of Study 3 was to incorporate the lived experience of parents with intellectual disabilities themselves, and the objectives included examining parent experiences with child protection using inclusive methods involving a co-researcher who had similar lived experience as participants. The qualitative analysis software NVivo (Lumivero, 2024) was used for data coding across all studies.

Study 1: Court Records

Since Study 1 was intended to be an exploratory study, the proposed sample of court cases was a total of 10 cases over a period of three years from 2019 to 2021. The rationale for this selection was to choose a manageable sample that met the inclusion criteria for an exploratory study and included cases immediately prior to and during the lockdown and social distancing measures of the COVID-19 pandemic (e.g., May 2020). All cases included at least one parent with an intellectual disability and included a mix of trial cases and summary judgement motions. The sample of cases also included both temporary custody cases and extended society care (formerly known as “crown wardship”). It was important to include a diversity of case types in order to take a comprehensive look at how cases involving parents with

intellectual disabilities were treated by family court judges. Further details about the databases and search terms used for Study 1 are provided in Chapter 3.

The cases selected for Study 1 ranged from 10 to 53 pages in length. Each published court hearing followed the publication format set by the Ontario Court of Justice (Ontario Court of Justice, 2024) with standard headings such as “evidence considered”, “capacity to parent” and “findings.” Every court hearing or proceeding in Canada, including provincial and federal hearings are a matter of public record, unless there is a publication ban or limit (Government of Ontario, 2023). For example, there may be censorship associated with family court hearings to protect vulnerable groups, including children. This may limit case information presented in a published court hearing and not all details from case files reviewed may be mentioned within a published hearing. The limitations of using published court records are further discussed within Chapters 3 and 6. The court records are publicly accessible for all readers via any internet search engine using the case numbers listed in Appendix B.

A qualitative content analysis approach was employed to analyze court records in Study 1. Qualitative content analysis can be defined as a “systematic reduction of content, analyzed with special attention to the context in which it was created, to identify themes and extract meaningful interpretations of the data” (Roller & Lavrakas, 2015, p. 232). Although the primary content analysis approach in this study was inductive, some preset codes were created during initial coding to ascertain case details such as type of case, type of custody, main child protection concern, ages of children, and final custody decision by the judge. Qualitative content analysis was selected because of its unique ability to support a combination of inductive and deductive coding, both of which were necessary to understand how child protection cases were judged in family court. A legal advisor was consulted prior to data analysis for Study 1 to better understand

the child protection framework in Ontario and important legal terms and processes for better comprehension of cases during data analysis. See Table 2.1 below lists the specific steps followed during qualitative content analysis of published court cases.

Table 2.1.

Steps of Qualitative Content Analysis (Adapted from Roller & Lavrakas, 2015)

Phase 1: Data Generation (Coding)	Description for Study 1
Step 1	Absorb content: read the published cases and understand the dataset as a whole
Step 2	Determine unit of analysis: Each court case with a unique identifier was determined to be the unit of analysis (available as open access)
Step 3	Develop unique codes: Start with deductive coding (a-priori coding structure) for specific case details and define each code; generate inductive codes for latent content
Step 4	Conduct preliminary coding: Conduct coding on 2-3 cases to test coding structure and adjust codes as needed based on patterns within the dataset (add, remove or collapse codes)
Step 5	Code content: Apply coding structure to the remaining data set and adjust codes as needed, staying close to the data
Phase 2: Data Analysis (Categorization/Interpretation)	
Step 6	Identify categories across codes: looking for meaningful categories across all published cases
Step 7	Identify themes/pattern across categories: generate themes based on categorization of data in previous step (this was done multiple times to ensure themes optimally represented the categories)
Step 8	Draw interpretations and implications: Writing implications based on the themes generated within the dataset (i.e., asking “what do these findings mean?”)

Studies 2 and 3: Perspectives of Child Protection Workers and Parents

See Chapters 4 and 5 for details about inclusion criteria, challenges with recruitment, interview questions and procedures for Studies 2 and 3. In terms of data analysis, interview transcripts from semistructured interviews were analyzed using thematic analysis (Braun & Clarke, 2012). Thematic analysis is a flexible and foundational method for engaging with qualitative data, particularly interview transcripts. It allows researchers to “systematically identify, organize and offer insights into patterns of meaning (themes) across a data set” as well as “to see and make sense of collective or shared meanings and experiences” (Braun & Clarke, 2012, p. 57). An inductive or “bottom-up” approach to thematic analysis was utilized to identify

common ideas or patterns of meaning across the dataset. The following specific analysis steps were carried out for Study 2:

Table 2.2.

Steps of Thematic Analysis (adapted from Braun & Clarke, 2012)

Phase	Description for Study 2
Phase 1: Familiarizing yourself with the data	Reading interview transcripts and listening to interview recordings several times to immerse within the data
Phase 2: Generating initial codes	Develop brief descriptive codes to develop initial coding structure and make more interpretative codes based on the dataset and the research questions asked
Phase 3: Searching for themes	Apply the coding structure to the dataset and add, remove or collapse codes as needed; generate themes based on common ideas or patterns within the data; look for opposite examples
Phase 4: Reviewing potential themes	Check the quality of coding by reviewing the themes generated; review coded dataset several times
Phase 5: Defining and naming themes	Provide a clear focus scope and purpose and builds on previous themes; themes are related to the research questions
Phase 6: Producing the report	Produce the final write-up and tell a compelling story about the data in relation to the research question; prepare manuscript for publication

Study 3 was conducted using inclusive methods, with the involvement of a co-researcher with intellectual disabilities. Inclusive research can be defined as research that champions the lived experience of co-researchers with disabilities and empowers them to make decisions that impact their own lives (Walmsley et al., 2018). Since being a researcher is considered a “valued social role” (Walmsley et al., 2018), this meant involving a co-researcher with lived experience in decisions regarding formulation of interview questions, data collection and data analysis in Study 3. The inclusive approach is described in detail within pages 109-114 of Chapter 5. During collaborative data analysis, some adaptations were made to the steps of thematic analysis presented above. These were implemented to support cognitive accessibility as well as challenge traditional power structures by involving the co-researcher in shared decision-making about the data. These adaptations also support the practice of reflexivity (see details below) in which this author acknowledged her position as a nondisabled person without the lived experience of the

co-researcher and the privilege of being an academic researcher. See Table 2.3 below for adaptations at each step.

Table 2.3.
Steps of Thematic Analysis Adapted for Study 3

Phase	Adaptation for Study 3
Phase 1: Familiarizing yourself with the data	Complete collaboratively with co-researcher by listening to audio recordings in a secure setting; researcher to read transcript several times
Phase 2: Generating initial codes	First take notes based on co-researcher's thoughts over several sessions, then generate initial coding structure; review coding structure with co-researcher
Phase 3: Searching for themes	Apply the coding structure to full dataset; identify patterns and overlap between ideas and generate themes
Phase 4: Reviewing potential themes	Do quality-checking and ensure coherence of themes by reviewing dataset; get feedback from co-researcher during coding and review themes multiple times to make sure they represent the data
Phase 5: Defining and naming themes	Ensure that themes answer the research question and tell a story about the data; review final themes with co-researcher (iterative process in which feedback is received multiple times from co-researcher and applied to the dataset)
Phase 6: Producing the report	Write manuscript for publication; write accessible language version for co-researcher to review

Quality Procedures in Data Analysis

Due to debates in qualitative research discourse regarding the use of intercoder reliability (ICR) in qualitative analysis (O'Connor & Joffe, 2020; Yardley, 2000; Nowell et al., 2017), ICR was not calculated for any of the studies in this dissertation. One of the primary reasons for not including ICR was that it is not coherent with the "interpretative agenda" of qualitative research (O'Connor & Joffe, 2020) and attempts an unnecessary quantification of subjective data, in which a researcher can never have an objective position. It is also typically recommended for large projects involving several coders and the sample sizes within the present studies would not justify the calculation of ICR. Reporting an ICR score for a study with a small sample could provide a false sense of transferability or strength of the evidence. Furthermore, there is a power imbalance between junior and senior researchers and calculation of ICR scores would further provide an inflated a sense of transferability when it may not be present.

Instead of ICR, other quality procedures were carried out to ensure trustworthiness and transferability of findings across the three studies. First, an audit trail (Merriam & Tisdell, 2015) was kept documenting all analysis procedures and decision points in detail (within meeting notes and video recordings). Second, a “thick description” was provided through detailed and thorough descriptions of participants, settings and findings (Merriam & Tisdell, 2015). Sufficient extracts to support each finding were presented in each manuscript. Third, an iterative audit process was used to foster dialogue and reflexivity among team members to achieve trustworthiness within the data. This was achieved by meetings regularly with research team members (junior and senior researchers familiar with the data and ongoing analysis) as well as using inclusive methods through the involvement of a co-researcher with intellectual disabilities. The co-researcher brought an insider perspective of lived experience as a parent with intellectual disabilities previously involved in child protection, a position that allowed for robust data collection and unique insights into the dataset in Study 3. Constant comparison was also carried out by categorizing “bits of data” based on shared experiences to form the initial coding structure. These codes were further refined through several rounds of coding, which involved looking for discrepant examples and reorganizing codes to generate overall themes (Dye et al. 2000). Lastly, the integrated narrative generated from the three distinct studies in this dissertation allowed for triangulation of several findings through multiple data sources (i.e., court decisions, perspectives of workers and perspectives of parents; Merriam & Tisdell, 2015). See Chapter 6 for a critical and comprehensive discussion of these findings.

Reflexivity Statement

Since qualitative data are subjective and open to interpretation, it is important to recognize the effect of a researcher’s position on data analysis. Reflexivity within qualitative

research can be defined as “turning of the researcher lens back onto oneself to recognize and take responsibility for one’s own situatedness within the research and the effect it may have on the setting and people being studied, questions being asked, data being collected, and its interpretation” (Berger, 2015, p. 220). To demonstrate reflexivity within this dissertation, this author included transparent reporting procedures in the Method section of each manuscript as well as within this chapter on data analysis. The limitations of each method are clearly described in each chapter. As Dodgson (2019) recommended, a positionality statement is also presented here in first-person to inform interpretation of the findings presented in the upcoming chapters.

I was the primary researcher in this dissertation and the three studies were carried out as part of my PhD research in Experimental (Community) Psychology. I am a South Asian woman in my mid-30s, a first-generation immigrant and a nondisabled mother. I have worked with families headed by parents with intellectual disabilities in various capacities prior to this research, including clinical work as a behaviour analyst and parenting intervention research. My position of privilege as an academic researcher, clinician, and as a mother without disabilities, may have influenced the way in which I interpreted the experiences of parents with intellectual disabilities within this research. At the same time, having encountered the persistent barriers faced by parents with intellectual disabilities and having experienced the strong support networks required for successful parenting may have allowed me to parse out idiosyncratic experiences within the current research. My cultural identity as a member of the South Asian diaspora in Canada may also have influenced my interpretations of the data, particularly family court judges pointing out “unsafe” parenting practices such as cosleeping, which are considered healthy and expected of new mothers in my eastern culture.

To strive against traditional power imbalances present in academia (historical exclusion of persons with intellectual disabilities from research) and avoid my own biases and assumptions to interpret the lived experience of parents, I was intentional about the inclusion of a co-researcher with lived experience in key aspects of this research. For example, while co-creating the interview guide, the co-researcher challenged the wording of specific questions about participants' child protection experiences to be more sensitive to intense emotions (decisions such as starting with a very broad question to allow participants time and space to share their story). The co-researcher's guidance was integral in removing unintentional/inadvertent judgement from child protection questions and allowed participants to open up in a way not possible without the co-researcher's insider experience. Using inclusive methods significantly increased accessibility of this research and allowed me to demonstrate true reflexivity within this dissertation.

CHAPTER 3:**Accessibility of child protection investigations during pandemic: A qualitative analysis
of court proceedings**

Tahir, M., & Cobigo, V. (2023). Accessibility of child protection investigations during pandemic: A qualitative analysis of court proceedings. *Journal of Applied Research in Intellectual Disabilities*, 36(2), 343-353.

ABSTRACT

Background: Qualitative research using published court records to examine contextual factors that contribute to child protection decisions in cases involving parents with intellectual disabilities is limited, particularly during the COVID-19 pandemic.

Method: The present study conducted qualitative content analysis on 10 published Ontario court cases to study child protection decision-making between 2019 to 2021.

Results: The findings corroborated previous literature with nine out of 10 cases resulting in loss of child custody. Four major themes emerged from content analysis: 1) Impact of COVID-19 pandemic on cases; 2) Systemic barriers to accessibility; 3) Attitudes and bias toward parents with intellectual disabilities; and 4) Ultimate reliance on intellectual disability status for final custody decision.

Conclusions: Conducting content analysis on published court cases is useful in learning about accessibility barriers for parents with intellectual disabilities and may help in understanding the impact of the COVID-19 pandemic on the child protection system.

Keywords: Child protection; parents with intellectual disabilities; published court cases; qualitative analysis of court cases; social impact of COVID-19; cognitive accessibility

INTRODUCTION

Parents with intellectual disabilities are often overrepresented in child protection investigations (Booth & Booth 2004a; Booth & Booth, 2005; McConnell et al. 2011, McConnell et al. 2021). An analysis of the Canadian Incidence Study (CIS-2003) found that over 10% of all child maltreatment investigations in Canada, which translates to over 22,000 children, involved parents with intellectual disabilities (McConnell, Feldman, & Aunos, 2008; McConnell, Feldman, Aunos, & Prasad, 2011). This is a high number for parents with intellectual disabilities, considering that the prevalence of intellectual disability in the adult population is estimated to be 1% (Lin et al. 2014). Prejudiced attitudes toward parents with intellectual disability and systemic barriers contribute to these statistics (Aunos & Feldman, 2002; Aunos, Goupil, & Feldman, 2003; McConnell et al. 2011; McConnell et al. 2021). However, systemic barriers to accessibility in the child protection system, such as transportation (e.g., Findley & Crutchfield, 2022), and cognitive accessibility barriers, have not yet been extensively studied. These barriers might have been exacerbated during the COVID-19 pandemic as we relied on virtual means of communication. This paper examines child protection decision-making in court cases immediately before and during the COVID-19 pandemic, involving at least one parent with intellectual disability.

International scholars have conducted extensive research in the area of child protection court involvement for parents with intellectual disabilities and repeatedly demonstrated their overrepresentation in child protection investigations, with over 15% of cases involving at least one parent with intellectual disabilities (Booth & Booth, 2004a; Booth & Booth, 2004b; Booth, Booth, & McConnell, 2004; Booth & Booth, 2005; Booth, McConnell, & Booth, 2006). These cases continue more frequently initial report, and are kept open for longer, even when child

maltreatment claims are not substantiated, compared to parents without intellectual disabilities (McConnell et al. 2008; 2011; 2021). Brown et al. (2018) found that almost 6% of newborns born to women with intellectual disabilities were discharged to child protection services compared to only 0.2% of newborns of women without intellectual disabilities.

When a parent involved in child protection is found to have intellectual disability, the case is often treated differently, and factors that would be weighed heavily in other cases such as history of prior involvement with child welfare agencies and nature of the child maltreatment concern, do not influence custody outcomes as much as having intellectual disability (McConnell et al. 2020). Parents with intellectual disabilities are often involved in complex social situations, such as single parenthood, poor or unstable housing, low-income status, substance abuse and more, which can adversely impact parenting style and parent-child interactions (Aunos, Feldman, & Goupil, 2008; Darbyshire & Kroese, 2012). Furthermore, parents with intellectual disabilities often describe challenges in understanding the court process and no accommodations are provided for cognitive accessibility (Booth & Booth, 2005; Cox, Kroese, & Evans, 2015). Canadian parents with intellectual disabilities are not referred to suitable parenting programs tailored toward supporting parents with intellectual disabilities as often as they are in the United States of America (McConnell et al. 2021; Slayter & Jensen, 2019).

Although research has demonstrated that IQ alone does not predict parenting capacity (e.g., Tymchuk, 1992), the diagnosis of intellectual disability and IQ scores continue to be used in parenting capacity assessments ordered by courts (Callow et al. 2016; Aunos and Pacheco, 2020). Often, when a parent with intellectual disabilities is involved in a child protection investigation, there is a hasty assumption that they are incompetent parents and the appropriate assessments may not be pursued to substantiate claims of child maltreatment (Feldman & Aunos,

2010; Mayes & Llewellyn, 2012; Aunos and Pacheco, 2020). The optimal way to assess parenting capacity is by completing a comprehensive assessment rather than psychological testing (Feldman & Aunos, 2010).

The perspectives of parents with intellectual disabilities as well as attitudes of professionals involved in child protection cases have also been studied using qualitative methods (Booth & Booth; 2004b; Sigurjónsdóttir & Rice, 2016; 2017; Rice & Sigurjónsdóttir, 2018). In a recent Iceland-based study (Sigurjonsdottir & Rice, 2017), the authors selected a sample of 56 national published court cases, between 2002-2014, to conduct a content analysis, following a grounded theory approach. They found that court professionals tend to assume that having intellectual disability precludes parents from ever having sufficient parenting capacity.

The prejudice faced by parents with intellectual disabilities in the child protection system is well-documented. It is imperative that we continue efforts to analyze child protection decision-making in diverse social contexts to prevent unnecessary parent-child separation that can be damaging for both parents with intellectual disabilities and their child, while keeping children's rights paramount. The present study contributes to the extant literature in this area by conducting a qualitative content analysis of published family court cases in Ontario, Canada, involving parents with intellectual disabilities. Only a handful of studies in English-language scholarship have conducted qualitative content analysis on published court cases to investigate custody and placement decisions made regarding children of parents with intellectual disabilities (Galliher, 1973; Glaun & Brown, 1999; Sigurjonsdottir & Rice, 2017).

Moreover, there are currently no studies examining the impact of the COVID-19 pandemic on parents with intellectual disabilities underdoing child protection investigations, particularly its effect on cognitive accessibility. Cognitive accessibility includes provision of

accommodations such as translating documents into plain language, providing visual aids, offering flexibility in schedules and timing, and other “cognitive ramps” for persons with intellectual disabilities (Yalon-Chamovitz et al. 2016; Cobigo et al. 2022). A recent conference proceeding on creating a cognitive accessibility toolkit for parents with intellectual disabilities specifically for access visits (including means for engagement, comprehension, and action) while involved in child protection is one of the first efforts in this area (Janeslätt, Springer, & Hammerin, 2019). Recent research on the impact of the COVID-19 pandemic on the child protection system overall has demonstrated that already-present issues in the system have been significantly exacerbated, such as suspension of in-person visitation, limited access to supports and cancellation of services for families and resources for frontline workers (Pisani-Jacques, 2020). The present study examined cases from one year before the COVID-19 pandemic and cases during two years of the pandemic.

The primary research questions are: 1) What individual, social and systemic factors influence decision-making in cases involving parents with intellectual disabilities, as identified in published court cases? 2) How has the COVID-19 pandemic impacted the involvement of parents with intellectual disabilities in child protection, particularly in terms of accessibility?

METHOD

Selection of Court Cases

In this study, the law databases Westlaw Next Canada and CanLii were used to search for family court case proceedings in which parents’ intellectual disability status was mentioned, and published between the years 2019 to 2021 in Ontario, Canada. It should be noted that parents with intellectual disabilities constitute a socially complex group and are described using a myriad of terms (IASSIDD, 2008), which are reflected in the search strategy. A range of keywords were

utilized to obtain the most inclusive results. In collaboration with a university law librarian, the list of keywords generated for the search included “cognitive impairment(s)”, “cognitive disability(ies)”, “mental deficiency”, “mental retardation”, “intellectual disability(ies) or impairment”, “developmental disabilities”, and “developmental delay.”

Data Analysis

All published case proceedings were imported into QSR NVivo 12 for analysis (QSR International, 2022). Case documents were analyzed using content analysis (Roller & Lavrakas, 2015). As a first step, an a-priori coding structure was developed using broad parameters, including demographics, type of case, main child protection concern, final custody decision, case timelines, and evidence used to support the case, to establish initial codes. The coding structure evolved with further rounds of data analysis. While developing the a-priori coding structure, the primary researcher consulted a child protection lawyer to ensure accurate interpretation of legal terminology.

Each case was analyzed several times to identify categories across codes, identify themes and patterns. Each code was mutually exclusive and allowed for data organization and preparation of data for refined analysis. Interpretations were drawn based on the themes identified (Saldana, 2021; Miles, Huberman, & Saldana, 2018).

Being mindful of the debates regarding the use of intercoder reliability (ICR) in qualitative analysis (O’Connor & Joffe, 2020; Yardley, 2000; Nowell et al., 2017), ICR was not calculated for this study since it is most often recommended for large projects involving several coders. It should be noted that reporting an ICR score for a study with a small sample could provide a false sense of transferability or strength of the evidence. An iterative audit process was used to foster reflexivity and dialogue among team members, as required for the trustworthiness

and dependability of data analysis and interpretation. The audit process involved two senior researchers (the first and second authors) who were familiar with the data and analyses. Regular audit meetings were held to provide an opportunity to discuss the creation of codes, themes, and specific definitions. Constant comparison with the original dataset was done to increase the trustworthiness of the analysis.

FINDINGS

A total of 10 cases that met the inclusion criteria were found between the years 2019-2021 and all were included in this study ($N=10$). The total pages in each case reviewed ranged from 10 to 53. See Table 3.1 for a case summary and demographics information, and Appendix A for each case citation.

Four major themes emerged from content analysis of the data: 1) Impact of COVID-19 pandemic on cases; and 2) Systemic barriers to accessibility for parents with intellectual disabilities; 3) Attitudes toward parents with intellectual disabilities; and 4) Ultimate reliance on intellectual disability status for final custody decision. All themes and sub-themes are summarized in Table 3.2 below.

Impact of COVID-19 pandemic on cases

6 out of 10 cases analyzed were ongoing during the COVID-19 pandemic. An exploration into the impact of the COVID-19 pandemic on child protection scenarios for parents with intellectual disabilities showed how systemic barriers for parents with intellectual disabilities may be exacerbated during a global pandemic.

Table 3.1
Summary of Cases and Demographics

Case number	Type of Case	Temporary vs. Extended†	Parents Involved	Age of Parents	Age of child in the case	Age of child when removed	Other children	ID Status	Child Protection Concern	Final Decision
1	Summary Judgement	Extended	Mother and father	Mother - 29 years Father – not listed	1 year	At birth ‡	3 other children – aged 10, 5 and 3 years	Intellectual Disability (mother)	History of involvement with child protection, denial of pregnancy	Paternal grandparents granted custody of the child
2	Summary Judgement	Extended	Mother and Father	Mother – 29 years Father – 46 years	1 year	At birth	expecting another child	Developmental Delay (mother and father)	Neglect (risk of)	Extended society care
3	Summary Judgement	Extended	Mother and father	Not listed for mother or father	4 years <i>Child is Indigenous</i>	2 years	none	Borderline intellectual functioning (father)	Substance abuse, unsafe home environment, neglect	Extended society care
4	Appeal	Extended	Father	Father – 31 years	4 years	At birth	1 other child – aged 10 years	Mild intellectual delay (father)	Neglect	Extended society care at trial and no access at appeal
5	Trial	Extended	Mother and father	Father – 41 years Mother – not listed	4 years and 5 years <i>Children are Indigenous</i>	2 years and 3 years	2 other children – 2 and 1 years	Limited cognitive functioning (mother and father)	Neglect, domestic violence, unstable housing, criminal involvement	Extended society care
6	Temporary Custody Motion	Temporary	Mother and father	Not listed for mother or father	2 months	2 months	4 older children under 6 years	Cognitive limitations (mother)	Neglect, domestic violence	Temporary custody granted to Children’s Aid Society
7	Summary Judgement	Extended	Mother and father	Mother – 31 years	2 years	At birth	None	Mild to moderate intellectual	Neglect	Extended society care

				Father – 37 years				disability (mother) mild range of mental retardation (father)		
8	Summary judgement	Extended	Mother and father	Not listed for mother or father <i>Father is Indigenous</i>	Less than 2 years <i>Child is Indigenous</i>	At birth	3 – ages not listed	Developmental delay (father) Autism and bipolar disorder (mother)	Neglect, domestic violence, criminal involvement	Extended society care
9	Trial	Extended	Mother	Mother – 39 years	3 years	2 months	None	Mild intellectual disability	Neglect	Returned to parent
10	Trial	Extended	Mother	Mother – 18 years	2 years	At birth	None	Mild intellectual disability	Neglect, substance abuse during pregnancy	Extended society care

Table 3.2*Themes and Subthemes*

Major Themes	Sub-Themes
Impact of COVID-19	Longer case timelines
	Inaccessible virtual access visits
	Lack of attachment
Systemic barriers to accessibility for parents with intellectual disabilities	Forms
	Access visits
	Instructions given
	Unsuitable parenting programs
Attitudes and bias toward parents with intellectual disabilities	Child protection workers' and other professionals' bias
	Extended family's bias
	Parents' own view of themselves
	Judge's impartiality in considering evidence
Ultimate reliance on intellectual disability status for custody decision	Intellectual disability often mentioned first or as a key deciding point
	Parenting capacity assessments focused on intellectual disability
	Primary child protection concern for this group of parents seems to be neglect

Longer case timelines. Due to nationwide lockdowns and emergency measures in 2020, resolution of child protection cases was inevitably delayed. This resulted in a long separation between parents and children who were removed from custody, thereby not affording the family a chance to rebuild:

Case 9: I am very mindful of the length of time that S. has been in society care and that he has been in care well past the statutory time limits. A significant part of this delay was caused by the global pandemic, an exceptional circumstance not anticipated by anyone. This trial was scheduled to proceed in the spring of 2020 but was adjourned to the fall sittings as a result of the suspension of regular court operations following the Ontario government's declaration of a state of emergency. Regular access visits and the ability to assess the mother's parenting of the child was also disrupted for several months.

Inaccessible virtual access visits. The pandemic also resulted in long-lasting social distancing measures and use of digital technology for meetings, and for socialization, became commonplace, which meant that parents were expected to have reliable internet and be able to use digital platforms without training and support. Furthermore, virtual visits compounded the gap in the parent-child relationship, particularly with young children who are unable to attend to screens for long periods:

Case 10: Between April 2020 and April 8, 2021, mother was having periodic virtual access visits with T.K. However, she was not always able to connect, or she missed her appointments. While the quality of those visits was inconsistent, they often went reasonably well. However, mother kept requesting in-person visits.

Lack of attachment. Another unfortunate consequence of the COVID-19 pandemic, as demonstrated through the case below, is the lack of reconciliation between new unforeseen circumstances and pre-pandemic benchmarks for parent-child attachment. Given the lack of contact between parents with intellectual disabilities and their children during the pandemic, a judgement recommending extended society care (or "crown wardship") due to lack of bonding and attachment should be unsubstantiated, as seen below:

Case 7: The child is over two years old and has never been in the care of her birth parents but for 16 days or so. She requires stability and the opportunity to bond (or continue to bond) with a family.

Case 10: Mother's infrequent in-person and virtual visits have not enabled any real bond or relationship to develop and to be maintained.

Systemic barriers to accessibility for parents with intellectual disabilities

In all cases reviewed, there was a marked absence of accessibility considerations. It is difficult to ascertain to what extent parents with intellectual disabilities involved in a child protection case understood what was happening, what to expect and how the decisions made by caseworkers, experts (e.g., psychologists or medical professionals), and the court judge affected them and their family. In many cases this lack of accessibility accommodations within the child protection system may have been misconstrued as noncooperation and refusal to follow through with demands set by caseworkers or court.

Forms. In the Ontario child protection system, parents are expected to complete Form 33B.1 (Answer and Plan of Care) when they come under investigation by Children's Aid Society. Although the "plan of care" is mentioned numerous times across all 10 cases, it is unclear whether parents understood all parts of the form, if they had any support in completing the form, or the information they were expected to provide, and where they could seek help with completion of forms, if needed:

Case 8: S.D. is not presenting a plan to care for the child. She seeks an Order for access with the child. As per the Minutes, S.D. takes no position with regard to the ultimate disposition, except as it relates to her access with the child.

This absence of accessibility consideration can also be noted when signing other documents, such as the Temporary Care Agreement, as seen in case 2021 ONCJ 258:

Case 9: "He [caseworker] believed that the mother was capable of signing the TCA [Temporary Care Agreement] even though he acknowledged that he had wondered if the mother had a learning disability.

Access Visits. Similar to completion of forms, a lack of consideration for accessibility is evident in arranging access visits for parents with intellectual disabilities. There was a lack of reminders about access visits, limited flexibility in scheduling and other logistical issues. This is seen in the appeal case for access visits below:

Case 8: J.L. does not recall his visits being increased to twice per week in October 2019. He does not recall the reason for his missed visits in November 2019.... J.L. does not recall that the Society had asked him to provide medical notes for his missed visits nor has he offered to provide them.

Instructions given. There was a disconnect between the instructions parents with intellectual disabilities were given by workers and parents' comprehension of the instructions and the actions they were expected to demonstrate. In several cases, when parents with intellectual disabilities struggled to understand what they were being told, they were presumed to be noncooperative or lacking capacity to parent as a result of their disability. As seen in the case below, no further attempts were made to communicate child protection concerns in a clear and accessible manner:

Case 7: The Mother, on behalf of the parents, has made it clear that she does not understand why J. cannot be in their care and regularly references the state of their home, which is just one of the CAS's concerns.

Unsuitable parenting programs. Parents with intellectual disabilities were referred for group-based or other unsuitable parenting interventions, which were not tailored for learners with ID. As a result, it is possible that no significant improvements in parenting skills were noted, as demonstrated below:

Case 5: Ms. T did not provide formal parenting instruction to the parents after October 2018 as the parents indicated that they did not wish to receive parenting instruction from the Society and were seeking parenting instruction from a different program.

In the case below, the parent was not referred to any parenting programs and the parent took it upon herself to see parenting education:

Case 9: On her own, the mother proactively attended and successfully completed two parenting programs: “Make the Connection, Birth to One” and the Nobody’s Perfect Program, both of which she completed in the summer of 2019. Neither of these programs were referred or arranged by the society.

Attitudes toward parents with intellectual disabilities

Biased attitudes toward parents with intellectual disabilities and their perceived ability to parent emerged as a key theme in the data. Most people involved in the lives of parents with intellectual disabilities lacked confidence in their ability to parent, including parents with intellectual disabilities themselves.

Professionals’ attitudes. Professionals, including child protection workers, medical professionals (doctors and nurses), and sometimes community support workers, were apprehensive of the parent’s parenting capacity and their future ability to care for their children. In some cases, once intellectual disability was identified, it was unduly used as a reason to explain a multitude of co-occurring problems in a case, whether or not related to the disability, without pursuing further inquiry. For example, in the case below, an observation is made about a parent under immense scrutiny “zoning out” during access visits; however, no medical information is obtained (e.g., to rule out seizures) and no efforts are made to check in with the parent:

Case 9: A number of workers observed that there were moments during the access visits when the mother appeared to be “zoning out”. The mother would start to stare at the wall and seemed to be unaware of S.’s needs in that moment. It was unclear why this was happening. However, these lapses did not last for more than 5 to 10 seconds at a time.

Extended family’s attitudes. Family members and relatives of parents with intellectual disabilities were often opposed to parents with intellectual disabilities in retaining custody of

their children and did not support the plan to continue parenting their child. In some cases, extended family members refused to take custody of the child, which resulted in the child not retaining any family ties when being placed for adoption:

Case 3: Unfortunately, none of the 10 individuals proposed agreed to move forward with the formal kinship assessment by the society.

Parents' own view of themselves. There was variability in how parents with intellectual disabilities viewed their own ability to parent, with some parents described as strongly expressing their desire and ability to provide adequate care for their child, while others were described as recognizing that they cannot parent due to their disability:

Case 2: The parents both admit that they have some challenges; however, they argue that the positives of each parent compensate for the negatives.

Case 10: To mother's credit, she recognizes that she is not in a position to parent T.K. on her own.

Judge's impartiality in considering evidence. The manner in which evidence was analyzed and weighed in court varied across judges. Some judges considered parenting capacity to be synonymous with intellectual functioning and therefore concluded that it is a static trait, unlikely to change and the parent could not improve their parenting skills due to 'developmental delays' as seen below:

Case 7: The parents have developmental delays which affect their reasoning skills and their ability to gain the knowledge required to parent J. through her changing developmental states.

One case was distinct in how the judge handled the evidence brought forward by the parent, which also influenced the analysis of the case and ultimate conclusion that the parent with ID was not given a chance to provide adequate parenting. This case also stood out in terms of the parenting capacity assessment, which was reviewed and critiqued by a psychologist retained by the parents themselves:

Case 9: I find that the society did not give the mother an adequate opportunity to parent. I find that the society concluded that the mother was incapable of parenting without accurately assessing the mother's parenting capabilities or providing the mother with the services necessary, including community services, to support her parenting of S.

Ultimate reliance on intellectual disability status for final custody decision

Despite each case presenting a detailed and thorough analysis of all psychosocial and environmental factors impacting parenting capacity, with affidavits and official reports, intellectual disability status was ultimately used as a key deciding point, in all but one court case.

Intellectual disability status mentioned as key deciding point. As indicated in the cases below, a diagnosis of intellectual disability was one of the primary concerns highlighted by the child protection agency seeking to permanently remove child custody from parents with intellectual disabilities:

Case 1: El. was removed from the mother's care on or about May 27, 2015 due to concerns regarding the mother's developmental delays, condition of the home and concerns regarding domestic violence. El. currently resides in the care and custody of the maternal grandmother.

Case 5: The concerns relate to transiency, neglect, domestic violence, parental capacity and the parents' low intellectual functioning.

Parenting capacity assessments focused on intellectual disability. Psychological assessments and IQ testing to assess parenting capacity were frequently used in the cases reviewed, as demonstrated below:

Case 2: Both parents have significant cognitive delays and [psychologist] concluded that the parents are not able to meet the needs of the children currently or over the long-term and that the high needs of the children are beyond the parents' capacity. It was also [psychologist's] opinion that any intervention offered to the parents is likely to be unsuccessful.

Primary protection concern was neglect. Neglect can be complex to evaluate because in many neglect cases, no actual harm has been demonstrated but the risk may be moderate or high.

There were several cases where parenting behaviours seemed typical of new or overwhelmed parents (e.g., ‘mom was on the phone’ or ‘dad fell asleep on bed with baby’).

Case 6: The position of the applicant is that the child would not be safe in the care of either parent because of the substantial risk of being exposed to domestic conflict or violence, and neglect of physical and emotional needs. The child has high medical needs requiring regular physician and hospital attendances. The child is in a body cast to correct the alignment of his leg.

However, there were at least two cases in which neglect caused actual harm (e.g., tooth decay from dental neglect, severe diaper rash due to unchanged diapers).

DISCUSSION

In nine out of the 10 cases reviewed in this study, parents with intellectual disabilities lost custody of their child, eight cases being permanent custody. In six out of 10 cases, the child was apprehended by child protective services at birth. These findings are consistent with a long line of previous research showing custody deprivation as a result of the parents’ intellectual disability (Booth & Booth, 2004a; McConnell et al. 2011; McConnell et al. 2020; Brown et al. 2018; Mayes & Llewellyn, 2012; Aunos and Pacheco, 2020; Callow et al. 2016), as well as judges’ negative attitudes (Sigurjonsdottir & Rice, 2017).

Aligned with previous research, neglect was the primary child protection concern, rather than other types of child maltreatment such as physical abuse (Booth & Booth, 2005; Slayter & Jensen, 2019). Bias and prejudice toward parents with intellectual disabilities was also demonstrated, similar to previous research (Aunos & Feldman, 2002; Slayter & Jensen, 2019).

Impact of COVID-19 Pandemic

This is the first study to explore the effects of the pandemic specifically on child protection cases involving parents with intellectual disabilities. The findings reveal a clear intensification of already-present systemic barriers for parents with intellectual disabilities

involved in child protection (Renov et al. 2022; Brown et al. 2022; Ferguson et al. 2022). The pandemic called for nationwide lockdowns, resulting in a sudden freeze on social and community services, and naturally leading to longer child protection case timelines (Goldberg et al. 2021). Children removed from their homes remained in custody for longer than they would have pre-pandemic, leading to missed or infrequent opportunities for parent-child contact (Pisani-Jacques, 2020). The sub-theme of longer case timelines is not a novel phenomenon for parents with intellectual disabilities, although it has been pushed into the limelight during the pandemic. Booth et al. (2006) described time as a “hidden dimension of discrimination” as deadlines and time limits enforced by the child protection system on parents with intellectual disabilities are often unmanageable and present major cognitive accessibility barriers, as identified by several recent studies (Cox et al. 2015; Collings et al. 2018).

Additionally, family access visits were entirely virtual for a period of time, which could be inaccessible for parents with intellectual disabilities, who may not have access to reliable internet or fully functional devices (Chadwick et al. 2022). Virtual access visits may also not be as meaningful for very young children who cannot attend to a screen, for even short periods of time. Considering the great emphasis placed on parent-child attachment in family courts (Forslund et al. 2022), virtual access visits did not enable parents to form a meaningful bond with their children. Despite the changes in case timelines and access visits, good enough parenting and parent-child attachment were measured with the same pre-pandemic yardstick (Goldberg et al. 2021), which unwittingly placed blame on parents with intellectual disabilities for circumstances that were out of their control. Further research is needed on how the COVID-19 pandemic impacted child protection decision-making for parents with and without intellectual

disabilities, to understand differences, if any, and to identify gaps in services for vulnerable families that could not be preserved due to factors heavily influenced by a global emergency.

Accessibility Considerations

Throughout the 10 cases analyzed, there is a marked absence of accessibility considerations, resulting in systemic barriers that stack the deck against parents with intellectual disabilities in child protection investigations. Parents with intellectual disabilities have expressed being mystified by legal procedures and court proceedings, not having adequate legal support, feeling severely anxious and depressed after an investigation began and even deciding on sterilization to avoid future pregnancies (Booth & Booth, 2005). Albert and Powell (2020) recommended increasing resources not only for parents with disabilities (including intellectual disability) but also resources for the child welfare system to increase knowledge and training on providing individualized support tailored to the needs of the parents.

As mandated by Articles 13 and 23 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), we recommend that parents with intellectual disabilities be provided with appropriate accommodations for cognitive accessibility in legal procedures and in all family services provided, including parenting education, court processes and access visits (similar to Janeslätt et al. 2019). Below are some broad considerations for cognitive accessibility in the child protection system:

- All forms to be completed and documents to be signed should be in Easy-Read format (Sutherland & Isherwood, 2016) or plain language as outlined by the Government of Canada (Government of Canada, 2021). Information should be explained to parents with intellectual disabilities in accessible language.

- The logistics of access visits should be explained to parents with intellectual disabilities in accessible language and additional reminders for visits (e.g., helping them set alerts on their phone) may help with consistent attendance. Flexibility in location and scheduling of access visits should be offered and accessibility of transportation as well as digital systems should be considered when scheduling visits.
- Child protection workers involved with parents who have intellectual disabilities should receive some basic training to understand the cognitive challenges associated with intellectual disability and how to deliver instructions in an accessible manner (such as short and direct instructions to be effective). It is also important to ask comprehension questions to ensure understanding. Lawyers representing the interests of parents with intellectual disabilities should follow the same recommendations and have access to similar training (Atkin & Kroese, 2022).
- Accessible resources (videos or pictorial brochures) should be developed to explain how a child protection case works so parents with intellectual disabilities can understand what happens at each step, what is expected of them, and what each decision means for their family and future.
- Lastly, parents should be referred to appropriate individualized parenting programs that are evidence-based for intellectual disabilities (Feldman, 1994; Wade et al. 2008) rather than generalized group-based parenting education in the community, which parents are primarily referred to.

“Cherry-Picking” of Evidence-Based Practices

There was a lack of clarity in the standards of evidence-based practices that were being used by child protection workers, court judges and other professionals. Subjective language was

often used, leading to seemingly arbitrary decisions about specific evidence-based practices. None of the parents were referred to individualized parenting programs, which are evidence-based for parents with intellectual disabilities (Feldman, 1994; Wade et al. 2008). In many cases, parents were not referred to suitable parenting programs and either received instruction from the protection worker or were referred to a community-based program that was unlikely to be effective for parents with intellectual disabilities. This lack of knowledge regarding appropriate service referrals and lack of inclusive services, has also been demonstrated in previous research (Pacheco et al. 2022) and must be addressed to avoid future scenarios in which the fate of a family is at risk when specialized resources could allow the family to stay together (Adolfsson et al. 2021).

Similarly, parenting capacity assessments were mostly based on psychological testing and measures of intellectual functioning, which contradicts best practices. Parenting capacity assessments should include data from multiple objective sources, should not constitute an IQ assessment (APA, 2010) and should include direct behavioural observations of parent-child interactions (Feldman & Aunos, 2010). Aunos and Pacheco (2020) found that child protection workers often concluded that parents with intellectual disabilities did not possess the capacity to provide adequate parenting compared to assessors from specialized developmental support agencies. This was observed in the single court case in which the parent retained their own parenting capacity assessor who specialized in this area.

Parent-child attachment was described as an evidence-based concept in the cases reviewed. The first year of life is crucial in establishing parent-child attachment (Seiffer et al. 1996; De Wolff & Van Ijzendoorn, 1997) and parents with intellectual disabilities in the reviewed cases were not always afforded this integral opportunity. In six out of 10 cases, the

child was apprehended at birth, limiting opportunities for the parents to build an attachment relationship with their very young child. The period immediately after birth is crucial for parent-child bonding and immediate removal of newborns can result in maternal suicide and child developmental problems (Brown et al. 2018).

Similarly, there was ambiguity in defining ‘good enough parenting’, which is consistent with the literature on what constitutes good parenting. Although there is agreement that good parenting involves putting the needs of the child first, unconditional love, and setting boundaries, it is a complex construct to define and often open to interpretation (Taylor et al. 2009; Choate & Engstrom, 2014). No definition or behavioural indicators for good enough parenting were provided in most cases. Without established standards, it is left up to the child protection professionals to exercise their judgement, which can mean great levels of scrutiny for parents involved in child protection. For example, one father with intellectual disabilities was censured for falling asleep in bed with his infant, a common occurrence for new and overwhelmed parents (Bartick & Smith, 2014), and in fact, a cultural practice for some others (Baddock et al. 2019; McKenna & McDade, 2005). It is crucial to provide a balanced picture and parse out decisions unduly made based on the parents’ intellectual disabilities versus decisions made due to substantive child protection concerns.

Strengths and Limitations of the Study

This study carried out content analysis on public case records, which has not been done extensively, with the focus previously being on quantitative analysis of court records. Qualitative content analysis allows for a deeper understanding of the social context surrounding child protection decisions, as demonstrated by earlier qualitative work on court cases (Booth & Booth; 2004b; Sigurjonsdottir & Rice, 2017). One advantage of conducting content analysis on open-

source publicly available court data is that it eliminates the discomfort of highly sensitive discussions that may occur in other qualitative methods, such as interviews. It also mitigates privacy concerns, especially for parents with intellectual disabilities who may feel immensely vulnerable and hesitate to participate in this type of research to avoid scrutiny. Since many of the findings of this study are aligned with previous literature, using published court cases can diminish the need to seek out full case records (such as assessment reports, meeting minutes, observation notes) that may require multiple approval processes to obtain access. However, it must be noted that published court cases are edited for inclusion in public record and full case records, when accessible, do offer a much richer and more complete picture of the child protection case.

The research objectives that can be targeted when utilizing court cases as a primary data source can be limited. This method is insufficient to understand parents' lived experience and precise contextual information (such as support network, access to services, and personal history) for each case could be missing or incomplete. Only information that is published can be analyzed and access to all referenced case documents may not be possible.

Another limitation is the lack of consensus in terminology used to describe parents with intellectual disabilities in court cases. Parents should be identified in consistent terms (i.e., a diagnosis based on the Diagnostic and Statistical Manual of Mental Disorders, DSM-5, as per the American Psychiatry Association, 2013). Most parents with intellectual disabilities are in the hidden majority, who may not be formally diagnosed with an intellectual disability, and may or may not be receiving developmental support services. As a result, cases involving parents who are mislabeled may not appear in court case search results, causing relevant and informative cases to be missed. Furthermore, some cases may have several other connected cases from

previous years that were not examined in this study. Lastly, this exploratory study examined a small number of cases and may not represent the diversity of cases that occurred as a result of changes to the justice system during the COVID-19 pandemic.

Conclusion

Further studies should continue to conduct qualitative content analysis on published court cases to examine changes in child protection decision-making during the post-pandemic era, with special attention paid to cognitive accessibility. To represent the multi-faceted identities of parents with intellectual disabilities, future research should include considerations of intersectionality. A phenomenon encountered in this study, but not explored further due to scope, is the process and outcome of cases in which parents have both intellectual disability and Indigenous background. This is particularly important in a Canadian context, as many parents met both criteria (See Table 5.1). Ontario law (*Child and Family Services Act*, 2017) states that children of Indigenous background in protective custody must be placed with kin. These cases present a complex decision-making scenario, which has not yet been explored in the literature.

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CHAPTER 4:**“I don’t think I have ever worked harder on a case”: Needs of Canadian child protection workers and parents with intellectual disabilities**

Tahir, M., & Cobigo, V. (2024). “I don’t think I have ever worked harder on a case”: Needs of Canadian child protection workers and parents with intellectual disabilities. In press for a special issue on parenting in *Journal of Applied Research in Intellectual Disabilities*.

ABSTRACT

BACKGROUND: The current literature has established that prejudice in child protection cases with parents with intellectual disabilities continues to persist. However, complexities of these cases are not well-understood from the perspective of child protection workers. This study aimed to identify the needs of child protection workers and their views on the factors that influence supports for parents with intellectual disabilities.

METHOD: This qualitative study conducted semistructured interviews with child protection workers who have worked directly with parents with intellectual disabilities across five child protective agencies in three regions in Ontario, Canada ($n=11$).

RESULTS: Three major themes emerged after content analysis of interviews: 1) training and support needs of child protection workers; 2) key sources of support for parents; and 3) intersecting factors impacting decision-making.

CONCLUSION: Agencies within the social services sector continue to be fragmented and better coordination across agencies is needed to meet the cross-sectoral needs of parents with intellectual disabilities.

KEYWORDS: child protection; parents with intellectual disabilities; training needs of child protection workers; intersectoral collaboration; intersecting social factors; supports for parents with intellectual disabilities

LAY SUMMARY

- The goal of this study was to find out what child protection workers think of working with parents with intellectual disabilities.
- We asked 11 child protection workers in Ontario, Canada, about what they find hard and how they get help when working with parents with intellectual disabilities. We also asked them what they think helps families stay together.
- Workers told us that having a healthy partner, family members, and other support services was very important for parents to keep their family together. We also found that workers did not take kids away from parents only because of intellectual disability. They also considered mental health, substance use, and other issues before making decisions.
- Child protection workers have a heavy workload and may get burned out. We need more research to find out how they can be better equipped to work with parents, lawyers and other professionals supporting parents with intellectual disabilities.

INTRODUCTION

There is a growing number of families headed by parents with intellectual disabilities in Canada and around the world (Lin et al. 2014; Man et al. 2017; Perez-Curiel et al. 2023). Despite increased prevalence and recognition of the rights of persons with disabilities to build a family (United Nations, 2006), parents with intellectual disabilities continue to be investigated by child protective services more often than parents without intellectual disabilities (McConnell et al. 2008a; 2011; 2021). Pacheco et al. (2022a) examined a sample of 15,980 child maltreatment investigations in Canada and found that 8% of all maltreatment cases involved parents with intellectual disabilities. These parents were referred to essential services such as financial assistance, mental health services and family reunification less often than parents without intellectual disabilities. Brown et al. (2018) found that 6% of newborns of mothers with intellectual disabilities in Ontario, Canada, were discharged directly from hospital to child protective services immediately after birth compared to less than 1% of newborns of mothers without intellectual disabilities. This statistic has not been updated in Ontario since the cessation of the Ontario birth alert system that required hospital staff and medical professionals to notify child protective services when a mother with intellectual disability arrived at the hospital to give birth (Government of Ontario, 2020). However, based on trend over the past several decades (e.g., Laliberte et al. 2024; Pacheco et al. 2022a), it can be expected that parents with intellectual disabilities continue to be overrepresented in child protection investigations.

Parents with intellectual disabilities may not always have a formal diagnosis of intellectual disability (International Association for the Scientific Study of Intellectual and Developmental Disabilities; IASSIDD, 2008; American Psychiatric Association, 2013). As indicated by IASSIDD (2008), they are often part of the “hidden majority” who are living in the

community without formal supports until they become parents and fall under the scrutiny of child protection services or other community service providers who may identify parenting challenges. This is when intellectual disability may first be suspected or identified, albeit with challenges due to inconsistent or missing information on parental history and characteristics. Parents with intellectual disabilities also form a heterogeneous group and may not fit neatly into one category, further complicating identification of intellectual disability. Feldman and Aunos (2020) presented and partially validated a contextual-interactional model of parenting, based on ecological and developmental approaches. The authors demonstrated that parenting ability is not a static trait impacted by intellectual ability but rather a complex and dynamic set of skills influenced by myriad sociocultural factors including social support and services, parental mental health, financial stability, history of abuse and trauma and life crises such as death and illness, amongst others. However, years of research has shown that intellectual disability is often conflated with lack of parenting capacity (e.g., Feldman & Aunos, 2020; Tahir & Cobigo, 2023; Aunos et al. 2024).

Social work with families headed by parents with intellectual disabilities is often complex and demanding (Jones, 2013), but relationship-based social work has immense benefits for families receiving child protection services (Marsh et al. 2012; Smithson and Gibson, 2017; Tilbury and Ramsay, 2018; Lehtme and Toros, 2020; MacIntyre et al. 2019; Tarleton and Turney, 2020; McGaw and Newman, 2005). When child protection workers build rapport and trusting relationships with parents involved in child protection investigations, it dramatically improves family outcomes including improved parental self-efficacy, improved parent-child interactions, and greater likelihood of family preservation (Tilbury and Ramsay, 2018; Lehtme and Toros, 2020). However, child protection workers often experience great levels of stress,

burnout, and emotional exhaustion (McFadden et al. 2015). Workload and compassion fatigue significantly influence turnover of workers in child protection agencies (Cabiati et al. 2020; Griffiths & Royse, 2017). Child protection workers' feelings of being overwhelmed with the caseload, the time-intensive work required on complex cases and lack of support from senior leadership within the organization comprise the most critical factors impacting retention (Griffiths & Royse, 2017; Nilsen et al. 2023).

Prejudiced attitudes amongst child protection workers toward parents with intellectual disabilities are well-documented noting that workers frequently make presumptions about parental incompetence based on the intellectual disability (Proctor & Azar, 2013; Callow et al. 2011; Gur & Stein, 2020; Lightfoot et al. 2010; Lightfoot & LaLiberte, 2011; Proctor & Azar, 2013; Strnadova et al. 2017; Tahir & Cobigo, 2023); however, the nuances of these experiences are not well-captured in qualitative research. Proctor and Azar (2013) conducted a quantitative study that found child protection workers had lower feelings of distrust and anger toward parents with intellectual disabilities (compared to parents without intellectual disabilities), but also had higher feelings of pity and a greater likelihood of expressing that parents with intellectual disabilities will provide inadequate care for their children. Gunderson et al. (2013) highlighted findings from focus groups showing that child protection workers recognized the stigmatization experienced by parents with intellectual disabilities and the resulting lack of appropriate supports and services. Workers noted the need for specialized child protection services for parents with intellectual disabilities because traditional approaches to risk assessment and “good enough” parenting do not take into account the special circumstances of social disadvantage experienced by parents with intellectual disabilities (Gunderson et al. 2013).

Although the perspectives of social workers have been explored, there are only a handful of qualitative studies directly exploring the perspectives of child protection workers involved in investigations with families headed by parents with intellectual disabilities (Norlin and Randell, 2023; Albert and Powell, 2020; Lewis et al. 2015). For example, Lewis et al. (2015) presented key findings from interviews with seven social workers engaged in child protection work with parents with intellectual disabilities. These included feelings of “hopelessness” and not knowing how to help parents with intellectual disabilities, particularly for workers lacking training and education in intellectual disabilities. In addition to feeling “underskilled”, workers also experienced “feeling torn” between the needs of the children and the parents (Lewis et al. 2015). These studies explored child protection workers’ struggle with operationalizing “good enough” parenting (Norlin and Randell, 2023), identifying limitations in specialized services for parents (Albert and Powell, 2021) and views of parenting ability as intrinsic and “not something that could be taught” (Lewis et al. 2015). Most studies did not explore specific case challenges experienced by child protection workers and the specific mechanisms of support perceived as valuable by child protection workers for themselves and the parents with intellectual disabilities they support is still not well-understood.

Based on the existing gaps in understanding the views of child protection workers, the following research questions were posed:

- What are the needs of child protection workers when supporting parents with intellectual disabilities?
- What factors are perceived by child protection workers as influencing supports for parents with intellectual disabilities?

METHOD

Context of Social Services in Ontario, Canada

It is important to contextualize the social services sector in the province of Ontario, Canada, to situate the present study. The Ministry of Children Community and Social Services (MCCSS; Government of Ontario, 2024) oversees the delivery of developmental services (i.e., services for persons with intellectual disabilities) as well as child protection services. The two types of services are governed by distinct legislations, the former being governed by the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SIPDDA, 2023), and the latter being governed by the Child and Family Services Act (2017). Both are offered by local and independent agencies receiving funds from the same ministry. Child protection agencies and developmental service agencies operate separately, which may limit opportunities for collaboration and lead to challenges in effectively supporting families that receive services from both types of agencies.

Study Design and Recruitment

This qualitative study used a thematic analysis approach (Braun and Clarke, 2012; Terry et al. 2017) with constant comparison to stay close to the data (Dye et al. 2000). After receiving institutional ethics approval, child protection workers employed across five child protection agencies in three Canadian regions across Ontario were recruited using a combination of convenience sampling and snowball sampling (Fowler, 2014). The inclusion criteria to participate in the study were broad: 1) to be employed in a Canadian child protection agency and, 2) to be involved in child protection investigations involving one or more parents with intellectual disabilities, currently or in past years.

Procedure

Recruitment was open for six months and a total of 25 child protection agencies across Ontario were targeted for recruitment. Several agency-specific ethics review processes were completed in addition to institutional ethics approval. A total of 11 child protection workers agreed to participate in the study, across five distinct child protection agencies, serving rural and urban areas. After obtaining informed consent using a secure digital document signing service, virtual interviews were scheduled with participants on Teams or Zoom. The interviews were semistructured and an interview guide was utilized to explore participants' experiences. The interview guide included demographic questions (see Table 5.1 for a summary), questions inviting case descriptions, questions about training and support needs of workers as well as parents, and questions regarding challenges faced when working with parents with intellectual disabilities. Below is a sample of questions included in the interview, although follow-up questions were variable based on the semistructured method:

- What supports did you have access to as you worked on this case?
- Did you receive training on intellectual disabilities at your organization or elsewhere?
- What communication methods did you use with parents with intellectual disabilities?
- What type of questions did parents ask you during interactions regarding the investigation?
- What programs were parents referred to and what supports were they connected with?

Interviews were carried out by the first author and lasted between 45-90 minutes in total and were videorecorded with participants' consent and later transcribed by senior research assistants.

Data Analysis

The interview transcripts were uploaded into NVivo, a qualitative data analysis software, (Lumivero, 2024) for content analysis. The first author was immersed within the data and used a memoing strategy (Birks et al. 2008; McGrath, 2021) prior to a first round of coding to develop an initial coding structure, which was reviewed and validated with a senior researcher. The first author continued on to line-by-line coding to refine the coding structure and identify themes within the dataset. Constant comparison was carried out by categorizing “bits of data” based on similar experiences to form the initial coding structure. These codes were further refined using memos and conducting further rounds of cross-case analysis to identify opposite examples within codes and reorganizing codes to identify overall themes (Dye et al. 2000). Reliability scores were not calculated due to their questionable validity and usefulness based on relationships between junior and senior researchers (Yardley, 2000; O’Conner and Joffe, 2020). Instead of reliability scores, other procedures were utilized to ensure quality such as constant comparison, iterative review of the coding structure and transparent reporting procedures (Merriam and Tisdell 2015).

Table 4.1. *Participant demographics*

Pseudonym	Age	Education	Numbers of years employed in child protection work	Number of years at current agency	Number of cases involving parents with intellectual disability
Lena	53	Psychology	27 years	27 years	3 or 4 every year
Mary	58	Social work and minor in Psychology	Unsure	9 years	Estimated 2
Sam	30	Social work, criminology, psychology, certificate in dementia studies	1 year	1 year	6
Chris	32	Social work and minor in Psychology	9 years	9 years	5
Amaya	32	criminal justice (college), Arts in criminology (bachelor), Social work (bachelor and master)	6.5 years	6.5 years	3
Freda	46	sociology in women's studies and social work	22 years	20 years	10
Jim	58	Social work & child protection	27 years	21 years	Estimated 12-15
Beth	40	social service in college	4 years	4 years	9 at the time of interview; several in the past
Holly	32	Native child and family services	Unsure	4 years	1
Sandy	62	BA in literary and taught design for 20 years	5 years	5 years	1
Joanne	39	Child and youth care	16 years	16 years	Several – no specific estimate

Table 4.2. *Summary of themes and subthemes*

THEME	SUBTHEME
1. Training and support needs of child protection workers	1.1. Heavy burden and workload for workers to navigate supports
	1.2. No training provided on disability, particularly intellectual disability
2. Key sources of support for parents	2.1. Informal sources of support
	2.2. Formal sources of support
	2.3. Identification of intellectual disability as catalyst for support
3. Intersecting social factors impacting decision-making	3.1. Intellectual disability itself not perceived as an isolated risk factor by workers
	3.2. Mental health as a complicating factor
	3.3. Complex intergenerational issues impacting some families headed by parents with intellectual disabilities

FINDINGS

Demographics of participants including education, years of experience in child protection work and estimated number of cases involving parents with intellectual disabilities are summarized in Table 4.1. Most participants had received education in Social Work prior to starting their role in a child protective agency. Participants were recruited from diverse geographical regions, including urban and rural areas across multiple agencies (agencies not named to minimize risk of identification).

Three predominant themes emerged from the dataset, each with subthemes, which are described below and summarized in Table 4.2.

1. Training and Support Needs of Child Protection Workers

The first major theme centered on the training and support needs of child protection workers. Most workers mentioned that they received no training in disability, let alone intellectual disability. As a result, most workers struggled to interact with and adapt communication methods for persons with intellectual disabilities. Barriers to accessibility and accommodation needs were not formally considered or assessed. However, the burden of providing these necessary adaptations and accommodations primarily fell on the child protection

workers, particularly for parents who had no other source of support within the community or their family.

1.1. Heavy burden and workload for workers to navigate supports

Several participants expressed the intensity of cases involving parents with intellectual disabilities and the amount of time spent of the cases due to resource navigation, communication challenges and service referrals. Often, workers did not have the experience or knowledge regarding intellectual disabilities and how to manage such cases. Mary mentioned:

Mary: Really, I don't think I've ever worked harder on a case. It's time laborious when you're actually meeting with them. You spend double the amount of time or at least time and a half. You have way more collateral communication. Basically this is all your side of the file, but it only counts as a file. But really it's a network and a network meeting is on top of your ministry standard in which you must see the family a minimum of 30 days. It doesn't include any of those other additional layers that you're doing – checking in with the network, outside of the meeting or meeting with collaterals or attending stuff with a client. Like I have sat there and had to be like “hey you haven't managed to get to the doctor so we're going to do a drop in because it is concerning what you're saying.”

Similarly, Jim mentioned the challenges of resource navigation that workers often end up doing because this service is often scattered or unavailable in the community:

Jim: I think on the first one carrying the resource role was heavy. Too heavy for me personally and I don't think we should have done it anyway, but we had to because of circumstances. I think just kind of having that resource worker for the first one was key and remains key.

1.2. No training provided on disability, particularly intellectual disability

Most participants highlighted the need for formal training or disability as part of their standard trainings and education. Some workers mentioned that they sought this training independently from external sources after experiencing challenges working with parents with disabilities, but most continued to have challenges due to lack of knowledge, experience and

skills related to adults with intellectual disabilities. For Chris, engaging meaningfully with families headed by parents with intellectual disabilities was a struggle:

Chris: But that is the biggest struggle, just the overall capacity and trying to engage, and that seems to be a struggle across every training we have. One of the worries is how do we work with families that have capacity issues? How do we work with families that have intellectual disabilities? THIS approach will not work with someone who has an intellectual disability. It is the criticism I have been saying for years.

Joanne also mentioned that workers receiving education at the right time can prevent hostile situations that occur from a lack of understanding and knowledge of how to support persons with intellectual disabilities:

Joanne: I think, in terms of our institution, I think there could be more education with workers, about the services and how to work with people with cognitive disabilities or differences, right from intake. Then it would not be so adversarial.

2. Key Sources of Support for Parents

All participants outlined specific key sources of formal and informal support for parents that helped in mitigating challenges for the parents and maintaining custody of their children.

2.1. Formal sources of support

Several sources of formal support were indicated, including parent education programs, service navigation, financial support, developmental services, and support with planning and organization (executive functioning tasks). For example, Lena described how critical the support of an adult developmental services worker was in helping the parent with intellectual disabilities with social participation and life skills, which subsequently aided in improving parenting skills and ability to take care of their children and family:

Lena: They both had [developmental agency] involvement, they both had adult protection workers. They both had community care access workers. I don't know if you know that as well, here in [this city] the community care access based on their eligibility criteria is done by the [developmental services access point]. It tells you what supports they are entitled to and if they're entitled to living support, then community care access will assign

a worker who essentially becomes like an external brain/home manager for them so that they can live in a supported place. And they are in there all the time. They are sort of like a parallel adult protection worker, but their focus is on maintaining safety in the community, the house, the rent, the like life skills portion.

Chris also mentioned a case with a family headed by two parents with intellectual disabilities who were involved in child protection prior to the child's birth, in which providing support at the right time to set them up for success:

Chris: They have a choice because it is voluntarily. Whether they want to work with us or not. These parents did work with me. It wasn't always smooth sailing, but they agreed to work with me prenatally. So, we talked about doctors' appointments, and just prenatal care getting them set up, replace stuff and do planning.

2.2. Informal sources of support

Outside of structured programs and service referrals, informal social support was highlighted as an indispensable factor in supporting parents with intellectual disabilities in various life domains including emotional support during child protection proceedings, advocacy, communication support, and parenting support. Having a supportive partner (in a marriage or long-term relationship) was the most frequently mentioned source of social support for parents with intellectual disabilities. For example, Mary pointed out that the parent she was supporting had continued involvement in child protection due to unstable relationships, but had a more successful experience in her relationship and subsequently in her parenting, leading to her child protection file eventually closing:

Mary: the thing you should know about this mom is that she went on to have another child within the next two years, and she was able to successfully parent that child but at that point she had a different partner who she was living with, and that partner was living with him mom, so that person was actually a good support.

Some workers even mentioned that if the parent they were investigating had a healthy relationship, it would make a key difference in maintaining custody of children:

Lena: if he had a healthy partner, he might be able to raise that little one all on his own. But it is more about the person being able to assist the person with the cognitive disability.

Amongst sources of informal support, having a social support network consisting of partners, grandparents, siblings, friends, and other relatives was perceived as particularly important. For example, grandparents played a key role in the lives of parents Amaya was involved with:

Amaya: Her network, like her father, her sister, her neighbors, friends, all chipped in to help her out. If she has difficulty paying a bill or finding food she'll call the food bank, she'll call her friends for assistance. Because basically this is a big concern for the family, but she finds ways. She is able to pick up the phone and call and advocate for herself in times of need, but she also reaches out to the people she trusts, who can help her advocate. If she doesn't feel like she can do it, she will call someone who can call and do it. So, that network is a huge piece in this family that has been able to really make a difference in her ability to care for her kids.

2.3. Identification of intellectual disability as catalyst for support

Several participants noted the importance of pursuing a formal evaluation for intellectual disability, not for the purpose of a parenting capacity assessment, but rather the determination of appropriate support needs and access to formal services such as a developmental support worker. For example, Freda mentioned that she attempted to have the parent in her case receive an assessment, but they refused based on their lawyer's advice that it would negatively impact their case:

Freda: So, I had initially said to her, has anyone talked to you about this? And would you be open to developmental services and doing an assessment? It would lead to more money, more funding, all these things and help support you in parenting your kids. It would help stabilize your parenting of your kids, and she was like, yes, yes, yes, signed consents and then lawyer says absolutely not and revokes consents. And that was four years ago now, we're in trial, four kids permanency planning for all four kids because a lawyer four years ago said no.

Similarly, Jim mentioned “gatekeeping” by a parent’s physician who stated that the parent did not need an evaluation despite the clear need for support that could not be accessed without a diagnosis:

Jim: That is what we were arguing for. We were advocating for [assessment] and we were suggesting, but the gateway is the doctor. And so the doctor doesn't agree and doesn't sign off on what kind of assessment she needs.

3. Intersecting social factors impacting decision-making

The third major theme was consideration of intersecting social factors and multiple identities in the child protection workers’ assessment of cases. Although not formally included in trainings or included in formal risk assessment tools in Ontario, most participants considered a balance of several key factors before making decisions about parenting capacity and risk of harm.

3.1. Intellectual disability itself not perceived as an isolated risk factor

One of the key subthemes highlighted that most participants did not consider intellectual disability itself as an isolated risk factor for parenting capacity issues and child protection concerns, particularly in the presence of formal or informal supports. The availability or presence of parental supports allowed workers to consider a more comprehensive social picture of the parent and family, including intersecting identities, additional social challenges and barriers that may result from having a disability. For example, Mary mentioned that often child protection concerns can be mitigated for parents with intellectual disabilities who have integrated services:

Mary: You might think “oh it’s a cut and dry, parents can't parent with ID”, no that is not the case you can frequently make things happen, if they have other supporting services. If there are ways that they can integrate some of these things, you’re able to mitigate the concerns.

Joanne clearly expressed that intellectual disability itself was not a child protection concern in her work and there must be a safety issue or risk of harm to the child in order to be investigated by child protection. However, Joanne also acknowledged that parents with intellectual disabilities without a social support network are more likely to end up being investigated:

Joanne: There would have to be safety threat attached to that [being a parent with intellectual disabilities]. I mean there are many parents with disabilities that are capable of caring for their children but where the concern comes into place or where the safety comes into place is when obviously the child is being put in harm or at risk of, because of different capacities and it depends on the support network. Sometimes we have families that have a huge support network. They have a big family behind them. But sometimes they have nobody or they have very little and the people that they do have around them are not in a place where they could provide support.

3.2. Mental health as an intersecting factor

Among the most substantial challenges mentioned by participants was mental health challenges due to the unpredictability it caused in family interactions for several parents. Jim mentioned:

Jim: I think that would be, maybe the mental health piece. I think we have had with parents' intellectual disability and mental health too. Intellectual disability is intellectual disability. You know you're not having great days and bad days. You are just having regular days, but that is compounded with mental health. For example, I'm working now with a woman who has got schizophrenia. With schizophrenia, you can be jumping off a building one minute and happy next. I had one parent back in the day with both of those that was really kind of [unpredictable] when it comes to being able to assess the risk because you never really knew, with the mental health piece.

Lena mentioned other mental health factors like having a history of trauma or ongoing trauma that greatly impacts parenting capacity:

Lena: When we see people with trauma, you'll see somebody go from zero to one hundred in anger in a split second, and as soon as I see that now I know there's some significant trauma in there, and I always ask. In this case, she [parent] and her sister had never gotten counseling for it.

Sandy expressed the importance of considering issues like social anxiety which may impact a parent's involvement in child protection:

Sandy: There is a bit of agoraphobia. We will meet earlier in the day because if you go to some of those places in the community, they don't want to be around too many people because that will trigger anxiety. There is stuff around anxiety from the parent.

3.3. Complex intergenerational issues impacting some families headed by parents with intellectual disabilities

Beth expressed the nuances of working within communities that may be impacted by social and economic disparities that transcend their current family issues. Beth, who worked primarily with Indigenous families, mentioned that social and economic inequities are persistent in the community where she works, making families vulnerable to substance use. Beth highlighted that substance use was an intergenerational issue that impacted most family members in the cases she discussed:

Beth: Both of these parents have large families but I could confidently say every single one of their family members except for one, the grandmother, have substance abuse issues. They would allow their family members to come into the home and stay with them. What comes with that is usage and so they don't have a positive support system in terms of their family. The grandmother works at [community agency] but doesn't live in town and has had about enough of them because it's lifelong. They've been her life, right? Dealing with these issues and she has said "I've had enough. You guys need to get your act together." But he [father] has a brother and his dad died. He has a brother who's an addict. He has a few other people are struggling with addiction. Her whole family, the mother's whole family, as well as her older kids now all struggle with addiction.

Similarly, Sandy also mentioned intergenerational poverty and challenges with unstable housing and homelessness as complex intergenerational issues:

Sandy: Yes, that is very common [mental health and substances]. Sometimes parents grew up in care, or grew up on the street, and they do not know what home looks like. Especially men. Most of the files are under a woman's name."

DISCUSSION

The present study set out to examine the perspectives of child protection workers in Ontario, Canada, identifying needs for themselves and factors that influence supports for the parents with intellectual disabilities involved in their cases. This study makes an important contribution to extant literature as it is essential to examine the experiences of child protection workers in each distinct jurisdiction because differences in legislations, policies and structure of social services may significantly influence experiences and perspectives. The key themes that emerged are aligned with extensive research showing that parents with intellectual disabilities who have strong support mechanisms, including formal and informal supports have positive outcomes and are more likely to keep custody of their children (Tarleton and Ward, 2007; Koolen et al. 2020; Starke, 2022).

Sources of social support including partners and extended family members were indicated as critical in helping to achieve positive family outcomes, as seen in extant literature (Koolen et al. 2020; Wilson et al. 2014). Being in a healthy and stable relationship with an emotionally supportive partner was a key perceived difference between parents with intellectual disabilities who kept their family together compared to those who did not. In fact, this study provided important evidence of the disadvantage experienced by parents with intellectual disabilities (both mothers and fathers) who frequently ended up in abusive or controlling relationships, which led to continued involvement in child protection, as highlighted by child protection workers. Lewis et al. (2015) also noted the importance of a key social support person identified by child protection workers and recommended selecting a “champion” for the parent with intellectual disabilities undergoing child protection. This can be their partner or another person within their social network who is deeply familiar with the family, has an established

trusting relationship with them and is available for communication support, emotional support, and advocacy (Collings et al. 2018; Atkin and Kroese, 2022).

Shouldering the burden: Needs of child protection workers

It should be noted that although this study centers on the challenges and barriers experienced by child protection workers, families headed by parents with intellectual disabilities continue to form the core of this research. As identified by workers in the present study and seen in decades of research, parents with intellectual disabilities experience numerous barriers and inequities, including living in poverty, having unstable housing, experiencing persistent discrimination and stigma, having children with disabilities and going through life crises (e.g., Feldman & Aunos, 2020). While child protection workers have pivotal and demanding roles, the challenges they experience are not pitted against the overwhelming difficulties experienced by parents with intellectual disabilities.

Child protection workers in this study practicing effective relationship-based social work were lauded by parents for providing them what they needed (also recently identified by parents with intellectual disabilities in Tahir and Cobigo, in press) . In these cases, the child protection worker was evidently in touch with the lived experience of the parent and was dedicated to providing the necessary resource navigation and accessibility accommodations to support the family. However, in cases where the appropriate supports for parents were identified and provided, it is essential to consider the heavy workload and burden of resource navigation for the child protection workers in the absence of professional support for themselves, which was clearly noted in this study. Child protection workers have previously left their jobs due to heavy workload, burnout, and emotional exhaustion (McFadden et al. 2015; Griffiths and Royse, 2017).

Workload may be exacerbated considering that workers may not have the necessary training and resources to provide accessibility accommodations for intellectual disabilities such as accessible information and communication. This need has rarely been explored in the literature (Malouf et al. 2017; Tahir and Cobigo, 2023; Powell et al. 2024). In the present study, the responsibility of providing accessibility accommodations for parents without a support network inevitably fell on the child protection workers. They highlighted substantial training needs and most child protection agencies do not provide training on intellectual disabilities or cognitive accessibility challenges that may be experienced by persons with intellectual disabilities. It is important that workers feel competent in their role to nurture constructive relationships with families.

This study also added to the evidence that formal supports like adult protective workers for intellectual disabilities, executive function supports, or life skills supports are perceived as essential mechanisms of support by child protection workers; a finding also highlighted by Koolen et al. (2020). In the absence of other structured supports or resource navigation, the child protection workers themselves constituted a critical source of support for parents with intellectual disabilities, similar to the findings of Tahir and Cobigo (in press) in a study focused on the perspectives of parents with intellectual disabilities.

Getting everyone on the same page: Considering the long-term needs of parents

To complicate the picture, the parents' lawyer may be positioned against the child protective agency. As seen in this study, lawyers may provide misguided legal advice to not pursue a developmental evaluation because a diagnosis of intellectual disability could weaken the parents' court case. This legal advice is based on a long history of court proceedings and extensive literature analyzing court samples showing that intellectual disability status is used as a

key deciding factor in removing child custody and terminating parental rights (Callow et al. 2017; McConnell et al. 2021; Tahir & Cobigo, 2023). However, lawyers may not be aware (or trusting) of shifting attitudes towards parents with intellectual disabilities, which may be detrimental in the long term. This study presented a nuanced perspective from workers: when parents decide against a developmental evaluation, they also forgo the supports they would have otherwise had access to, which would have enabled them to improve their parenting skills, access supports, and get accessibility accommodations. As a result of this missed connection, parents with suspected intellectual disabilities may not receive the support they need to care for their children, leading to continued involvement in child protection. It is necessary to investigate how lawyers and child protection workers can collaborate to align their goals regarding the families they support. See section on Moving Forward below for further discussion on aligning goals.

Consideration of intersecting social identities in child protection work

Another key finding of this study was that child protection workers usually did not make risk assessments (that form basis for custody decisions) solely on intellectual disability, or disability at all. Substance abuse and mental health were considered greater risk factors than intellectual disability. This finding is similar to Norlin and Randell (2023), but contradictory to results of child protection proceedings noted by Aunos & Pacheco (2021) and Tahir and Cobigo (2023), who found that intellectual disability status heavily influenced workers' child removal decisions. Although workers in the present study noted that intellectual disability plays a limited role in their risk assessments, they mentioned the importance of parents with intellectual disabilities having a support network, suggesting that intellectual disability may lead to social vulnerabilities making parenting difficult without support. It is possible that there are regional differences between experiences of workers due to access to training and education specific to

intellectual disabilities in some regions of Ontario, Canada. Examining regional or agency-specific differences warrants further attention in future research because access to disability-specific training has implications for positive changes in attitudes toward parenting with intellectual disabilities.

Working with families impacted by intergenerational issues emerged as an important subtheme that requires more attention. Workers mentioned that some of the families they supported struggled with substance abuse and mental health issues that were not limited to the parents and impacted the whole family and sometimes the whole community in which they lived. In these cases, workers gave precedence to these issues more than intellectual disability status when assessing risk and planning for supports.

Looking forward: Making the case for a better community-based approach

The fragmentation of social services indicated in this study highlights the need for a coordinated strategy across developmental services and child protection services. Interagency collaboration between these types of services is essential because the needs of parents with intellectual disabilities often cross multiple sectors. Pacheco et al. (2022b) also highlighted the need for worker training, accommodative caseload management, and interagency planning and coordination. In fact, the need for integrated services has long been noted in the literature (e.g., Tymchuk, 1999) but has not translated to changes in public policy and community practice, at least in Ontario, Canada. As it stands, the expertise required to communicate and interact effectively with persons with intellectual disabilities exists in the developmental services sector but not yet in child protection services.

To conceptualize a coordinated service program, lessons can be learned from a local as well as an international stage. For example, the *Healthy Start* program in Australia was a

government-funded and technology based network that provided support to parents with intellectual disabilities in the early years of parenthood (McConnell et al. 2008). With contributions from leaders across the country, it aimed to build capacity in organizations and service providers supporting parents with intellectual disabilities. Organizations across health, education and welfare domains were represented. The program was discontinued due to lack of funding after 2011 (Royal Commission, 2023). On a local level in Ontario, Canada, a lesson in intersectoral collaboration can be taken from the provincial dual diagnosis strategy (Government of Ontario, 2008). The Ministries of Health, Long-Term Care and Child and Community Social Services collaborated to create a joint policy to integrate developmental services and mental health services for persons with intellectual disabilities and a mental health diagnosis (Government of Ontario, 2008), which continues to be implemented today. Dual diagnosis is recognized as a complex condition that requires health, legal and social services. The dual diagnosis strategy mandates shared responsibility of these services and provides guidelines for breaking down barriers to service access, creating partnerships and expanding linkages through local and regional community and health networks.

Similar to dual diagnosis in Ontario, sexuality, relationships and parenthood must be domains embedded within services for persons with intellectual disabilities and there must be provincial mandates for collaboration between disability service providers and the child protection agencies. It is imperative that child protectional professionals, legal professionals and developmental service providers engage in dialogue, exchange training and learning resources, and become informed about accessibility, disability rights, and effective support mechanisms for adults with intellectual disabilities who choose to become parents. A technology-based network

and regional champions can pave the way to form partnerships between agencies and collaborate effectively, similar to *Healthy Start* (McConnell et al. 2008).

Lastly, it is critical to explore the resource pathways that enable child protection workers to effectively practice relationship-based social work as they support families in child protection without burning out from the workload, resource navigation and providing supports that they have limited training and capacity to provide. This must occur at an organizational and systemic level as research has shown that organizational satisfaction is a stronger predictor of worker retention than reducing workloads (Brown et al. 2019; Nilsen et al. 2023). Child protection agencies must invest time and effort in needs assessments and program evaluation to ensure that workers feel well-supported in their demanding roles.

Limitations

This study is not without its limitations, and these must be noted. First, the participants in the study were self-selecting and possible bias may have been introduced because only workers intending to create positive social change for parents with intellectual disabilities may have volunteered to participate. Second, there were concerns about gatekeeping within child protective agencies in Ontario and this led to significant challenges in recruitment of workers. “Gatekeepers” are conceptualized as keepers of power who influence the parameters of what information reaches certain groups and how (Barzilai-Nahon, 2009). Gatekeeping in this context can be understood as child protection organizations controlling the flow of information that reaches frontline workers. Several agencies had complex review processes for sharing research requests with workers and some agencies entirely refused to participate. A wider sample across diverse Canadian regions and other provincial jurisdictions would provide more robust data on varied perspectives and needs of child protection workers. Third, the needs of indigenous parents

could not be fully explored and further research on the complex lived experience of indigenous parents with intellectual disabilities is warranted. Although some research has shown that indigenous parents with intellectual disabilities are overrepresented in child protection proceedings (Collings et al. 2017), their experiences remain unexplored in qualitative studies. This is essential to examine considering the historic socioeconomic inequities experienced by indigenous communities as well as Canada's recent legislative changes that allow Indigenous self-determination in child protection work for indigenous communities (Supreme Court of Canada, 2024). Fourth, inclusive research methods (Walmsley et al. 2017; Ghaderi et al. 2023; Tahir & Cobigo, in press) were not utilized in this study, and it would be highly valuable to develop an interview guide in collaboration with a co-researcher with intellectual disabilities to determine which specific challenges to explore with child protection workers.

Conclusion

The present study aimed to examine the needs and experiences of child protection workers in Ontario, Canada, supporting parents with intellectual disabilities. Future research should look toward the changing landscape of child protection in Canada and the promising shift in sociocultural attitudes toward parenting by persons with intellectual disabilities demonstrated in this study. The need for disability-specific training and resources highlighted by workers shows that agencies within the social services sector in Ontario continue to be siloed and need better coordination to meet the cross-sectoral needs of parents with intellectual disabilities. Social service agencies across sectors (or within the same sector in Ontario) must communicate and collaborate to build competencies in workers and plan supports for these incoming families. As it stands, the expertise required to effectively support persons with intellectual disabilities currently exists in the developmental services sector but not yet in child protection services.

Lessons can be learned from international programs such as *Healthy Start* in Australia and local policies, such as the dual diagnosis strategy in Ontario. Furthermore, future research must be mindful of challenges associated with gatekeeping and recognize participation bias when it occurs; positive trends noted in research may not always be representative of child protection agencies in every jurisdiction.

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CHAPTER 5:**“They helped me stand on my own two feet”: Canadian parents with intellectual disabilities in child protection**

Tahir, M., & Cobigo, V. (2024). “They helped me stand on my own two feet”: Canadian parents with intellectual disabilities in child protection. *Journal of Intellectual Disabilities*.

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ABSTRACT

Research on the lived experience of Canadian parents with intellectual disabilities involved in child protection is limited, particularly inclusive research with parents with intellectual disabilities involved in Canada's changing child protection system. This inclusive study was done in collaboration with a co-researcher with intellectual disabilities who had lived experience as a parent. 13 parents from three Canadian regions participated in semistructured interviews about their involvement in child protection. Four major themes emerged in the findings: 1) key supports that contributed to positive outcomes; 2) parents' attitudes toward child protection agencies and perceived attitudes about themselves; 3) systemic barriers impacting accessibility and the child protection experience; and 4) parents' advice to other parents and professionals in child protection. This study provides a promising picture of child protection agencies as a key support despite existing barriers. Implications for social service providers are offered and areas for further exploration are discussed.

KEYWORDS: parents with intellectual disabilities and child protection; lived experience of parents in child protection; supports for parents with intellectual disabilities; facilitators of positive outcomes in child protection; inclusive research

INTRODUCTION

An increasing number of adults with intellectual disabilities are choosing to become parents (Perez-Curiel et al. 2023) or expressing the desire to form a parental identity (Guenoun et al. 2022). Most parents with intellectual disabilities are part of a hidden majority, who may not have a formal diagnosis and may or may not be receiving developmental support services (IASSIDD 2008). Sometimes, intellectual disability in parents is observed by service providers when parenting concerns arise, or child protection services become involved (IASSIDD 2008). Parents with intellectual disabilities have a regrettable history of stigma, marginalization, and social exclusion due to presumptions of parental incompetence by service providers and family members (Aunos et al. 2003; Aunos and Feldman 2002; McConnell et al. 2011, 2021). They are often under more scrutiny from child protection agencies than parents without intellectual disabilities (Booth and Booth 2004a, 2005; McConnell et al. 2011, 2021).

Parents with Intellectual Disabilities Involved in Child Protection

The prejudice faced by parents with intellectual disabilities in the child protection system is well-documented. They are overrepresented in the child protection system at over 15% of cases (Booth and Booth 2004a; Booth and Booth 2004b; Booth, Booth, and McConnell 2004; Booth and Booth 2005; Booth, McConnell, and Booth 2006). In Canada, 6% of newborns born to mothers with intellectual disabilities are removed at birth by child protection services compared to less than 1% of newborns born to mothers without intellectual disabilities (Brown et al. 2018). Intellectual disability in parents impacts custody outcomes more than social factors and these cases are kept open for longer compared to parents without intellectual disabilities (McConnell et al. 2008; 2011; 2021).

Complex social situations, such as substance abuse, unemployment, unstable relationships, and poor housing can have detrimental effects on parent-child relationships and parenting behaviours (Aunos, Feldman, and Goupil, 2008; Darbyshire and Kroese, 2012). Parents with intellectual disabilities are more likely to be involved in child maltreatment cases involving neglect (compared to their peers without intellectual disabilities) and less likely to be involved in cases involving other types of child abuse (such as physical or sexual abuse) compared to other parents (Slayter and Jensen, 2019).

Parents with intellectual disabilities often describe challenges in understanding court processes and no accommodations are provided for cognitive accessibility (Booth and Booth, 2005; Cox, Kroese, and Evans, 2015; Tahir and Cobigo, 2023). Canadian parents with intellectual disabilities are not referred to suitable parenting programs tailored toward supporting their unique challenges as often as they are in the United States, although there is an evidence base for such programs (Feldman, 1994; Wade et al. 2008; McConnell et al. 2021; Slayter and Jensen, 2019). Prejudice is also evident in current formal risk assessment tools published across several Canadian provinces that indicate intellectual disability itself as a risk factor for child protection concerns (Government of Manitoba, 2013; Ontario Association of Children's Aid Societies, 2021).

Positive Parental Outcomes in Child Protection

Relationship-based practice in child welfare and child protection social work has been well-established as the optimal method to achieve positive child welfare outcomes such as children's safety, retention of child custody, and improvement in parenting skills and parental self-efficacy (Marsh et al. 2012; Smithson and Gibson, 2017; Tilbury and Ramsay, 2018; Lehtme and Toros, 2020). Child outcomes and improved parent-child interactions are considerably

influenced by parent satisfaction with child protection services, which is closely related to positive client worker relationships (Tilbury and Ramsay, 2018). When child protection workers can build rapport and trusting relationships with parents, parents perceive conviction in the workers' attitudes about their ability to be good parents. This leads to improved parental self-efficacy and positive outcomes, including being able to retain custody of their children (Tilbury and Ramsay, 2018; Lehtme and Toros, 2020).

Additional positive parental outcomes include being able to access and avail services to meet parents' support needs, which directly impact parents' ability to meet their children's needs (Feldman and Aunos, 2011). For example, services that aid in meeting basic needs such as food security, stable housing, and employment have a critical impact in positive parenting behaviours for parents with intellectual disabilities (Aunos et al. 2008). Several supports have been identified as beneficial for parents with intellectual disabilities including informal social supports (such as peer support; Starke, 2022; Collings et al. 2019; Potvin et al. 2016); formal support networks (Koolen et al. 2020); effective individualized parent education programs (Feldman, 1994; Wade et al. 2008), specialist advocacy services (Atkin and Kroese, 2022) and delivery of services in a respectful and sensitive manner that champions a sense of autonomy and agency for parents (Theodore et al. 2018).

Although the support needs of parents with intellectual disabilities have been widely explored, challenges in providing consistent and timely support services continue to persist (Koolen et al. 2020). These can include referrals to ineffective parenting interventions (Pacheco et al. 2022); accessibility challenges (Tahir and Cobigo, 2023; Malouf et al. 2017; Matthews and Stansfield, 2014); a lack of formal guidelines in Canada for working with parents with intellectual disabilities (such as ones published in the United Kingdom; Tarleton, 2017);

fragmented and siloed services and lack of access to primary healthcare and mental health services (MacIntyre et al. 2019; Brown et al. 2022; Malouf et al. 2017); unstable social relationships and experiences of interpersonal trauma (McConnell et al. 2021; Hammarlund et al. 2023); and persistent prejudice toward parenting with intellectual disability (Correa et al. 2021; Franklin et al. 2022). There also continues to be a lack of professionals' training in intellectual disability (MacIntyre and McGregor, 2019). Recognizing intellectual disability in parents and providing referrals for diagnosis has recently been identified as the first line of support (McConnell et al. 2021).

Lived Experience of Parents with Intellectual Disabilities

Parents with intellectual disability have expressed the desire for parenthood despite the ongoing societal stigma they face (Genoun et al. 2022; Theodore et al. 2018). The perspectives and lived experience of parents with intellectual disabilities involved in child protection cases have not been sufficiently captured in recent research, particularly in Canadian samples. A handful of studies have directly studied the lived experience of parents with intellectual disabilities undergoing child protection investigations, revealing themes of powerlessness, lack of appropriate supports, feelings of fear and distrust and lack of adequate legal representation during complex legal proceedings (Booth and Booth, 2004; 2005; Sheerin and Keenan, 2013; Atkin and Kroese, 2022). A case study by Stefansdottir et al. (2023) examining the lived experience of a mother and father with intellectual disabilities found that supportive family members, advocates, and social service professionals were essential in achieving positive outcomes.

Inclusive Research with Parents with Intellectual Disabilities

Walmsley et al. (2018) defined inclusive research as research that incorporates the lived experience of persons with intellectual and developmental disabilities, recognizes their contributions to research, and empowers persons with intellectual disabilities to be collaborators in research and “stand with” the issues that are important to their lives. Inclusive research with parents with intellectual disabilities, particularly those involved in child protection, is limited. Only four inclusive studies were found examining the parenting and support experiences of parents with intellectual disabilities with collaboration from co-researchers with intellectual disabilities (Theodore et al. 2018; Collings et al. 2019; Strnadova et al. 2019; Franklin et al. 2021). They explored different types of social supports available to parents, the importance of structured peer supports, recognition of the need for professional services and resources despite pervasive assumptions about lack of parenting capacity, and the desire of parents with intellectual disabilities to engage in family planning. However, none of these inclusive studies directly examined the lived experience of parents within child protection investigations.

Research Gaps and Question

Most inclusive studies involving parents with intellectual disabilities included co-researchers with intellectual disabilities who may not be parents themselves. In the present study, we set out to fill this research gap by working in partnership with a co-researcher with intellectual disabilities who had the lived experience of being a parent involved with child protection. Her contribution to the research design and interpretation of findings was intentionally planned to increase the research validity. We asked the following research question: What were the facilitators of, or barriers to positive parental outcomes based on the lived experience of Canadian parents with intellectual disabilities involved in the child protection system?

METHOD

Developing an Inclusive Research Design

Being Intentional

This study utilized a qualitative inclusive research design. An intentional inclusive research plan was developed to contextualize the perspectives and voices of parents with intellectual disabilities within a place of lived experience. With consultation services from the social enterprise Open Collaboration for Cognitive Accessibility (Open, 2024), research materials were developed in accessible language, following Easy-to-read guidelines for documents (Inclusion Europe, 2024). Easy-read guidelines offer specific parameters for presenting information to persons with intellectual disabilities that aids comprehension (Sutherland & Isherwood, 2016). The guidelines published by Inclusion Europe (2024) include but are not limited to using short sentences, including only one idea per sentence, explaining difficult words, reducing visual clutter, using accessible fonts (such as Arial or Tahoma), and using active voice. As part of the recruitment strategy for inclusive methods, a co-researcher with intellectual disability and lived experience as a parent was recruited from Open's team members to collaborate on the following phases of research: 1) review and validation of materials to ensure accessible language; 2) data collection; and 3) data analysis. All materials used to recruit and train the co-researcher were in accessible language, including an Advisor recruitment letter, contract, and consent form.

A contract was signed with the co-researcher to recognize the value of their contribution in this study and provide fair remuneration for their time.

Research Training

At each phase of the study in which the co-researcher was involved, individualized training was carried out in person using strategies tailored to their learning style. The co-researcher expressed that their confidence increased when given the opportunity to practice and discuss prior to completing a task. Therefore, a Behaviour Skills Training (BST) approach (Leaf et al. 2015) was used to provide training in research skills: 1) verbal guidance; 2) modeling how to perform a skill or complete a task; 3) practice or rehearse how to perform a skill; 4) provide feedback on the practice or rehearsal. Prior to conducting participant interviews collaboratively during data collection, two training sessions were completed with the co-researcher using the BST approach. The training sessions included diverse learning and communication strategies, using accessible language, roleplay, repeated practice and feedback, use of multimedia and creative activities. Similarly, prior to data analysis, three teaching tutorials were provided using examples from archival and public data.

Privacy and Confidentiality

Prior to having access to any participant data, the co-researcher reviewed and signed a confidentiality agreement in accessible language. Interview recordings were only accessed using the researchers' computer in a secure research office. The importance of confidentiality and upholding participants' privacy was thoroughly discussed with the co-researcher.

Length of Involvement

A total of 20 meetings varying from 1 to 1.5 hours in length were carried out over a period of 8 months (January to August 2023). Some collaborative work, such as review of documents and providing comments on the coding structure during data analysis, was carried out remotely using a shared folder in cloud storage (no confidential data were shared via cloud storage).

Recruitment and Participants

Ethics approval was obtained from the institutional ethics board (File #H-02-22-7670). Subsequent to institutional ethics approval, ethics approval was also obtained from specific local and regional developmental support agencies in two Canadian provinces, Ontario and Manitoba, to proceed with recruitment.

Recruitment of participants was carried out with the support of several local and regional developmental support agencies (i.e., organizations providing support services to persons diagnosed with an intellectual disability) who shared recruitment letters within their networks and provided program contacts. The inclusion criteria for participants included: 1) being a parent; 2) having an intellectual disability, in the form of a formal diagnosis or receipt of developmental support services, and 3) being involved with child protection at any point in their lives.

A total of 13 participants who met inclusion criteria participated in virtual or in-person semistructured interviews for this study ($N=13$). Participants were recruited across three Canadian regions, including Ottawa and region, Toronto and region, and Winnipeg and region (see Table 5.1 for a complete list of demographics).

Materials

All materials used in this study, including the participant recruitment letter, consent form, and interview guide, were developed in accessible language in both official languages of Canada, English and French. Each document was reviewed by an Easy-to-read expert at Open. After ensuring that each research material met Easy-to-read guidelines, the materials were reviewed and validated by the co-researcher.

The interview guide was further adapted for the co-researcher to embed their own introduction. Questions in the interview guide included demographic information, experience with child protection, accessibility issues, support needs and challenges, perceptions of disability and advice for other parents with intellectual disabilities and professionals.

Data Collection

In addition to signing an accessible consent form, participants were also asked for verbal consent prior to scheduling the interview. Semistructured interviews with participants were carried out virtually (on Zoom or Teams) or in-person, with or without the presence of a support person, based on the participants' preferences. Participants were provided with flexibility in how and when they shared information. For example, the choice of answering questions in written format via e-mail was given to participants; most participants chose to answer questions verbally during interviews. Participants were also asked what style they would prefer for questions (e.g., specific questions vs. broad questions) and assured that they could choose to skip any questions or end the interview at any time. Interviews were recorded for data analysis, with participants' consent. Each participant received an honorarium for taking part in the study.

A total of 12 participants completed the interview in English and one participant completed the interview in both French and English. After receiving interview training, the co-researcher collaboratively carried out one bilingual interview with a participant (English and French).

Data Analysis

Thematic analysis was completed on the data (Clarke and Braun, 2012; Terry et al. 2017) after adapting the process into an inclusive and iterative procedure. After receiving data analysis training from the researchers, a collaborative data analysis form was developed with the co-

researcher, who expressed that they would prefer to listen to audio recordings of the interview and verbally discuss, instead of reading transcripts and taking written notes.

All data analysis meetings were recorded, with consent from the co-researcher. The researcher took notes on the collaborative data analysis form based on the discussion with the Advisor.

To immerse within the data, the co-researcher and first author listened to an interview together prior to discussing and taking notes. The co-researcher and researcher listened to 4 out of 13 (30%) interviews together. The co-researcher was invited to share their ideas and points first before the researcher added their points, to remain authentic to the co-researcher's perspective as a co-researcher with lived experience.

Based on the co-researcher's ideas from the four interviews analyzed together, the first author developed a preliminary coding structure for the dataset in NVivo, a software for qualitative data analysis (Lumivero, 2024). The coding structure was provided to the co-researcher in accessible language to review and validate (i.e., confirm whether the codes are consistent with the interview discussions). After receiving feedback on the coding structure, the first author updated and applied the structure to the remaining interviews in the dataset.

Reliability scores were not completed in this study due to the ongoing debates about the validity and usefulness of calculating reliability scores in qualitative research (Yardley, 2000; O'Conner and Joffe, 2020). This is especially relevant in this inclusive study, in which objective coding of data was not realistic, nor desirable (O'Connor and Joffe, 2020). Since the goal is to understand the data from a place of lived experience, some degree of interpretation is required while being mindful of reflexivity. In lieu of calculating an intercoder reliability score, we embed

other quality criteria such as constant comparison, transparent reporting of procedures, and “thick description” of participants’ experiences (Merriam and Tisdell, 2015).

Table 5.1

Participant Demographics

Name*	Age	Location	Ethnicity	Number of children and their ages	Relationship status	Length of involvement with child protection	Retained or lost custody of children
1. Becky	38	Ottawa	White	One child aged 11 years	Single	6 months	Lost custody (adoption)
2. Talia	30	Winnipeg	Black	Two children, aged 10 and 15 years	Married	2 years	Retained custody
3. Christa	30	Winnipeg	Data unavailable	Two children aged 10 and 15 years	Single	5 months	Retained custody
4. Todd	38	Winnipeg	Data unavailable	Two children aged 7 and 10 years	Married	1 year	Retained custody
5. Maryam	40	Ottawa	Arab	One child aged 11 years	Divorced	1 year	Lost custody (continued access)
6. Avril	43	Toronto	Black	Two children aged 1 and 9 years	In a relationship	9 months	Retained custody
7. Tanya	32	Toronto	Arab	Four children between aged 3-7 years	Married	Data unavailable	Retained custody
8. Maria	29	Toronto	Indigenous and White	Four children between 9 months and 9 years	In a relationship	10 years	Retained custody
9. Remy	32	Toronto	Indigenous and White	Seven children, ages unavailable	In a relationship	12 years	Lost custody of four children at birth; retained custody of three children
10. Casey	42	Toronto	Black	Three children between ages of 3-6 years	Single	Data unavailable	Lost custody of three children and retained custody of two children
11. Taylor	41	Toronto	White	Two children aged 4 and 15 years	In a relationship	1 year	Retained custody
12. Lauren	36	Toronto	White	One child aged 9 years	In a relationship	Data unavailable	Retained custody
13. Alex	Data unavailable	Toronto	Data unavailable	Two children aged 5 and 7 years	Single	Data unavailable	Retained custody

Table 5.2. *Themes and subthemes*

THEMES	SUBTHEMES
Key supports	Child protection agency in a supportive role
	Importance of a supportive partner
	Other strong social supports
Attitudes	Attitudes of parents toward child protection agency
	Perceived attitudes of others toward parents and their disability
	Parents' views about their own abilities
Systematic barriers impacting accessibility and the child protection experience	Specific accessibility challenges
	Communication with child protection workers
	Challenges during the first visit or contact with child protection agency
Advice for other parents	Advice on communication
	Advice on being assertive
	Advice on finding support

FINDINGS

See Table 5.1 for a summary of participant demographics and see Table 5.2 for a summary of themes and subthemes identified in this study.

Key Supports

Child protection agency in a supportive role

Parents from three different Canadian regions had varied experiences with their respective child protection agencies. Some parents described negative experiences and poor relationships with their child protection workers, while others identified significant positive experiences with child protection. The co-researcher identified this subtheme with surprise and cautious optimism upon hearing several parents express Children's Aid Society (CAS; chapters of child protective agencies in Ontario, Canada) as being the strongest support and most positive influence in their lives. For example, Lauren attributed her confidence in her ability to parent and take care of her family to CAS:

And someone in the building where I was staying, so found my place, before I ended up in a shelter, called on me. And the CAS lady that came said he's hyperactive, I said oh yeah, from the time he wakes up till the time he goes to bed. And she goes, there's nothing wrong with him. There's no bruises, no nothing. So they were fine with me being a mom. But they've helped me go get my diagnosis of a learning, mental disability. And get my son into a really good school. They helped me to where I am today, standing on my own two feet.

Avril expressed that the child protection agency believed in her ability to parent and played an instrumental role in helping her regain custody of her child and preserve her family unit:

They helped me with my son, they helped me know that my son is back with me in my custody. They helped me that my fiancée could see my son, and I could see my son.

Importance of a supportive partner

Another key source of support that parents expressed was their partner (spouse or long-term relationship partner). Some parents mentioned the absence of a supportive partner and being in unstable romantic relationships as a major influence on their poor family functioning and inability to meet their needs. Talia described her partner's role as critical in helping her access the right services, in facilitating communication with workers, and in their family preservation:

They live with me now, and that is because of my husband. If my husband was not to be here, or probably was not around, my kids would have been taken away from me.

Similarly, Remy, who experienced unstable relationships through most of her life, described improvements in her family life, access to supports and stability in her children's lives after she found herself in a healthy long-term relationship:

Ever since we've been together, things have been going uphill with us. He's been very supportive with me.

Todd, who is a father with intellectual disabilities, described a more nuanced experience and mentioned that it was easier for him to compromise with his partner (without intellectual disabilities) in order to continue seeing his children:

Because in most cases I believe it's always better to let your partner have her way. For instance, in my own case it would have, the issue would have escalated more if I didn't consent to her caring for the kids.

Other strong social supports

Many parents expressed that informal social support including extended family members and friends have been a strong support while they were undergoing child protection concerns and for parenting in general. Maryam mentioned that her own parents were always there to support her:

They help me with my daughter. She used to play and she's really stubborn. They know better than I do everything on my own. When I ask for help, they come.

Attitudes

Attitudes of parents toward child protection agency

Beyond the regional differences described above, several parents described being fearful and having distrust in child protection agencies at the outset. Remy, a mother who lost custody of four of her children immediately after birth, recounted her experience:

I don't like how they just come into the hospital and just, pretty much up front saying we're taking your child after you just gave birth. I don't think they should be doing that. I think they should wait a couple minutes after. Because if the mother's had an epidural or something and after having a child, it does not help at all. It puts them in a depressed mode and that's where I think they should not be doing. It's a very fragile moment right there and then.

Talia expressed that she continues to be in a state of constant anxiety because she is unsure of when child protection workers will show up and what they will do:

I don't know if you have ever been in my situation, you will always feel insecure when they are around. I mean anything could happen. I still have the problem now. I am still in this condition, this mess right now. I am still not free from them taking away my children. It's just that my husband is by my side.

Perceived attitudes of others toward parents and their disability

Parents' perceptions were varied in terms of whether child protection workers and other service providers had biased opinions toward their parenting capacity because of their disability. Maria mentioned that she never felt workers discriminated based on disability and she has never been referred for a parenting assessment:

No, they never thought that my disability or like my mental health, would affect the way I parent. So like, I've never had to go for one.

Avril mentioned that child protection workers in her experience preferred to do an observation to ensure good parenting skills and did not make presumptions about her parenting ability:

My children's worker she followed me to my other big program that I had with my son and she observed me and I was a good parent, observed that I picked up my baby good, I sat down carefully, I feed my baby I did everything right you know. And I'm a good mother not a bad mother as people would think or say that.

Remy mentioned that she has been involved with child protection services for more than 10 years and in the early years, child protection workers often made assumptions about her parenting capacity based on her diagnosis:

Because I have a learning disability, they think that I won't be able to protect my child or take care of them or anything like that.

Parents' views about their own abilities

Parents' confidence in their own parenting skills and self-efficacy presented in a complex picture influenced by the people in their lives, including family members and service professionals. Becky expressed that she felt judged by everyone in her life and this contributed to her strong feelings of failure in parenthood:

I couldn't take care of her at the end, I was surviving for myself. Like I tried my best, but it wasn't enough.

Maryam was more confident in describing her parenting ability and felt more reassured that she had a network of support to help her in areas she could not manage herself:

Well for me it's clear, I can't do it by myself and my ex-husband too he understands so the grandparents used to always take care of the little one.

Systematic barriers impacting accessibility and the child protection experience

Specific accessibility challenges

Many of the parents described cognitive accessibility challenges while involved in child protection. Barriers such as complex court processes, difficult language, rigid timelines, and lack of accessible information (including navigational directions, timings, and building access) were mentioned by several parents. For example, Taylor, who was a newcomer in Canada, was often confused about timings and directions provided by workers, due to both language and learning challenges:

The time for everything was confusing. Everything was difficult to understand. Everything was confusing my English is very bad. I have mental health and [a learning] disability, but this time I did not have those diagnosis.

Becky expressed that her difficulties in understanding the complex court processes influenced her workers' and family members' perceptions of her parenting capacity:

Like it's still hard today. I'm a good person, trust me, I mean I love my daughter, I want everything for her, it's just hard for me because the process, I didn't really understand 100% what was going on.

Lauren spoke about the inaccessible language used during meetings and on forms and documents, that she would not be able to understand without the support of her developmental support worker and her mother:

There's so many different freaking words that I don't even understand.

Communication with child protection workers

Many parents emphasized the importance of having a positive and trusting relationship with their child protection workers. In cases where the workers did not believe in the parents' ability to meet their children's needs, there was distrust from the beginning of the involvement that negatively impacted the relationship throughout the case. Lauren mentioned that she kept open and honest communication with her worker, so nothing came as a surprise to them during regularly scheduled visits:

And if I needed to call my worker about something up, like update her on something, I'd call her or e-mail them like they always got an update from me before they came to the house.

Similarly, Maria also indicated how critical it was to be honest with the child protection workers:

I'll be honest with them, and if you're honest with them and cooperate on everything that they're asking you to do, or like any questions they're asking you just be truthful and helpful and it would like they'll be the workers will be helpful and truthful to you.

Challenges during the first visit or contact with child protection agency

When asked about their first contact with child protection, many parents were emotional as they described feeling helpless and terrified of losing their children. Casey, who was given no information about the child protection process, mentioned feeling scared when she found out she could no longer see her children after being removed by the child protection agency:

I'm saying I did not understand. I'm thinking, well when they take them to the foster home that the parents can go there and see them.

Although Lauren went on to have a positive experience, she described her initial feelings of fear about the child protection agency because she had heard stories from other parents:

They came the first time, and my mom was there because I thought I was going to lose my kid. A lot of people think oh when CAS comes to your house, they're going to take your kid. I had nervous breakdowns over it because it was the first time, they've ever been called on me. I'm like, I'm not losing my kid.

Advice for other parents and workers

Advice on communication

Parents in the study provided some key advice for other parents with intellectual disabilities who may find themselves in a similar situation as well as for child protection workers. Many parents expressed that having good communication and being cooperative with the child protection workers was important for positive outcomes. Lauren mentioned:

Just keep that communication always open. Make sure the parent understands that you're not going to take the child away unless you do not the certain things that we need you to

do. And just to always double check everything. Because sometimes the parents don't understand what's going on too. Like I didn't understand when they got called on me. Like, why did they get called on me like? Five years, six years. There's got to be something.

Advice on being assertive

Remy noted the importance of being assertive and expecting to be treated with respect even when involved in child protection and having her parenting evaluated. When a worker asked Remy personal questions about future pregnancies, she reached out to the agency:

Yeah, I reported him. I told them like I need a new worker because I'm not going to have somebody like that who's going to ask me those kinds of questions which I don't want to answer.

Advice on finding support

One of the main areas in which parents provided advice for other parents with intellectual disabilities was in seeking out supports, one of them being the child protection agency itself, especially if there was previous experience with child protection. Remy mentioned reaching out to the agency herself:

At first, I went to CAS, I told them like, hey, I'm pregnant. I know you guys are going to apprehend him by birth because you did it with the other four. I'm here to get some support and see what I can do to have him in my care. Because I want my child in my care.

Becky mentioned the need for peer support groups, so parents do not feel like they are alone in what they are going through:

They should have the support groups [with other mothers], they should have like a way to say you're a good person but let's meet another time and see what we can do to help you out. And maybe remind them that they're not bad you know. Seeing maybe the same person, see how they're doing.

Maria noted that parents should be connected to services and resources to help meet basic needs:

I feel like maybe having more resources like food cards and basic things that people would need access to right away, like formula and diapers and clothing and access to more stuff like that.

Importantly, based on the interviews and within the context of their own experiences, the co-researcher identified the need for timely and consistent services for parents with intellectual disabilities, instead of “waiting until they get in trouble” with child protection services for something they could have received help for when they first became parents, or even before giving birth.

DISCUSSION

In this study, four out of 13 parents experienced permanent loss of child custody as a result of child protection investigations. Nine out of 13 parents who were involved in child protection had ongoing cases within the protection agency but did not experience child removal.

Social Supports

The findings of this study contribute important evidence on the support needs of parents with intellectual disabilities. Social support from peers, particularly the presence of a supportive partner and being in a stable marital or romantic relationship, was mentioned as a key influence in positive child protection outcomes, also shown in extant literature (Koolen et al. 2020; Starke, 2022). The co-researcher’s collaborative data analysis was instrumental in understanding various dimensions of support needs mentioned by parents, including proper timing of supports, coordination and consistency between supports and the long-term nature of supports. The types of support identified as critical were social support from extended family, friends and partners, formal parenting programs, mental health, and emotional support particularly in the postpartum period, and counselling for trauma and intimate partner violence.

In fact, the inverse was also identified by parents: having poor relationships with partners and family members was perceived as a key reason parents continued to be investigated by child protection agencies. Parents with intellectual disabilities often have increased experiences of interpersonal trauma and intimate partner violence (Slater and Jensen, 2019; Collings et al. 2020). These experiences identify an important area of support that must be recognized and provided by local developmental support agencies (such as Developmental Services Ontario in Ontario, Canada; DSO, 2024) as they build Individual Support Plans in line with social inclusion goals for parents with intellectual disabilities (Herps et al. 2016). In Ontario, Canada, once eligibility for developmental services is confirmed, formal social support, advocacy, case management and service coordination are provided by an adult protective worker (Adult Protective Service Association of Ontario; APSAO, 2024). In addition to this formal support, developmental support agencies must also enable parents with intellectual disabilities to build informal social networks in their community by providing platforms for healthy social interactions for parents struggling with social isolation or unstable relationships. This process must begin with a formal assessment of support needs, which is often not conducted as part of child protection investigations for parents with intellectual disabilities (Feldman & Aunos, 2020). There is an immense need for developmental support agencies to closely collaborate with local child protection agencies as they can play a vital role in identifying social strengths and needs for parents with intellectual disabilities. Currently, parenting support aimed at adults with intellectual disabilities is not mentioned or identified in any form within adult developmental services in Ontario (APSAO, 2024; DSO, 2024).

Child Protection Agency as Instrumental Support

Several parents described the child protection agency itself as an instrumental support system that helped their family retain child custody and access other essential services, which has not been demonstrated in previous literature involving parents with intellectual disabilities. This was especially true for parents in this study who lacked a social support network. This finding contrasts past research indicating adversarial relationships between parents with intellectual disabilities and child protection professionals (Proctor and Azar, 2013; Lewis et al. 2015; Albert and Powell, 2021).

Some parents notably attributed their success as parents to children with complex needs to the involvement and support of their local child protection agency. Parents with favourable views of child protection indicated that the agency helped with getting a diagnosis of intellectual disability, which in turn allowed access to a multitude of services that they would not otherwise have (such as an adult developmental support worker, financial support, and parenting support). McConnell et al. (2021) demonstrated similar findings in which a diagnosis of intellectual disability of parents involved in child protection was identified as a first line of support to open the door to other service referrals.

Furthermore, parents with positive views noted that the child protection agency provided coordination and seamless navigation across services for some parents, while enabling a sense of agency and respecting their parental identity. Parents mentioned having positive and trusting relationships with their workers and some even requested for their case file to be kept open. Open and honest communication as the basis of a strong relationship with workers was also a recurrent theme in the advice given by parents in this study. These findings highlight the significance of exploring the nuanced social context in cases represented in quantitative research indicating that child protection case files of parents with intellectual disabilities are kept open for

longer (e.g., McConnell et al. 2012). Parents with intellectual disabilities have complex and long-lasting support needs (e.g., MacIntyre et al. 2019) that may have caused cases to be kept open for longer, which was not perceived negatively by parents but rather viewed as an important support mechanism for parents to stay connected to professional services.

It is important to acknowledge that although building positive parent-worker relationships is essential for positive child protection outcomes (Lehtme & Toros, 2020), in some of the cases in the current study, workers may have resorted to playing the coordination or case management role due to service system constraints and a lack of appropriate supports by local developmental support agencies. It is essential for child protection agencies and developmental support agencies to collaborate and ensure continuity of support for families who no longer have child protection concerns but are requesting their cases to be kept open to stay connected to services, as seen in the present study. Developmental support agencies must step in to ensure ongoing and consistent support for parents with intellectual disabilities at various stages of parenthood for positive family outcomes and to avoid unnecessary encounters with child protection for parents who do have a formal diagnosis of intellectual disability. In Ontario, these supports must fall within the purview of the adult protective services program (APSAO, 2024). This includes integrating tailored parenting education programs for parents with intellectual disabilities (e.g., Feldman, 1994; Wade et al., 2008) as part of individual goal planning. These changes must happen at a systemic level by creating effective communication pathways between child protection agencies and developmental support agencies.

It should be noted that planning for social supports at the developmental support agency level can become complicated for parents who may not have a formal diagnosis of intellectual disability and, as a result, may not be receiving services from their local developmental support

agency. When parents involved in child protection are suspected of having an intellectual disability but may not be formally identified (as seen in extant literature; IASSIDD, 2008), it presents collaboration challenges for child protection agencies and developmental support agencies. The parents who participated in the present study were largely recruited through developmental support agencies, which may limit our understanding of the experiences of parents with intellectual disabilities who are involved in child protection but are not connected to developmental support agencies.

Based on demographics data, parents who reported positive experiences with child protection agencies were from the same geographical area in Canada. It is unclear if they were involved with the same child protection agency. Further exploration is needed to determine whether this is a geographical difference or agency-based difference. Much of the research on specialized parenting interventions and supports for parents with intellectual disabilities in the 1980s and 1990s was centered in the area where these participants received services (e.g., Feldman et al. 1985; Feldman et al. 1986; Feldman et al. 1989; Feldman, 1994) and has influenced present day developmental support programs (e.g., Feldman & Surrey Place Centre, 2020).

In addition to geographical differences, it is important to explore the service load on the child protection workers supporting parents with intellectual disabilities. As mentioned by many parents who viewed child protection services as a key support, their workers often reached beyond their welfare role and played a service coordination or navigation role. It is crucial to further examine workers' need for training and resources and perceptions of their own knowledge and ability to succeed in their role (Pytlowana and Kroese, 2021). It is also important to examine the impact of the service navigation workload on child protection workers as research

has linked high turnover rates in child protection agencies to emotional exhaustion, burnout, and compassion fatigue experienced by workers in their demanding work (McFadden et al. 2015; Griffiths and Royse, 2017). Furthermore, research has shown that child protection workers often lack knowledge of intellectual disabilities and feel uncertain of how to effectively support parents with intellectual disabilities (e.g., Lewis et al. 2015), which may contribute to burnout and emotional exhaustion. Child protection workers often take a needs-based approach in evaluating parenting capacity, while developmental support agencies focus more on the parents' strengths (Aunos & Pacheco, 2021; MacIntyre et al. 2019). Child protection workers would benefit from direct training on intellectual disabilities and focusing on parenting strengths to mitigate bias in their decision-making.

Systemic Barriers: Cognitive Accessibility

One of the primary systemic barriers adversely impacting the child protection experience for parents with intellectual disabilities is the lack of consideration of cognitive accessibility barriers. This lack of cognitive accessibility awareness occurred across every level of service provided during child protection. Based on parents' experience, there was a lack of accessible information, lack of adapting case procedures and documents in accessible language, lack of flexible timelines and lack of accessibility support for parents at various stages of their child protection case. Also noted in Tahir and Cobigo (2023), in child protection cases, parents' intellectual disability is identified but the need for accommodations and disability rights are not considered when planning for support. The only accessibility support described is informal communication support provided by family members or developmental service workers, which is only available inconsistently.

Several parents described not understanding what was happening during the first contact with child protection and feeling bewildered by the language used. Cognitive accessibility barriers can inadvertently make parents who experience accessibility barriers seem uncooperative or unwilling to avail themselves of supports they are referred to (Albert and Powell, 2021). The need for accessible information to be delivered in a child protection context has been identified in previous literature (McIntyre et al. 2019; Matthews and Stansfield, 2014) and while some resources exist in the United States and Australia (ProudParents, 2023; The Wash House, 2023), no such resources exist for Canadian parents. Region-specific resources are essential because child protection processes vary greatly across jurisdictions. Workers often do not have training to adapt communication methods based on accessibility needs of parents with intellectual disabilities. This lack of training and inability to provide appropriate supports may be related to persistent negative attitudes toward parents with intellectual disabilities within specific agencies and presumptions about parenting capacity on the basis of intellectual disability (e.g., Callow et al. 2016; Feldman and Aunos, 2020; Tahir and Cobigo, 2023).

Looking Forward in Inclusive Research

An important methodological contribution of this study is its inclusive approach (Beail and Williams 2014; Ghaderi et al. 2023) with the inclusion of a co-researcher with intellectual disabilities who had lived experience as a parent experiencing child protection involvement. The first author consciously worked to resist the power imbalance inherent in academic research settings (Chalachanova and Gjermestad, 2021). The co-researcher was invited to contribute to most major stages of the research process, including recruitment, data collection and data analysis. At each stage of research collaboration, information in documents and processes was adapted into Easy-to-read (Inclusion Europe, 2024) and accommodations were provided based

on the needs of the Advisor. It is important to note that providing research training to co-researchers is essential for them to understand the context of the research study and provide meaningful contributions to the research process, as we would provide to new researchers. Therefore, the first author provided accessible tutorials and interactive training workshops to the co-researcher to practice interview skills and contribute to qualitative data analysis.

The co-researcher provided positive and constructive feedback throughout the research collaboration, which was an essential learning experience for the research team. For example, the first author initially prepared an accessible feedback form to enter notes during data analysis. The co-researcher shared that it would be most accessible to listen to audio recordings of interviews and share thoughts verbally in a real-time data analysis collaboration session. This important feedback allowed the first author to capture more accurate reactions and notes during data analysis which aided in building the initial coding structure.

There were some key lessons learned during the inclusive research process. For example, training materials need to be adapted into accessible language and flexible learning strategies at every stage. Transportation is a major consideration, and researchers must ensure that co-researchers are able to reach their destination during interviews and data analysis sessions. There also needs to be flexibility in timelines and extra time provided for review of documents.

We offered the co-researcher scientific authorship in this paper and discussed what it means to be an author on a research paper. After reflecting further on this responsibility, the co-researcher expressed that they would prefer not to be an author and instead focus on knowledge mobilization within the community, an endeavour the Advisor considered more valuable than authorship.

Limitations

This study is not without its limitations, most notably in the limited representativeness of the parents included in this study. Due to the difficulties in recruiting from this population, inconsistent descriptions of parents with intellectual disabilities and gatekeeping by social service agencies, many parents were recruited through an organization providing parenting support services to parents with intellectual disabilities in one specific, albeit large, Canadian region.

A second limitation is that only one father with intellectual disabilities was included in this study, which limits the understanding of the lived experience of fathers. Research has shown that fathers with intellectual disabilities often feel left out and may have varying support needs compared to mothers with intellectual disabilities (Ćwirynkało and Parchomiuk, 2023).

It may have been beneficial to include additional co-researchers to inform the data collection stage, which was the third limitation of this study. Given the sensitivity of the topic, it is expected that participating parents would feel more comfortable expressing their thoughts and sharing their story with another parent who has lived experience rather than an academic researcher (as shared by one parent whose interview was conducted by the Advisor).

Lastly, a fourth limitation was that the indigenous identity and other intersecting factors were not explored within this study, although 4 out of 13 parents identified as being indigenous. The unique lived experience of indigenous parents with intellectual disabilities must be explored in-depth to fully understand their contact with the child protection system in Canada. This is important given the context of truth and reconciliation with indigenous peoples in Canada in the wake of historical injustices, including residential schools and forced removal of children (Government of Canada, 2023).

Future Research

Future research should continue to explore the lived experience of parents with intellectual disabilities in child protection within inclusive research designs. It is essential to incorporate an intersectionality framework in research with parents with intellectual disabilities to examine how indigenous identity and other intersecting identities influence the child protection experience. It is particularly essential to conduct a closer examination of the evolving landscape of child protection in Canada and its impact on Canadian parents with intellectual disabilities. With the removal of restrictive practices in some provinces such as birth alerts (Ontario Association of Children's Aid Societies, 2021) and closed adoptions (Government of Ontario, 2020), certain inequities have been removed and may have aided in mitigating some of the barriers faced by parents with intellectual disabilities. However, bias and prejudice in attitudes toward parenting with an intellectual disability continues to persist despite the growing number of parents. Future research must pay closer attention to agents of cultural change and mitigating systematic inequities and barriers for parents with intellectual disabilities.

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CHAPTER 6: GENERAL DISCUSSION

Overview of Dissertation

This dissertation aimed to examine what influences child protection decisions in cases involving parents with intellectual disabilities. Specifically, we aimed to understand the systemic conditions in which parents with intellectual disabilities keep custody of their children in contrast to parents who do not keep custody of their children. Parents with intellectual disabilities are growing in numbers (Lin et al. 2017; Man et al. 2017) and are overrepresented in child protection investigations in Canada (McConnell et al. 2011; 2012; 2021) and across the globe (Booth and Booth, 2004; Tøssebro et al. 2017; Laliberte, 2024). Chapter 1 presents a review of the current literature on parents with intellectual disabilities and their involvement in child protection. Chapter 2 presents an overview of data analysis methods used across the three studies. Chapters 3-5, summarized below, present three studies examining child protection experiences from three perspectives: 1) family court judges; 2) child protection workers; and 3) parents with intellectual disabilities.

Chapter 6 presents a critical discussion of the implications of this dissertation using *Inequities Conceptual Framework for Disabled Parents Involved with the Child Welfare System* (Powell et al. 2024). Using this conceptual model, it is demonstrated that the conditions that set parents with intellectual disabilities who retain custody of their children apart from parents with intellectual disabilities who do not retain child custody can be understood as systemic inequities resulting from barriers that exist at a contextual, institutional and individual level. The levels of the conceptual model are discussed in detail below.

Summary of Three Perspectives

In Chapter 3, we present a manuscript published in the *Journal of Applied Research in Intellectual Disabilities* (Tahir & Cobigo, 2023). The objectives of this study were to explore the individual, social and systemic factors that impacted child protection decisions as well as to examine how the COVID-19 pandemic affected accessibility in child protection cases involving parents with intellectual disabilities through published family court cases in Ontario, Canada. To date, there are no other studies examining the impact of the COVID-19 pandemic on child protection investigations with parents with intellectual disabilities. Moreover, very few studies have used published court cases as a source of data to examine child protection decisions (Galliher, 1973; Glaun & Brown, 1999; Sigurjonsdottir & Rice, 2017). A total of 10 published cases were reviewed, eight being permanent custody cases.

In six out of 10 cases, the child was apprehended from parents at birth, consistent with previous literature showing elevated statistics for custody deprivation of parents with intellectual disabilities at birth (Brown et al. 2018). The findings of this study demonstrated ongoing reliance on intellectual disability status to make final decisions regarding removal of child custody, as shown in numerous studies (e.g., McConnell et al. 2021; Laliberte et al. 2024). Although several other reasons were listed for child protection concerns (e.g., mental health concerns, lack of support, lack of stable housing and more), judges often pointed at lack of parenting capacity due to intellectual disability as the main reason for permanent loss of custody, even in cases that continued throughout the pandemic. In these cases, parents were faced with inaccessible virtual access visits, longer case timelines and a seeming lack of parent-child attachment imposed by national health guidelines in Canada (e.g., social distancing measures). Furthermore, cognitive accessibility accommodation needs were not considered, leading to barriers in procedures, forms, access visits and instructions given to parents. Although cognitive accessibility barriers were

acknowledged in some cases, failure to complete instructions was misconstrued as unwillingness to cooperate with child protection professionals, which is also shown in previous literature (e.g., Albert & Powell, 2020). Forms, documents or plans of care were not available in accessible language to parents as far as could be gleaned from published cases in Chapter 3.

Courts also tended to “cherry pick” evidence-based practices; there were no firm guidelines or rules described for which evidence-based practices were being used for decision-making. For example, attachment theory was often mentioned but evidence-based parenting education programs for parents with intellectual disabilities (e.g., Feldman, 1994; Wade et al., 2008; Zijlstra et al., 2023) were rarely mentioned (parents were not referred and it was unclear if these programs were even available for parents). In addition to these systemic barriers, parents also faced negative attitudes toward parenting with intellectual disability, demonstrated in language used within courts across several cases, consistent with existing literature (e.g., Pacheco et al. 2024). Recommendations for professionals regarding accessibility for parents with intellectual disabilities were provided in this manuscript.

In Chapter 4, we present a manuscript centered on the perspectives of Canadian child protection workers accepted for publication in a special issue on parenting with intellectual disabilities at the *Journal of Applied Research in Intellectual Disabilities*). The objectives of this study were to identify needs of child protection workers supporting parents with intellectual disabilities during child protection investigations and to examine what workers think influences supports for parents. A total of 11 child protection workers employed in diverse regions of Ontario were interviewed. Workers had experience in child protection ranging from 1 to 27 years and commonly had an educational background in social work. Exact numbers of cases involving

parents with intellectual disability were difficult to estimate due to challenges with defining intellectual disability.

The findings of this study presented a more nuanced picture of what happens in child protection investigations outside of the formal court proceedings seen in Chapter 4. Child protection workers in Chapter 4 expressed feeling overwhelmed by the intensity of their role (also expressed by social workers in Pacheco et al. 2022a and Lewis et al., 2015), in which they provided multidimensional supports to parents with intellectual disabilities. These included coordination and navigation of services, social support for parents, connecting supports for children (daycare, respite, therapy, medical services), as well as informal accessibility accommodations, such as explaining documents in plain language. Workers identified that they received no training in intellectual disabilities or how to assess and provide accessibility accommodations. Furthermore, workers expressed feeling unsure of how to support parents in cases where lawyers recommended against a developmental evaluation on grounds that it could hurt the parents' court case. Workers identified that parents who had an identified intellectual disability had more access to supports and were more likely to keep custody of their children than parents who did not have access to specialized services. Moreover, despite lack of training and despite biased language in formal child protection guidelines (e.g., Eligibility Spectrum; OACAS, 2021), workers often took a layered approach to assessing child protection risk. They did not rely solely on intellectual disability status and considered factors such as poverty, mental health and social support in custody decision-making, in contrast to previous research (e.g., Pacheco et al. 2021).

This study highlighted the need for coordination between agencies providing adult developmental services and child protection services. Although these services are provided by

the same sector and ministry in Ontario, service providers are often siloed. More collaboration between adult developmental services and child protection services could enable this sector to provide more effective services for parents with intellectual disabilities.

In Chapter 5, we present a manuscript that reports an inclusive research study conducted with parents with intellectual disabilities accepted for publication at the *Journal of Intellectual Disabilities* (currently in press). In conducting research examining child protection decisions in Canada, it was essential to include the voices of parents with intellectual disabilities themselves and analyze their perspectives using inclusive research methods. The primary study objective was to examine the barriers and facilitators of positive parental outcomes in child protection based on the lived experience of parents with intellectual disabilities. This study was conducted in collaboration with a co-researcher who identified as having an intellectual disability and was also a parent with lived experience of undergoing a child protection investigation.

The manuscript provides a detailed method section regarding the involvement of the co-researcher, who was a key research team member and was involved at several stages of the research process, including development of accessible research materials, recruitment, data collection and data analysis. Several tools were used to orient the co-researcher to complex research processes including how to conduct interviews via roleplays and modeling. Furthermore, several practice sessions were completed before conducting collaborative data analysis sessions.

The findings highlighted that social supports, particularly relationship/marital partners and extended family members, were considered key supports by parents with intellectual disabilities, consistent with previous literature (Koolen et al. 2020; Potvin et al. 2019). Parents who were socially isolated commented on the lack of such support and recognized how valuable

it would be in their lives. Parents who were socially isolated also identified the child protection agency as an instrumental source of support. In fact, some parents attributed their positive family outcomes to their child protection worker. The findings of Chapter 5 demonstrated that some child protection workers practiced relationship-based social work, which was directly related to positive outcomes for parents (e.g., Tarleton & Turney, 2020); however, this also highlighted the need for adult developmental support services. Despite the emerging positive experiences, parents experienced many accessibility challenges throughout the child protection process in this study. These included difficulties understanding the investigation processes, feeling bewildered with the complexity of court systems, reading documents with complex language and having little to no support with executive function tasks (such as scheduling and planning meetings). Furthermore, some parents had internalized negative attitudes and presumptions about lacking parenting capacity, while others had more conviction in their ability to parent with support.

Parents also provided advice to other parents who may be undergoing similar experiences by expressing the importance of being vocal about supports, being assertive when treated unfairly and having open and honest communication with child protection workers. Chapter 5 presents implications for using inclusive research methods to connect with lived experience of parents, mitigating accessibility barriers in the child protection process as well as implications for enabling parents to build a strong social support network, as this is a key factor in determining positive family outcomes. There may also be regional differences in social work practice in child protection agencies across various regions of Canada (even within Ontario) that are discussed in Chapter 5.

Inequities Conceptual Framework

The sections that follow present the implications of this dissertation using the *Inequities Conceptual Framework for Disabled Parents Involved with the Child Welfare System* as a baseboard for a critical discussion. Figure 6.1 presents the original inequities model as proposed by Powell et al. (2024). As described in Chapter 1, this is the first conceptual model in current scholarship on parents with intellectual disabilities to present a structure to understand the specific inequities experienced by parents with intellectual disabilities in matters of child protection. It should be noted that the terms “child protection system” and “child welfare” are used interchangeably within this chapter (and throughout the dissertation). Based on the social model of disability (e.g., Barnes, 2019), the Inequities Conceptual Framework is divided into three levels: 1) Contextual level, which refers to societal barriers; 2) Institutional level, which refers to organizational or agency-specific barriers, and 3) Individual level, which refers to parental or familial characteristics, history and interactions. A more detailed description of the factors covered at each level of the model is presented in Chapter 1. The inequities resulting from barriers at each level include overrepresentation within child protection, lack or denial of appropriate supports and services and high rates of termination of parental rights.

This dissertation has important implications at each level of the conceptual model and each factor’s relevance to this dissertation is discussed below, followed by proposed interactions between factors (see Figure 6.2). It should be noted that a new factor is proposed at the Individual level (relationship between children protection workers and parents).

Application of Conceptual Framework to Dissertation

Barriers at the Contextual Level

Societal attitudes. Many community stakeholders, including teachers, health providers, social service workers, school professionals, and legal professionals have negative attitudes

toward persons with intellectual disabilities having children, leading to presumptions about parenting capacity (e.g., Strnadova et al., 2017), which in turn may lead to inequities such as inadequate services and supports and unfair referrals or reports to child protection by community members (e.g., DeZelar & Lightfoot, 2020). Societal attitudes in this dissertation can be best understood as a twofold concept: 1) attitudes toward parenting in general, and 2) attitudes toward persons with intellectual disabilities as parents.

As explored in Chapter 3, parents with intellectual disabilities are often held to unfairly high standards of parenting ability in the name of ‘good enough parenting’ (Choate and Engstrom, 2014), a concept that is still not well-defined in the literature (apart from a breakdown into 12 components proposed by Zijlstra, 2012). There is consensus that good enough parenting entails providing children unconditional love, setting boundaries, meeting needs and having positive interactions with children (e.g., Eve et al., 2014). Parenting is conceptualized as a complex process and dynamic group of activities necessary for nurturing and raising a child (Horowitz, 2014). In Western or Eurocentric societies, parenting has largely been understood as a task performed by a mother and father that comprise the traditional nuclear family unit (Vicedo, 2017, Sear, 2016). However, the reality is that the definition of family and parenting has undergone significant evolution over the past several decades (Sear, 2016). In the changing social landscape of the 21st century, family can no longer be defined as a nuclear unit. Similarly, parenting can no longer be conceptualized as an independent activity or task performed by a mother or a father in a social vacuum; it is heavily influenced and informed by the social fabric in which a family exists, including extended family, friends, neighbors, community and social supports, and service providers (Tilbury & Tarleton, 2023).

Despite the understanding that being a parent is an incredibly complex role that no person receives training or preparation for and for which most parents are expected to need help and support, when a parent has intellectual disabilities, social service professionals often revert to an outdated understanding of parenting, evident in parenting capacity assessments and judgements made (about intellectual disability) within court cases (as seen in Chapter 3). This “attitudinal legacy” toward parenting with intellectual disabilities traces back eight decades as demonstrated in a well-established body of literature (McConnell et al., 2021b; Spencer et al. 2024). This leads to a troubling implication of this dissertation that negative societal attitudes are driving provincial courts in Ontario, Canada (and likely the rest of the country), as recently as 2022, to rely on intellectual disability as the primary reason to terminate parental rights.

As Spencer et al. (2024) argued, when service professionals misunderstand the parenting role as an independent activity, the resource implications are overwhelming and lead to poor judgements about parenting capacity. If parenting can be reframed as an interdependent activity, in which there are other essential social players that provide ongoing and long-term support for parents with intellectual disabilities, the question becomes not of parenting capacity for one individual, but rather of “resource allocation and viability” (Spencer et al. 2024). If we continue to conceptualize provision of parenting supports as short-term solutions that lead to absolute independence for parents with intellectual disabilities, this vulnerable group of parents will likely continue to have repeated encounters with the child protection system and the inequities they face will be perpetuated. Although emerging positive attitudes were noted in Chapters 4 and 5, the shift in attitudes has not yet made its way to legal professionals. As seen in Chapter 4, child protection workers reported that lawyers advised parents to not undergo developmental evaluation because they likely assume it is a parenting capacity assessment, which they perceive

as detrimental to the parents' case. It is imperative to identify collaborative solutions in these cases where workers are taking a rights-based approach, but the unfortunate history of the child protection system prevents them from following through with this support. Parents may also feel discouraged from seeking help and support due to persistent negative attitudes as it was clear in Chapter 5 that many parents have internalized negative attitudes toward parenting with intellectual disability.

State and federal laws and policies. In Canada, there is no specific legislation or law related to persons with disabilities (and by extension persons with intellectual disabilities). Canada ratified the UNCRPD in 2010 which clearly states the rights of persons with disabilities to build a family and become parents. The United States has a defined legislation proclaiming the rights of Americans with Disabilities (Americans with Disabilities Act; ADA; U.S. Department of Justice, 2015) and a federal report highlighting the injustices toward parents with intellectual disabilities and guidelines for protecting their rights (National Council on Disability, 2012); however, Canada has no such equivalent. This absence of disability rights legislation likely has a major impact on persons with disabilities involved in the justice system who have little legal recourse to assert their rights, particularly parents with intellectual disabilities involved in child protection proceedings, where the rights of children are paramount and often considered in direct opposition to the rights of parents with disabilities (Powell et al., 2020).

Relevant legislations in Canada include the Accessible Canada Act (Government of Canada, 2019) and some provincial legislations including the Accessibility for Ontarians with Disabilities Act (Government of Ontario, 2016) and Accessibility for Manitobans Act (Province of Manitoba, 2023), amongst others. These legislations provide broad guidelines for building accessibility standards and policies for provincial organizations. Although child protection work

falls under provincial jurisdiction, accessibility within child protection services is not directly mentioned within any legislative framework across provinces (or even federally). The rules for compliance and reporting are unclear leading to inconsistent implementation (or no implementation at all). No existing organizational policies or plans for accessibility at child protection agencies (aimed at parents undergoing investigations) across Canada currently exist although the aforementioned legislations call for development of specific accessibility plans. It should be noted that although accessibility is mentioned for different disability groups within provincial and federal legislations in Canada, cognitive accessibility as it pertains to persons with intellectual disabilities is not acknowledged anywhere. For parents with intellectual disabilities in child protection, cognitive accessibility accommodations would mean simplified processes, forms and documents in plain language, instructions adapted for easy comprehension, support for organizational and executive function tasks, and tailored parent education programs (Janeslatt et al., 2019; Wade et al. 2008).

It was evident across all three studies conducted in this dissertation that neither disability rights nor (cognitive) accessibility accommodations were formally considered or evaluated at any stage of the child protection process, starting from the initial contact and ending with a court trial. This marked absence of accessibility considerations was noted in published court cases in Ontario, expressed by parents with intellectual disabilities as well as mentioned by child protection workers supporting parents with intellectual disabilities without training in disability or accessibility. It can be argued that inequities such as inappropriate supports and services or denial of supports and services (Powell et al. 2024) continue to persist due to a lack of clear legal mandates of accessibility and disability rights for child protection agencies. Similarly, there is a lack of established policies on how to support adults with intellectual disabilities considering

parenthood leading to no support and parents falling through the cracks, culminating in child protection investigations.

To further complicate the picture, unforeseen contextual factors such as global health emergencies (e.g., COVID-19 pandemic) may result in additional regulations and policies across the country or province that can exacerbate existing barriers for parents with intellectual disabilities. As demonstrated in Chapter 3, cases had longer timelines with limited access visits between parents and children as a result of the pandemic; however, these barriers were often not taken into consideration during custody decision-making, where a lack of parent-child attachment was indicated despite it being a byproduct of the pandemic. This finding supports the argument made by Pacheco et al. (2024) that attachment frameworks may not be appropriate for child protection decision-making for parents with intellectual disabilities, similar to Indigenous parents (Choate & Tortorelli, 2022).

Availability of formal services and supports. Powell et al. (2024) described formal services and supports as community-based services provided by governments and regional organizations to support persons with disabilities. This may include a variety of services including funding programs, housing support, parenting education, family supports, respite/daycare, and independent living support. These services are meant to help persons with disabilities support themselves and their families to participate in society. Services for parents with intellectual disabilities tend to be scarce and siloed within sectors (e.g., Pacheco et al. 2022a). For example, in Ontario, child protection services and disability services are governed by the same ministry (Ministry of Children, Community and Social Services; MCCSS); however, there is no coordinated strategy between agencies across these two types of services. Chapter 4 of this dissertation highlighted the unmistakable gaps in training for child protection workers

who had little to no knowledge of intellectual disabilities, received no training or resources about cognitive accessibility specifically for this group of parents, and felt overwhelmed and burned out due to the heavy demands of their role. Siloed social services are a common theme in literature on services and supports for parents with intellectual disabilities (e.g., Pacheco et al., 2022a; Brown et al., 2022).

Chapters 4 and 5 highlighted the experiences of parents who identified the child protection agency itself as an instrumental support system, which contrasts with research showing that child protection workers are usually in a more adversarial role (e.g., Strnadova et al., 2017). We know that social support is a protective factor in child protection and parents with intellectual disabilities who have strong social support fare better than parents who are socially isolated (Koolen et al., 2020). Based on parent experiences reflected in Chapters 4 and 5, parents without a social support network often attributed their positive family outcomes to the child protection workers who helped them get a diagnosis for their own disability leading to formal disability supports as well as services for their families. However, these experiences do not reflect the norm in child protection practice and may be a regional difference as suggested in Chapter 5. Formal services and supports as well as social work practices may differ across geographical regions and impact not only the availability of services and supports, but also access to available services, coordination across service programs and ability to avail services. This dissertation provides important evidence of the need to examine regional child protection practices separately to identify what works in achieving positive outcomes for families headed by parents with intellectual disabilities.

Barriers at the Institutional Level

Agency-systemic factors

Institutional ableism. As defined in Chapter 1, ableism is a way of thinking that perpetuates prejudiced attitudes towards persons with disabilities leading to discriminatory practices and policies (Bogart & Dunn, 2019). This is particularly evident in provincial child protection standards across Canada. In Ontario and Manitoba, the child protection standards include discriminatory language related to parents with intellectual disabilities. As mentioned by child protection workers in Chapter 4, intellectual disability is coded as a “moderate risk”, which is also noted within formal published child protection standards in Ontario (OACAS, 2021). Overall, the provincial and organizational policies are not inclusive and tend to have several limitations including short timeframes for child protection decision-making by social workers who feel out of depth. These policies likely discourage relationship-based social work practice, which is the recommended evidence-based standard in social work and leads to the most positive family outcomes in child protection (e.g., Lehtme & Toros, 2020).

Training for staff about disability. As indicated in Chapter 4, a majority of child protection workers’ experiences reflected the lack of disability training, and by extension, intellectual disability training. There are no government-sponsored training programs or agency-organized workshops or learning resources to learn how to work effectively with parents with intellectual disabilities that were mentioned by child protection workers in Chapter 4. This is in line with previous literature showing that social workers often do not receive specialized knowledge or education in intellectual disabilities (e.g., Norlin & Randell, 2019). This lack of knowledge and training may lead to difficulties in practicing relationship-based social work because workers may not understand the complex needs of families headed by parents with intellectual disabilities, which can subsequently lead to bias in custody decision-making, which was reflected in the experiences of many parents in Chapter 5.

In this dissertation, child protection workers expressed their demanding and intensive role that includes necessary tasks and activities that parents are not being offered elsewhere (or are unable to access it elsewhere). For example, they shouldered the heavy burden of navigating services and supports and offering a service coordination role while not having sufficient information about services themselves or knowledge and education about how to assess specific needs and connect parents with services that fulfill those needs. Workers engaged in relationship-based practice were praised by parents who had no other supports, but it may have come at the price of burnout and frequent turnover in child protection agencies, as shown in previous literature (Cabiati et al. 2020). Parents with intellectual disabilities have cognitive accessibility needs that were not formally addressed as reflected in parents' experiences (see Chapters 4 and 5); however, child protection workers took upon themselves to provide accommodations such as adapting information in plain language, creating organizational materials to support parents with executive function, and even advocate for them to access services. These parents may ask for their cases to be kept open for longer, which child protection agencies may not have capacity to provide as they are often working with limited resources. These gaps in knowledge, training and resources for child protection workers attempting to do well in a difficult role highlight the need for changes to occur at an organizational level to increase capacity within the system rather than leaving it entirely up to the child protection worker.

Accessibility. Accessibility emerged as a hallmark factor that interacted with a multitude of other factors at all three levels and impacted inequities experienced by parents with intellectual disabilities highlighted in Chapters 3-5. This factor is closely connected to the contextual factor: state and federal laws and policies. For accessibility to be considered or implemented at an institutional level, laws must first exist to mandate accessibility in child

protection services and consideration of human rights and disability rights must take place at a contextual level. Subsequently, laws must be translated into organizational accessibility policies and plans. No such framework for considering the rights of parents with disabilities exists in Canada, leading to a lack of guidelines at the child protection agency level. Although some physical accessibility accommodations were provided in court proceedings in Chapter 3, there was no formal process, consideration or even mention of the need for cognitive accessibility accommodations outside of the support provided to parents by workers practicing good relationship-based social work (in Chapters 3-5). This may not always be the case and inexperienced workers may incorrectly evaluate accessibility challenges as uncooperativeness or even child protection concerns. As Powell et al. (2024) pointed out, we must widen our understanding of accessibility to include not only things such as wheelchair-accessible buildings but also accommodations during complex court processes, parent education classes, as well as forms and documents. This dissertation makes a strong case for organizational policies on cognitive accessibility for parents with intellectual disabilities at an agency level.

Relationship with disability community. Powell et al. (2024) described this factor primarily as it related to child protection services having a relationship with disability advocacy groups. However, it may also include forming linkages between child protection services and formal disability service providers. These linkages are key to positive family outcomes as seen in the present dissertation. In cases where parents who received both disability services (i.e., adult developmental services) simultaneously with child protection services, there is collaboration and communication between the disability service provider and the child protection worker. Child protection workers in Chapter 4 expressed decreased intensity in their own roles when disability supports were also being provided to parents with intellectual disabilities. These findings further

highlight the need for better collaboration across the two types of services: child protection and disability supports. This implication is explored further in a following section (Aligning Goals).

Parenting assessments. Much of the existing literature on parenting capacity is focused on deficits or indicators of poor parenting rather than what constitutes good (or ‘good enough’) parenting (Choate & Engstrom, 2014). Parenting capacity assessments conducted for the purpose of evaluating parenting skills when there are child protection concerns have historically focused on psychological evaluation (e.g., Azar et al., 2012). However, psychological evaluations or IQ assessments are considered inappropriate in a child protection context (APA, 2013). Inadequate parenting capacity assessments have long been used to justify termination of parental rights in child protection cases involving parents with intellectual disabilities (e.g., Callow et al. 2017; Aunos & Pacheco, 2021). Chapter 3 corroborated this trend in court proceedings in Ontario demonstrating ultimate reliance on parental IQ or intellectual disability status to remove custody of children.

In recent years, Ontario has reconceptualized child protection services (Government of Ontario, 2020); as a result, parents are no longer referred to parenting capacity assessments for child protection evaluation. In Chapter 4, many workers commented that parenting capacity assessments are no longer conducted, making their job much more difficult because of parents who may have suspected intellectual disability, but are not identified and therefore receiving no supports and services. If child protection workers mentioned an assessment or evaluation, parents’ lawyers immediately assumed that it may be a parenting capacity assessment and a diagnosis of intellectual disability would hurt their case; therefore, they discouraged parents from pursuing any assessment (as reported in Chapter 4). Future research must examine how new organizational policies resulting from legislative changes (i.e., no more capacity assessments)

impact inequities experienced by parents. In other words, parents with intellectual disabilities may not experience prejudice by way of parenting capacity assessments but instead end up disconnected from necessary support services which may lead to repeated contacts with child protection agencies.

Although the extant literature paints a grim picture, the present dissertation shows a promising shift in attitudes in child protection workers who conduct risk assessment based on a careful balance of social factors, including mental health, poverty and other social conditions instead of only considering parental intellectual disability, as demonstrated in Chapter 4.

Human decision-making factors

Bias. Bias is also rooted in negative attitudes and presumptions about the parenting ability (or lack thereof) of parents with intellectual disabilities, which can directly impact child protection decisions. At the institutional level, child protection workers conducting risk assessments and making judgements about whether a parent should keep custody of their child are directly impacted by bias regarding the “static” nature of intellectual disability (e.g., Powell, 2017). In the present dissertation, bias in decision-making was noted in Chapter 3 focused on published court cases. In some instances, judges concluded that although parents have the necessary supports, they will always have intellectual disability, which will *necessarily* continue to impact their parenting capacity (see Chapter 3). However, in Chapters 3-5, a surprising lack of bias toward parenting with intellectual disabilities was noted and this led to parents receiving more adequate services, being more well-connected within the community, and developing strong and trusting relationships with their workers. This dissertation has implications for developing and strengthening reflexive practices at child protection agencies that encourage workers to evaluate their own biases and presumptions when engaged in child protection

decision-making with parents with intellectual disabilities to decrease the disparities experienced by this group.

Lack of disability-cultural competence. Cultural competence and humility refers to obtaining a cross-cultural understanding of the practices and attitudes towards social roles (such as parenting; Ortega & Faller, 2011). Although this dissertation was not focused on cross-cultural themes, understanding disability culture is a key component of disability knowledge and skills that was missing from the repertoire of most child protection workers, as reported in Chapter 4. Building this competence is important because it is a key influence in human decision-making (Boyd, 2014). When there is an institutional understanding of social roles and activities as interdependent, especially parenting (e.g., Tilbury & Tarleton, 2023), child protection workers will be expected to make decisions based less on individual capacity and more on available resources and how to keep parents with intellectual disabilities connected with services for long-term supports (Spencer et al. 2024). This was demonstrated in Chapters 4 and 5, in which child protection workers extended beyond their roles to connect parents with appropriate support services.

Inconsistent decision-making. The above two institutional factors likely interact to directly impact decision-making, which can become inconsistent in the absence of established policies and guidelines at the institutional level. Child protection workers may have varying levels of bias and disability competence (i.e., the previous two institutional factors), leading to inconsistent judgements about parenting capacity in the absence of formal policies at the agency level. As reported in Chapter 4, workers were often uncertain of how to properly support parents with intellectual disabilities owing to their own lack of training and knowledge. This may have led to inconsistent decisions about custody, where some parents with intellectual disabilities keep

custody and some do not, depending on the workers' best judgement with the limited tools and resources available to them. These findings highlight the need for child protection agencies clearer guidelines to support decision-making when conflicting rights must be balanced (i.e., rights of the parents and rights of the child).

Barriers at the Individual Level

Parent and family characteristics

Disability experience. Powell et al. (2024) described the type of disability as a basic individual factor that likely leads to inequities in the child protection system. As discussed extensively thus far, this dissertation and the extant literature demonstrate that a parent having an intellectual disability leads to termination of parental rights more often than a parent not having an intellectual disability (e.g., Brown et al. 2018; Tahir & Cobigo, 2023). Some parent experiences in Chapter 5 also reflected child protection agencies' negative attitudes toward disability that impacted custody decisions and led to the permanent loss of child custody.

Sociodemographic characteristics. This individual factor was not directly examined in this dissertation. However, it should be noted that workers took intersecting social identities into consideration during decision-making in Chapter 4. They considered parents' mental health, low-income status and social factors other than their intellectual disability, which acknowledging that parents are more likely to experience these adverse conditions when they have an intellectual disability.

Social supports. As demonstrated in a well-established body of literature (e.g., Koolen et al. 2020; Potvin et al. 2019), social supports were found to be an instrumental individual factor for parents with intellectual disabilities in the present dissertation. In Chapter 5, partners, grandparents and extended family members were essential in providing social supports to parents

and advocating for their needs. Parents identified their spouse or long-term relationship partner as an essential source of social support. This likely impacted their ability to avail themselves of social services, improve their parenting skills and improve their social conditions leading to more positive family outcomes (thereby decreasing the inequity of having parental rights terminated due to lacking social supports). Furthermore, parents also gave advice for other parents with intellectual disabilities to be vocal about the supports they need (see Chapter 5). This dissertation underscores the need to build capacity within families to establish appropriate social support networks. This can begin at an institutional level via trainings for workers and various platforms for parents to build a social support network (such as parent support groups). This would result in mitigating this individual barrier for parents and increase social connectedness, while becoming a protective factor against child protection investigations (Lietz et al. 2011). This would also reduce the burden for workers who essentially become the only source of social support for parents who are not well-connected in their community and are socially isolated, as shown in Chapter 5. Enabling parents to expand their social supports may also reduce the need to keep cases open for longer because parents are meeting this need via other avenues, rather than relying on their child protection workers.

Interactions with the child protection system

Prior involvement. Parent experiences captured in this dissertation demonstrated that parents with intellectual disabilities who became involved with the child protection system either had previous involvement or continued to stay involved (i.e., case files kept open). This is similar to previous research showing that parents who had a history of losing child custody during child protection have a greater likelihood of having the same experience (e.g., McConnell et al., 2008a). Parents with intellectual disabilities are also likely to have their cases remain open for longer (e.g., Llewellyn & Hindmarsh, 2015). However, the present dissertation presented a

nuance previously unexplored, in which the child protection agency itself became a key support for parents. Some parents in Chapter 5 requested their files to remain open because they had access to social and emotional support and resource navigation that was not otherwise available to them. This has important implications for research because what may look like inequity in the child protection system (i.e., longer case timelines and more scrutiny) for parents with intellectual disabilities is, upon closer look, a lifeline of support for parents who are otherwise socially isolated and disconnected. It is essential to explore pathways for parents to access these supports outside of the already intensive and demanding roles of child protection workers.

Relationship with child protection staff during involvement. This is a new proposed factor to capture the importance of relationship-based child protection practice. As evidenced in Chapters 4 and 5 (and existing knowledge base in child protection such as Lehtme & Toros, 2020), good relationship-based social work involves building rapport and trust with parents being supported. When parents with intellectual disabilities can see that their worker believes in them and their parenting ability, is committed to helping the family meet their needs, parents are able to improve their family situation, improve parent-child interactions, seek the help they need, and avail themselves of the supports available to them (e.g., Tilbury & Ramsay, 2018). This scenario was demonstrated in several parents' experiences in Chapter 5. However, relationship-based practice may only be possible when the appropriate tools and resources are available to child protection workers at the institutional level to build competencies and skills related to disability needs, culture and accessibility. This would directly impact involvement with child protection agencies (the previous individual factor) and build positive experiences over time and ameliorate the pejorative meaning associated with longstanding support for parents with intellectual disabilities that leads to inequities (Spencer et al. 2024).

Out-of-home placement. This factor was not directly examined in this dissertation. However, it should be noted that many parent experiences described in Chapter 5 did not include permanent loss of custody. This could be due to recruitment bias as participants were mainly recruited from parenting support agencies and several of them were well-supported in their parenting roles.

Proposed Interactions Between Factors

Based on the discussion above, proposed interactions between factors in the Inequities Framework are presented in Figure 6.2. Orange lines hypothesize relationships that likely exist but were not explored directly in this dissertation. The blue box is a new factor introduced at the individual level in the conceptual model (i.e., relationship with child protection staff during involvement). Black lines depict interactions explored in this research but need to be empirically validated. Some relationships are proposed to be bi-directional while others are unidirectional.

Accessibility is moved to a space between the three levels as it interacts with factors at all three levels, but really begins at the contextual level. Due to a lack of specific legislation related accessibility within child protection services or family courts, there is no accessibility **training provided to staff**, which impacts **disability competence** along with **institutional ableism** as seen in courts and in experiences of parents in this dissertation. Where there is low **disability competence**, the chance of **bias** related to disability and assumptions about disability are increased and lead to poor and **inconsistent decision-making**. Tools are not available for workers to be competent in disability-related decisions which presents in the form of inequities such as **denial of appropriate supports and services**, which loops back to **availability, access and coordination of appropriate supports** at the contextual level. At the individual or relational level, **relationship between workers and parents** is an important new proposed

factor that likely interacts with **social supports**, which subsequently interacts with availability of supports and services.

Aligning Goals: Coordination of Services

A major policy implication of this dissertation is the immense need for coordination of social services for adults with intellectual disabilities. Despite operating within the same sector in Ontario and being governed by the same ministry (MCCSS), child protection services and disability services for adults with intellectual disabilities are severely fragmented and do not communicate effectively with each other, or at all. It can be argued that this lack of planning results from a lack of anticipation that adults with intellectual disabilities will become parents and need parenting support. This roots back to contextual and institutional attitudes that ignore the sexuality of persons with intellectual disabilities (e.g., Correa et al. 2022) and discourage them from becoming pregnant and pursuing parenthood (e.g., Strnadova et al., 2017)

As corroborated in this dissertation and demonstrated in recent studies, obtaining a diagnosis of intellectual disabilities could be the catalyst for accessing appropriate supports and services (McConnell et al., 2021a). Lawyers or legal representatives may discourage developmental evaluations due to a history of discriminatory practices. Although child protection workers in this dissertation reported that capacity assessment are no longer conducted in Ontario, child protection practices may vary across provinces and jurisdictions. This breakdown in communication underscores the necessity for child protection services, disability services, as well as legal services to collaborate and discuss best practices to ensure that comprehensive and effective support systems are in place for parents.

The need for interagency collaboration and coordination of services for parents with intellectual disabilities has long been recognized in the literature (Tymchuk, 1999; Pacheco et al.

2022a). There have been recent examples of nationwide programs to provide coordinated and early support for parents with intellectual disabilities (e.g., McConnell et al., 2008b). However, these are often temporary and supports for parents remain scattered (Spencer et al., 2024). For example, the *Healthy Start* program in Australia was a federally funded organizational-level program aimed at building capacity within the system to support parents with intellectual disabilities in the early years of parenthood (McConnell et al., 2008a). It was led by local champions and state leaders across the country and utilized several capacity building strategies including top-down, organizational approaches (infrastructure and policy changes), bottom-up organizational approaches (staff knowledge and skills related to intellectual disability), network partnerships (building and strengthening relationships between organizations) and community organizations (engagement and leadership of community members). Specific organizations across health, education and welfare domains were represented. *Healthy Start* was organized as a technology-based network, with resources publicly available on an online repository (Healthy Start, 2014). McConnell et al. (2008a) reported over 900 practitioners being part of the network. However, due to lack of funding and introduction of new federal initiatives (Royal Commission, 2023; Spencer et al. 2024), the Healthy Start program was discontinued. As MacIntyre et al. (2019) pointed out, the resource implications for supporting parents with intellectual disabilities can be extensive, leading to them being overlooked and falling through the cracks, despite practitioners knowing the disparities impacting these parents.

In Ontario, the expertise required to communicate and interact with persons with intellectual disabilities exists in disability service agencies but not yet in child protection services. Using a strategy similar to *Healthy Start* (McConnell et al., 2008a), on a smaller scale, these two types of social service providers can engage in dialogue, exchange training and

learning resources, and become informed about accessibility, disability rights, and effective support mechanisms for adults with intellectual disabilities who choose to become parents. A technology-based network and regional champions can pave the way to form partnerships between agencies and collaborate effectively. More specifically, disability providers and child protection agencies can collaborate to offer tailored parent education programs, sexual health education, and relationship counseling to adults with intellectual disabilities as they enter social services. Planning for these life stages as part of standard service planning for adults with intellectual disabilities can prevent later reactive interventions such as child removal and termination of parental rights. In fact, a proactive approach may mitigate many of the contextual and institutional barriers faced by parents with intellectual disabilities, which become conflated with individual barriers.

In the Ontario context, it is important to take lessons from the intersectoral collaboration between the Ministries of Health, Long-Term Care and Child and Community Social Services on the dual diagnosis strategy, which integrates developmental and mental health services for persons with intellectual disabilities and a mental health diagnosis (Government of Ontario, 2008). The dual diagnosis strategy states that it is a complex condition that requires multifaceted services from health and social services. Furthermore, it mandates shared responsibility of services for persons with a dual diagnosis in Ontario. The strategy also provides guidelines for breaking down barriers to service access, creating partnerships between organizations and expanding linkages through local and regional community and health networks. Similar to the dual diagnosis strategy, sexuality, relationships and parenthood must be domains embedded within services for persons with intellectual disabilities at the outset (i.e., first point of contact at

Developmental Services Ontario; DSO, 2024), and there must be provincial mandates for collaboration between disability service providers and the child protection agencies.

In planning for coordination across disability services and child protection services, it is crucial to explore resource pathways that enable child protection workers to effectively practice relationship-based social work without burning out. This must occur not only at the individual level but also an institutional level, as research has shown that organizational satisfaction is a stronger predictor of worker retention than reducing workloads (Brown et al. 2019; Nilsen et al. 2023). Child protective agencies must invest resources in training needs assessments and program evaluation to ensure workers feel well-supported in their demanding roles. Investing time and resources in building relationships is crucial, both in helping parents develop their social support networks and in fostering positive relationships between parents and workers during child protection proceedings. The concept of "slow social work," as proposed by Spencer et al. (2024), advocates for allowing time and space for extended support periods without judgment or punitive measures. This approach facilitates relationship-based practice, which has an established evidence base for its effectiveness, provided time is allowed for it to take place. It is imperative, in Ontario, that we seriously consider how to incorporate slow social work for better family outcomes.

Overall, we must re-evaluate how we think about support services for parents with intellectual disabilities. Rather than offering band-aid solutions, we need to provide longstanding support. As mentioned previously, parenting can be re-conceptualized as an interdependent activity, not merely an individual undertaking, but a collective responsibility. Understanding parenting in this way necessitates planning for support at both policy and community levels.

Strengths and Limitations

In addition to the myriad research, practice and policy implications discussed above and a theoretical contribution to the *Inequities Conceptual Model* (Powell et al. 2024), this dissertation has two major methodological contributions: 1) use of published court records in Ontario for qualitative content analysis; and 2) use of inclusive research methods.

Use of Published Court Records

This dissertation's first strength is the use of a scarcely used data source in qualitative research on child protection. Although some research has utilized published court cases for quantitative data analysis (e.g., Galliher, 1973; Glaun & Brown, 1999), only a handful of studies have used these as a qualitative data source for qualitative content analysis (e.g., Aunos & Pacheco, 2021; Sigurjonsdottir & Rice, 2017). Published case records at the trial and appellate level (both of which get published in Ontario) offer many advantages in child protection research as outlined in Chapter 3. These include ease of access to publicly available data, which includes key case elements, including the parents' sociodemographic information, evaluations and assessments, the workers' decision-making process and the overall analysis of the cases conducted by the court judge. These layers of information could otherwise be difficult to access directly due to logistical and ethical challenges. Due to the sensitive nature of child protection research, and gatekeeping in social services (e.g., Williams, 2020), parents with intellectual disabilities may be difficult to recruit or engage regarding their contact with child protection (as seen in Chapter 5). Court case records provide an alternative source of data to circumvent these challenges while advancing research in this area. Published case records also provide a solid vantage point from which to examine institutional and systemic barriers that may be experienced by individual stakeholders (including parents, workers, family members, etc). The case records

often provide a comprehensive or “big picture” view of the child protection case from start to finish and how decisions were made at various points.

Published case records are not without limitations and these are also noted in Chapter 3. First, published case records on child protection can be heavily censored to protect the privacy of families and children, resulting in incomplete information on the case. Second, published case records do not offer nuanced details about the case such as parent perspectives or workers’ challenges or the relationship between the child protection workers and parents in each case. These insights can only be obtained by directly involving these stakeholders in research. Third, different provinces/jurisdictions across Canada may have varying rules and guidelines about what type of cases get published, resulting in insufficient information.

Use of Inclusive Research Methods

The second methodological strength of this dissertation is the use of inclusive research methods to involve persons with intellectual disabilities in research decision-making. Persons with intellectual disabilities have historically been excluded from research concerning themselves and the academic research sector has a sordid history of marginalizing this group (Feudtner & Brosco, 2011). Recently, co-researchers with intellectual disabilities have made notable contributions in the literature (e.g., Franklin et al. 2022). However, there are no established guidelines on how to conduct inclusive research. While there is wide consensus on the need for empowerment and justice for persons with intellectual disabilities, and the need to involve them as experts with lived experience (e.g., Walmsley et al. 2018; Nind & Vinha, 2014), very few tools/resources exist for researchers seeking to learn inclusive research methods and strategies. In our study outlined in Chapter 5, we take an inclusive research approach that builds on the lessons learned from the literature (e.g., Nicolaidis et al., 2019; Ghaderi et al. 2023) and

within our own team. A key element of inclusive research is to recognize the contributions of co-researchers with intellectual disabilities. We did this by recruiting a co-researcher with lived experience with intellectual disability as well as being a parent who had contact with child protection (recruited through Open Collaboration with Cognitive Accessibility; Open, 2024). A detailed contract including a schedule of activities and payment schedule was developed with the co-researcher to ensure fair remuneration of their time and expertise. The co-researcher was given tailored training on specific research skills, including how to conduct interviews and how to do qualitative data analysis using strategies such as modelling, visual aids, roleplay and repeated practice (Leaf et al., 2015). They were involved in research decision-making at several key stages: development of research tools (adapting recruitment materials, consent form and interview guide into accessible language), data collection (carrying out a bilingual interview in person) and data analysis (collaborative data analysis sessions using audio recordings of 4 out of 13 total interviews). At each stage, cognitive accessibility accommodations were considered and processes were adjusted to meet the needs of the co-researcher.

The co-researcher's involvement as a research team member impacted the study in key ways. First, the co-researcher made important recommendations to not only make the language more accessible (Easy-to-read; Inclusion Europe, 2024) but also to make questions about child protection experiences more delicate considering their sensitive nature. For example, they suggested asking participants what their preference is in terms of starting with a broad question about their experience (to allow time and space to share their story) or asking them if they would like specific questions (because some parents may feel stuck about where to start and feel uncertain about what to share). Second, the co-researcher carried out one interview in person and the participant commented feeling comfortable and safe sharing their story with another parent.

Third, during collaborative data analysis sessions, the co-researcher guided the process by recommending that it would be more accessible for them to hear audio-recordings of interviews and sharing live feedback verbally (while pausing the recordings at specific points) rather than writing down notes. All training sessions and modifications to processes were documented to create an audit trail and led to improved rigor and validity of the inclusive research methods utilized in Chapter 5.

Limitations

Specific limitations across each of the three studies are addressed in Chapters 3-5. There are overall limitations of this dissertation that must be noted. First, despite carrying out inclusive methods with careful planning and utilizing all available resources, there were logistical and practical challenges associated with the inclusive approach in Chapter 5. Several of the interviews with parents were completed virtually due to geographical limitations and personal preferences. However, virtual interviews were not accessible for the co-researcher which meant they could not lead more than one interview. Transportation challenges are also essential to consider and anticipate even when co-researchers can independently travel using public transportation. On some scheduled meeting days, the co-researcher's most accessible method of transport was out of service, causing challenges with wayfinding and leading to distress. Another lesson learned was to have an open discussion with co-researcher about which stages of research they found most valuable. We offered them authorship on the manuscript in Chapter 5 after discussing the roles and responsibilities of authorship. However, the co-researcher declined noting that data collection and data analysis were most meaningful for them to feel like they are helping other parents and making a difference in their future. It is also important to think more broadly about inclusive research and apply these methods to other groups, such as child

protection workers. A co-researcher who has experience working in child protection with parents with intellectual disabilities would have been a key addition to gaining deeper insights into workers' perspectives in Chapter 4.

The second overall limitation is that other stakeholders at the institutional and contextual levels were not included in the Chapter 4 sample of participants. Gathering the perspectives of decision-makers at the institutional level such as agency directors and the contextual level such as government representatives would lead to a better understanding of why barriers persist at systemic levels (MacIntyre et al., 2019). This would also help to identify specific barriers to developing coordinated services for parents with intellectual disabilities in specific regions.

The third overall limitation is that intersectional factors affecting the child protection experience of parents with intellectual disabilities, particularly ethnic and cultural factors, were not examined. Several parents in Chapter 5 self-identified as having an Indigenous background. Moreover, many workers in Chapter 4 reported working with indigenous parents. However, the role of specific cultural experiences associated with Indigenous cultures could not be examined within the scope of this dissertation. This is imperative for future research given the Canadian context and dark history of forced child removal from Indigenous families (Government of Canada, 2024).

Future research should aim to conduct a comparative analysis of child protection best practices with parents with intellectual disabilities across provinces and territories in Canada. In doing so, recent legislative changes and their impact on child protection practices must be studied. Future research must also examine the barriers contributing to siloed services and preventing interagency planning and collaboration, which lead to persistent inequities for parents with intellectual disabilities.

General Conclusion

This dissertation makes important contributions to the existing knowledge base on parents with intellectual disabilities in child protection and how human decision-making is carried out from various perspectives, under the influence of societal, institutional and personal attitudes and biases toward parenting with disability. Pacheco et al. (2022) noted that parents with intellectual disabilities need not only access to supports but also access to justice. This access to justice can only occur when changes are made at a contextual and institutional level. Positive attitudes are emerging among child protection workers, who have become more receptive to justice for this vulnerable group of parents. However, this shift has not yet reached all stakeholders, including legal and court professionals. It is crucial to examine our cultural and collective conceptualizations of parenting and family-building. Are parents with intellectual disabilities held to the same ‘good enough parenting’ standard as other parents, despite the unique individual, institutional, and contextual barriers they face? To ensure long-term positive outcomes for these families, we must take steps forward to ensure parents with intellectual disabilities are valued members of society, capable of building and raising families with appropriate support. This means creating inclusive policies and procedures, fostering interagency collaboration, and ensuring accessibility accommodations and long-term support. By doing so, we can build a more just and supportive environment and enable this group of parents to raise their families with dignity and respect.

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Figure 6.1

Conceptual Framework by Powell et al. 2024

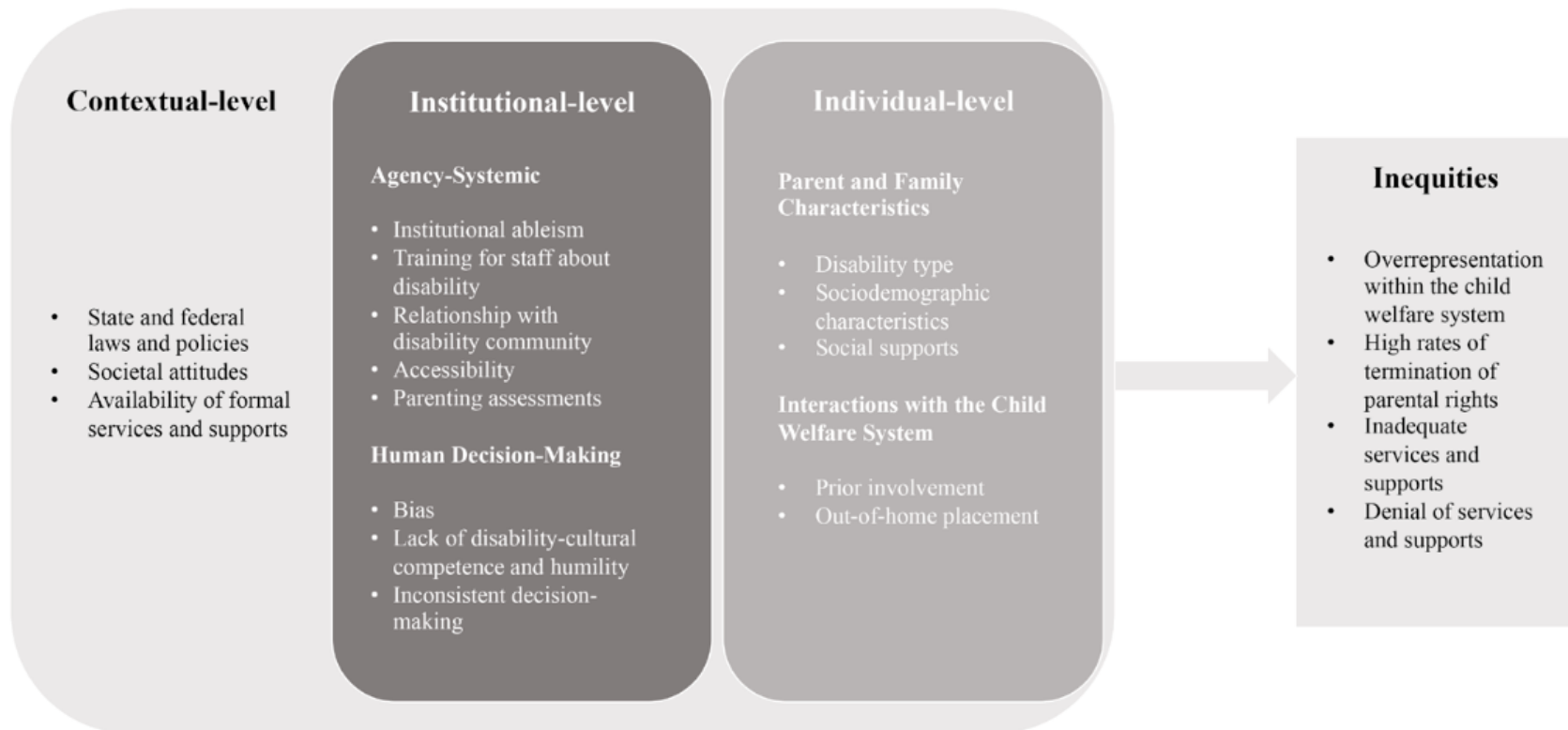
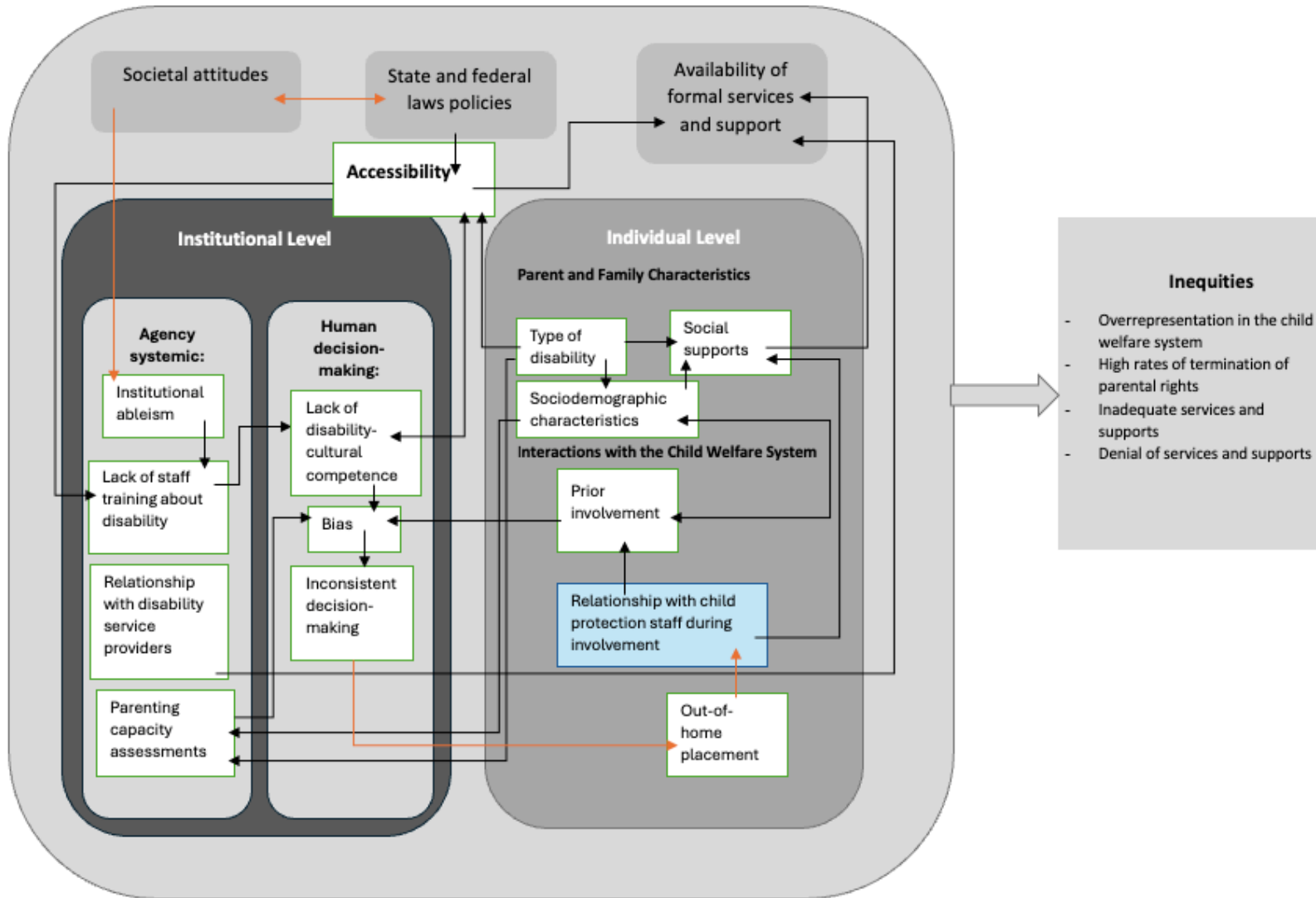


Figure 6.2

Revised Inequities Framework



APPENDIX A
Certificate of Ethics Approval

22/03/2022

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-02-22-7670
Titre du projet / Project Title	Understanding Child Protection Decision-Making in Court Cases Involving Parents with Intellectual Disabilities
Type de projet / Project Type	Thèse de doctorat / Doctoral thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	22/03/2022
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	21/03/2023

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Munazza TAHIR	École de psychologie / School of Psychology	Chercheur Principal / Principal Investigator
Virginie COBIGO	École de psychologie / School of Psychology	Superviseur / Supervisor

Conditions spéciales ou commentaires / Special conditions or comments

APPENDIX B
Supplemental Data - Court Cases Reviewed

All cases below were retrieved from the WestLaw Next database through the University of Ottawa.

Case 1: *Kina Gbezhgomi Child and Family Services v. D.B.-R.*, 2019 ONCJ 891

Case 2: *Simcoe Muskoka Child Youth and Family Services v. K.R.*, 2019 ONSC 3693

Case 3: *Kawartha-Haliburton Children's Aid Society, v. AR and DB*, 2019, ONSC 4191

Case 4: *North Eastern Ontario Family and Children's Services v. M.H.*, 2019 ONSC 952

Case 5: *Huron-Perth Children's Aid Society v. A.C.*, 2020 ONCJ 251

Case 6: *Highland Shores Children's Aid Society v. K.A.D. and A.V.*, 2020 ONSC 4688

Case 7: *The Children's Aid Society of the Regional Municipality of Waterloo v. M.A.L.T. and D.V.*, 2020 ONSC 6313

Case 8: *The Children's Aid Society of Ottawa v. S.D. and J.L.*, 2020 ONSC 7662

Case 9: *Children's Aid Society of Toronto v. A.L.*, 2021 ONCJ 258

Case 10: *Children's Aid Society of Toronto v. S.C.M.K.*, 2021 ONCJ 347

APPENDIX C

Study 2 Interview Guide

**Screening questions: Have you previously worked with a parent with intellectual disability (ID)? How many cases involving parents with ID have you managed? How was ID identified? Please note that you may need to refer to your notes or case files for some interview questions.*

Interview Guide (Caseworkers)

Participant ID#: _____

Demographic Questions

Participant Age: _____

Participant Gender: _____

1. In what field of study did you complete your education? Can you share what degree/diploma you completed (e.g., Bachelors, Masters, Certificate, etc)?
2. How long have you been working with this child protection agency (year you started)?

Case-Related Questions

3. Have you received training or support on handling cases involving parents with disabilities (in general, and specifically, ID)? If so, was it from your agency or other sources of training?
4. What are the reasons for which you typically decide to investigate a child protection call further?
 - i. What was the reason in this case (i.e., the one we are discussing)?
5. What was the reason for the initial call to child protection for the parent with ID? (**may expand this question for multiple cases*)
 - i. Who made the call (without revealing identity – e.g., concerned neighbour, doctor, teacher, etc)?
 - ii. What did you tell the parent about why they were being investigated (and how was this communicated to the parent?)
 - iii. How did you initially contact the parent with ID? (i.e., phone, home visit, or other method)
6. How was the assessment of the situation carried out overall (parenting capacity or other psychological testing)?
7. What documents or sources of information did you consult as you made your decisions?
 - i. Did you consult with other team members or professionals as you made your decisions?
8. What supports did you have as you worked on this case, if any (e.g., organizational or community)?
 - i. Are there any supports that could have been helpful, but were not available?

9. Regarding your ongoing contact with the family and the parent with ID?
 - i. How many contacts did you have in total and how many of these were home visits?
 - ii. Did you observe instance of child maltreatment while you were in their home?
Overall, what were your observations about the parent-child relationships and family dynamics in this case?
 - iii. What methods of communication did you use? Did the parent with ID have a preference for a certain method of communication?
 - iv. Did the parent with ID (and partner, if applicable) understand what was happening in the case?
 - v. What concerns did the parent with ID express to you, if any? (e.g., what questions did they ask?)
10. What programs was the parent with ID referred to? Did they attend the programs?
 - i. Are there other supports you think may have been helpful for the parent with ID?
11. At what points throughout the process did you have to make a decision (e.g., to keep the file open, to close the file, to go to court, etc)?
12. Did you make a final decision regarding child placement/custody? If so, what was the decision?
 - i. What was your reason for this decision?
 - ii. Who else in your agency (in terms of job title) is involved in making decisions about child custody?
13. Did the case go to family court? If so, what is the process for a case going to court?
 - i. Did you continue to stay involved in the case after it went to court?
14. What decision was made by the court?
 - i. Were you expected to appear in court or make any statements during the court process?
15. Did the parent with ID have legal representation?
 - i. Did the parent with ID express the need for legal representation at any point in the process?
16. Did the parent with ID ask you any other questions throughout the child protection process? (**here we want to know whether the parent ever indicated that they don't understand something*)
 - i. Did the parent ask if/when they will see their child(ren) again?
 - ii. Did the parent appeal their case (in case they lost custody)?
17. Was the family reunited after the investigation and court process was complete?
18. Is there anything I haven't asked you that you would like to share about the case(s)?

Thank you for taking part in this study!

APPENDIX D

Study 3 Accessible Interview Guide

We are doing a study on the experience of parents with intellectual disabilities with child protection. Your perspective can help make the system more accessible.

*Do you agree to participate in this study? **If yes, continue.***

*Are you okay with me recording our conversation? We will need to go back and take notes, but nobody other than the research team will hear the recording. **If yes, continue***

I know this is a hard topic to talk about. I am here to listen and I want to give you space and time to tell me your story. It can be hard to answer some of the questions. I want to remind you that you can skip or refuse to answer any questions you don't want to answer.

Do you have any questions before we start?

Can you please fill out these questions before we start:

Age: _____

Gender: _____

Location (City): _____

Language: _____

Background (specify if indigenous): _____

BACKGROUND QUESTIONS

1. How many children do you have and how old are they?
2. Do your children live with you?
 - i. Does anyone help you take care of your kids?
3. Are you working right now?
 - i. Do you work part-time or full-time?
 - ii. Who takes care of the children while you are working?
4. Do you get ODSP or any other disability funding?
 - i. Do you receive services or supports for intellectual disability?

MAIN QUESTIONS

5. Please share your story – feel free to begin wherever you feel comfortable.
6. Have you ever taken a parenting program?
 - i. If yes, which program?
7. Have you been involved with Children’s Aid Society (CAS)?
8. When did they first contact you?
 - i. Did they tell you why they were contacting you?
 - ii. Did you understand why CAS was involved?
9. How many times did they call or visit you?
 - i. What questions did you ask your CAS worker?
 - ii. Is there anything your CAS worker helped you with at home? (e.g., parenting, organizing, etc)
10. Were your children ever taken away from your home?
 - i. If so, for how long were they gone?
 - ii. Were you able to visit them?
 - iii. Did they tell you why the children were taken away and where they were going?
 - iv. Did you know what was happening when they were taken away? (i.e., were you confused about anything?)

*****Would you like to take a break or keep going?****

11. Did CAS ask you to go to a parenting program?
 - i. If yes, which program and how long was it?
 - ii. Did you go to the program?
12. Did you talk to a psychologist about your parenting?
13. Have you been to court to decide where your children will live?
 - i. Who told you that you have to go to court?
 - ii. Did you understand the decision that was made about your children?
 - iii. Did anyone tell you why the decision was made?
14. Did you have any legal help (lawyer) in court to help with your case?

15. Was there anything you did not understand at any point CAS was working with you?
16. What would have been most helpful for you while CAS was involved?
17. Is there anything else you want to share about your experience that I have not asked you?
18. What do you want to tell other parents with intellectual disability? Do you have advice for them?

Thank you for your time.

We really appreciate you sharing your thoughts.

You will get a gift of \$30 in the next week for taking part in this study.