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Parenting Experiences Among Adults With Intellectual Disabilities: A Scoping Review

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ABSTRACT

Background: Parents with intellectual disabilities face many barriers to accessing efficacious supports and services designed to support thriving in their parenting role. A review of research in this area may identify a nuanced understanding of common experiences, including potential barriers and facilitators to success and thriving.

Methods: A scoping review of 28 studies was conducted to offer a comprehensive answer to the question What are the parenting experiences as shared by adults with intellectual disabilities in the literature over the last two decades (2005–Present)?

Findings: Key study characteristics and recurring themes are shared. Ableism was a recurring theme experienced across multiple systemic levels including: (1) institutional: broader society and child welfare systems, (2) interpersonal: formal and informal supports and (3) internalised: identity as a parent.

Conclusions: This study identified that discriminatory assumptions about people with intellectual disabilities and their capacity to succeed in the role of parent generate and exacerbate barriers to autonomy, empowerment, and independence. Opportunities to further research and practice in this area are shared.

1 | Introduction

Parenting is a complex journey, and many families benefit from supports and services throughout the various stages of pregnancy and parenting. Unfortunately, parents with intellectual disabilities face barriers to accessing efficacious services designed to support thriving in their parenting role (Burch et al. 2024; Franklin et al. 2022). Many available parenting supports are not designed with the needs of recipients with intellectual disabilities in mind (Albert and Powell 2021).

Historically, people with intellectual disabilities have been met with policies and practices that have stripped them of basic human rights; for example, through eugenics, institutionalisation, and forced sterilisation that prevented them from becoming parents (Malacrida 2012, 2020; McDonagh et al. 2018; Tilley et al. 2012). Though the United Nations Convention on the Rights of Persons with Disabilities was passed in 2006, disability stigma and many of these practices remain persistent on a global scale (Shrestha et al. 2022; UN General Assembly 2007; Werner and Scior 2022).

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Summary

- This study looked for research on the experiences of parents with intellectual disabilities.
- This study is important because we know that parents with intellectual disabilities often face discrimination and judgement.
- We found 28 studies.
- Ableism was a theme in all the studies.
- Parents with learning disabilities faced discrimination and judgement in society, child welfare systems, support networks, and how parents with intellectual disabilities see themselves.
- More research needs to be done with parents who aren't already connected to service agencies, and parents in minority groups.

Researchers have suggested that disability stigma may have an oppressive influence on how service providers and child protection workers around the globe assume and perceive capacity of parents with intellectual disabilities, which can exacerbate barriers to success and thriving in their role as parents (Albert and Powell 2021; McConnell and Phelan 2022; Pacheco et al. 2022).

In British Columbia, Canada, the crown agency responsible for supports to adults with intellectual and developmental disabilities (Community Living British Columbia [CLBC]) has anecdotally identified systemic gaps faced by parents with intellectual disabilities, preventing parents from receivingsupport that aligns with their needs. A community-academic research partnership was sought by CLBC to pursue empirically grounded information about the experiences and needs of parents with intellectual disabilities, to inform discussions about practice and policy changes at the provincial and federal level. As the first stage of this project, CLBC sought to learn what is already known in the research realm to date. Unfortunately, much of the empirical knowledge in this area has centred the perspectives and experiences of service providers, policy makers, and researchers (Feldman and Aunos 2020), which may be exacerbating ableist assumptions and biases about parents with intellectual disabilities. While some research has been conducted on the lived experiences of parents with intellectual disabilities, a comprehensive summary of this study has not yet been captured. To align with the goals of CLBC, the current study shares findings from a review of research in this area that identifies a nuanced understanding of common experiences, including potential barriers and facilitators to success and thriving as parents; as well as opportunities for future research and practice to continue to move forward by centreing knowledge in the lived experiences of this population.

2 | Methods and Materials

2.1 | Research Design

This scoping review was the first phase of a broader academic-community partnership project coordinated by CLBC who subcontracted the University of British Columbia Canadian Institute for Inclusion and Citizenship to lead the design and implementation of a multiphase research study examining barriers and facilitators to supporting parents with intellectual disabilities in British Columbia, Canada. Funding was provided by Community Living British Columbia, UBC Research Funding #F21-05587.

The overall project was informed theoretically by critical disability scholarship (Minich 2016), prioritising inclusive research design and implementation. Prominent scholars in the field of intellectual disability have advocated for better inclusion and centreing of people with lived experience in the design and implementation of research in this area (see e.g., de Haas et al. 2022; Feldman and Aunos 2020; Frankena et al. 2015; Grace et al. 2024; Gustafson and Brunger 2014; Walmsley et al. 2018). This project was designed with these priorities in mind and was conceptualised and conducted in partnership with a self-advocate (MG) who has lived experience as a parent with intellectual disabilities. MG was crucial in conceptualising the project and contributed throughout the research process. In addition, MG led the drafting of the accessible summary and was instrumental in planning for accessible knowledge translation of the findings.

The first stage of this project captures what is already known about the lived experiences of parents, and answers the question: *What are the parenting experiences as shared by adults with intellectual disabilities in the literature over the last two decades*? A scoping review was chosen, as it offers a comprehensive picture of the key themes and gaps, and highlights opportunities for future research, education, policy, and practice to progress forward (Munn et al. 2018; Peters et al. 2015).

2.2 | Literature Search and Screening Strategy

This scoping review follows the objectives set out in the PRISMA-ScR (Tricco et al. 2018) and the PRISMA-S (Rethlefsen et al. 2021). The search protocol was developed by University of British Columbia research librarian (AL) through consultation with MG, LW and RH. The protocol is not formally registered. Existing knowledge syntheses did not overlap with the goals of this project or lacked transparency to determine overlap. The scope of this review was to analyse published peer-reviewed English language publications sharing primary research and released between 2005 and 2023 (including pre-print articles available to the date of searching) that discussed parenting experiences of adults with intellectual disabilities. The start date of 2005 was recommended by AL to capture a two-decade span, noted to be a standard timeframe for a review study designed to inform current practices. The adults could have any relationship with the child (e.g., foster parent, guardian, etc), so long as they had or currently were formally partaking in the raising of the child or children. Studies including only autistic participants (with no identified co-occurring intellectual disabilities) were excluded. Grey literature, editorials/opinion pieces, and knowledge syntheses were excluded.

The searches were run twice over a period of 6 months. Search terms were developed based on previous knowledge syntheses authored by RH and AL, and Koolen et al. (2019). Citation searching was not utilised for this review. See Supporting Information: Appendix A for more detail on search terms.

Preliminary results were imported directly by AL into Covidence for de-duplication and screening. After de-duplication, results were reviewed through title and abstract screening by LW, and manual duplicates were flagged in the system along the way. The 42 remaining articles underwent a full-text review and screening completed independently by both LW and RM. Any questions or interrater disagreements were resolved through discussion between LW, RH and RM. Of these, 14 were excluded, which resulted in 28 citations.

All of the updated database search results were imported directly by AL into Covidence, de-duplicating against the preliminary search results. The updated search yielded an additional 172 unique results that were screened for eligibility. Of these, 170 were excluded through title and abstract screening by LW. A full-text review was conducted on the two remaining articles, which were screened out by LW. Overall, a total of 28 citations were included in this review. A full breakdown of the search and screen process can be found in Figure 1.

2.3 | Data Extraction and Analysis

The final 28 included studies were examined in depth, and data about key study characteristics were extracted from each using an Excel workbook. As per scoping review guidelines, critical appraisal of data and methodological rigour was not gleaned (Peters et al. 2015).

The final 28 articles were uploaded into NVivo software (QSR International 2021) for thematic data extraction and analysis by RM. An emergent coding approach was utilised first to capture verbatim findings from each study to form individual codes, followed by an iterative and reflexive process of emerging theme identification through review and discussions among all research team members who had differing levels of experience and expertise in the topic and data set (Peters et al. 2015). The final themes were reviewed and approved for alignment by MG with their lived experience as a parent with intellectual disabilities.

3 | Results

3.1 | Key Study Characteristics

Of the 28 studies included in this review, the majority were conducted in the UK ($n = 12$). The first author disciplines most represented were Psychology ($n = 12$) and Social Work/Social Policy ($n = 8$). Thirteen studies made reference to incorporation of some form of inclusive research design processes and/or procedures, including consultation ($n = 7$) or collaboration/co-researcher partnership ($n = 6$) with one or more parents with intellectual disabilities.

The most prevalent focus of enquiry was on parental experiences during or following child protection involvement and removal of a child or children from their care ($n = 6$). Nine studies explored only the experiences of mothers. A total of 410 parents (331 mothers and 79 fathers) participated. Participant numbers per study ranged from 1 to 91 (median = 8.5, mean = 15.36), with five articles gathering data from less than six participants. None of the studies mentioned co-occurring autism diagnoses among participants. While some studies specified recruitment of other parental identities beyond ‘mother’ and ‘father’, these were the only two identities represented or identified by participants.

Most studies used convenience and purposive sampling, with many opting to share calls for participants with front line professionals who directly offer support for adults (sometimes specifically parents) with intellectual disabilities ($n = 26$). Data was most commonly collected via qualitative interviews ($n = 27$). See Table 1 for more information on key study characteristics.

3.2 | Thematic Findings

An overarching and recurring theme of ableism was identified across all studies as impacting experiences of parenting. Ableism was described across multiple systemic levels including: (1) institutional, (2) interpersonal and (3) internalised.

3.2.1 | Institutional: Broader Society and Child Welfare Systems

3.2.1.1 | Broader Society. Participants shared a recognition that people with intellectual disabilities are often perceived negatively by broader society, for example as 'stupid' (Baum and Burns 2007, 7), 'eternal children' (Gould and Dodd 2014, 32), or as a 'cultural offence' (Pacheco and McConnell 2017, 505); and are not competent to be parents (Gould and Dodd 2014; Heifetz et al. 2019; MacLeod et al. 2022; Starke 2010; Symonds et al. 2021; Theodore et al. 2018). Participants also associated their intellectual disabilities with limited opportunities for gainful employment; lack of access to financial, housing, and daily living skill development; and health related information, supports, and resources (Ćwirynkało and Parchomiuk 2022; Forslund et al. 2022; Heifetz et al. 2019; MacIntyre and Stewart 2012; Strnadová et al. 2019a; Symonds et al. 2021; Tarleton and Ward 2007).

Many identified the trauma of facing this stigma and associated unmet needs throughout their lives had direct impacts on their confidence and self-determination as parents (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Ćwirynkało et al. 2022; Franklin et al. 2022; Gould and Dodd 2014; Heifetz et al. 2019; MacLeod et al. 2022; Pacheco and McConnell 2017; Pytlowana and Kroese 2021; Theodore et al. 2018). For example, leading to increased dependence on others, self-scrutiny, and fear around asking questions, seeking support, or advocating for their needs in relation to parenting (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Franklin et al. 2022; Gould

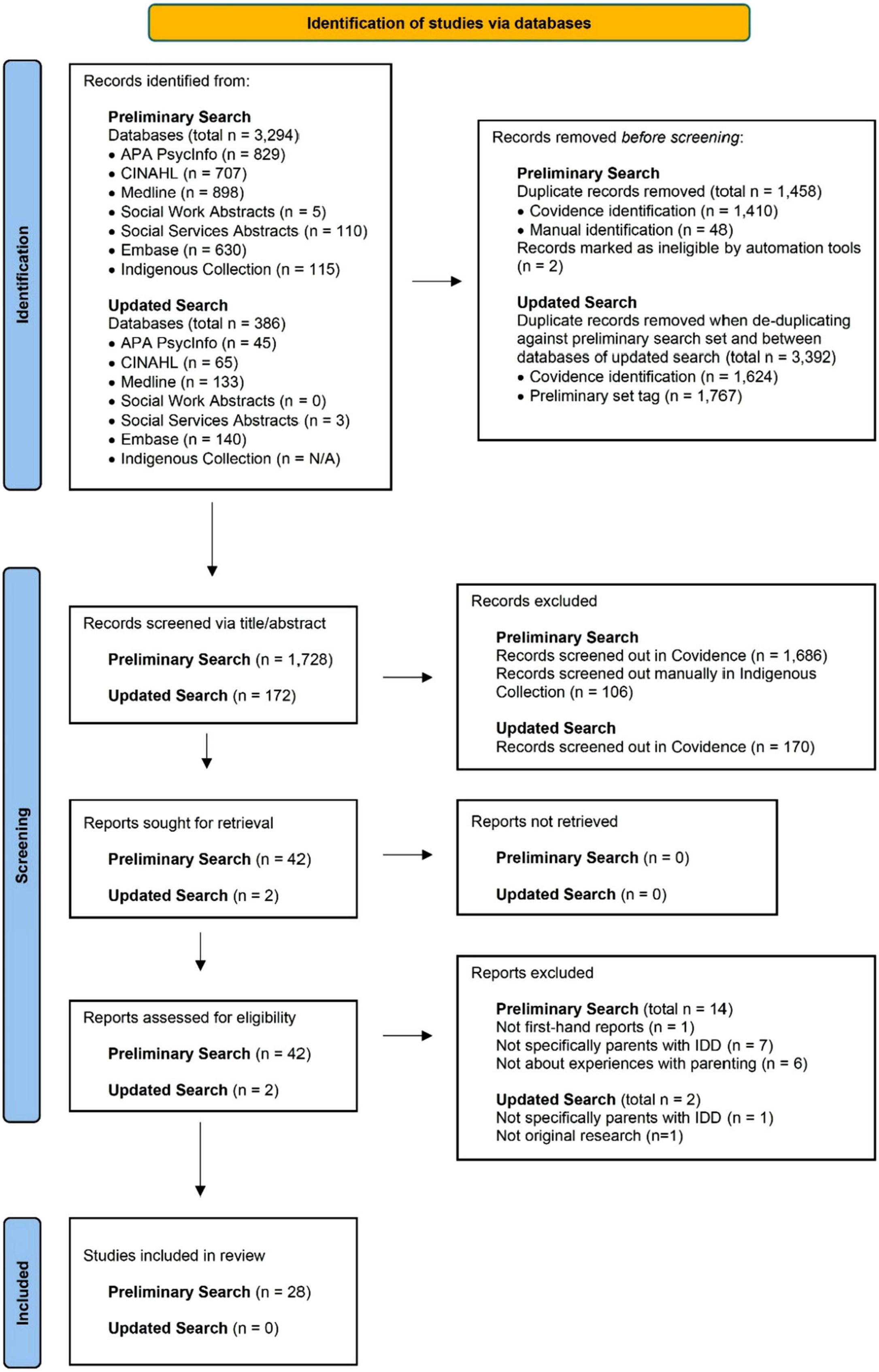

FIGURE 1 | PRISMA flow diagram.

TABLE 1 | Key study characteristics.

First author (year)	Location of study	First author discipline	Focus of study	Inclusive methods	Data collection methods	Sample size and parent role (total $N = 405$)
Aunos et al. (2008)	Canada	Psychology	Mothering with intellectual disability	n/a	Qualitative Interviews	$n = 32$ mothers
Baum and Burns (2007)	England	Psychology	Experiences of mothers with losing custody	n/a	Qualitative Interviews	$n = 8$ mothers
Booth and Booth (2005)	England	Sociology/Social Policy	Experiences in child protection	n/a	Qualitative interviews with therapeutic aim	$n = 22$ parents (18 mothers, 4 fathers)
Conder et al. (2011)	New Zealand	Nursing	Experiences of parenting and informed decision making	Advisory group including parent with intellectual disability monitored processes throughout	Qualitative interviews	$n = 6$ parents (4 mothers, 2 fathers)
Ćwirynkało and Parchomiuk (2022)	Poland	Special Education	Fathers' experiences of support	n/a	Qualitative interviews	$n = 20$ fathers* same participants as below
Ćwirynkało et al. (2022)	Poland	Special Education	Experiences of fathers	n/a	Qualitative interviews	$n = 20$ fathers* same participants as above
Forslund et al. (2022)	Sweden	Psychology	Experiences post-pandemic	Interview guide pilot-tested by parent with intellectual disability	Qualitative interviews	$n = 10$ parents (9 mothers, one father)
Franklin et al. (2022)	UK	Psychology	Experiences of stigma	Inclusive methods throughout: Community and academic partnership with self-advocate co researchers	Qualitative interviews	$n = 22$ (17 mothers, 5 fathers)
Gould and Dodd (2014)	UK	Psychology	Experiences of mothers who have had child removed from care	n/a	Qualitative interviews	$n = 9$ mothers
Guay et al. (2017)	Canada	Social Work	Mothers and experiences making infant-feeding decisions	n/a	Qualitative interviews	$n = 4$ mothers
Heifetz et al. (2019)	Canada	Psychology	Mental health among mothers	n/a	Focus groups	$n = 12$ mothers
MacIntyre and Stewart (2012)	Scotland	Social Work	Lived experience of parents	n/a	Interviews	$n = 5$ mothers
MacLeod et al. (2022)	England	Psychology	Experience of parenting following removal of child	Participant documents produced collaboratively with the participant	Qualitative interview	$n = 1$ mother

(Continues)

TABLE 1 | (Continued)

First author (year)	Location of study	First author discipline	Focus of study	Inclusive methods	Data collection methods	Sample size and parent role (total $N = 405$)
Mayes and Llewellyn (2012)	Australia	Health Sciences	Narratives of mothers following removal of child	n/a	Qualitative interviews	$n = 7$ mothers
McConnell et al. (2022)	Canada	Occupational Therapy	Childhood experience, family support, and parenting experiences	Interview protocol piloted with feedback sought from 3 parents with intellectual disability	Structured interviews	$n = 91$ parents (82 mothers, 9 fathers)
More and Tarleton (2022)	Austria	Education	Parenting experiences	n/a	Qualitative interviews	$n = 11$ parents (6 mothers, 5 fathers)
Pacheco and McConnell (2017)	Canada	Social Work	Experiences of mothers from ethnocultural communities	Participants determined when interviews ceased (when richness and thickness achieved). All participants invited to review and confirm accuracy of representation of their story	Qualitative interviews	$n = 8$ mothers
Potvin et al. (2016)	Canada	Psychology	Experiences of social support during pregnancy and childbirth	n/a	Qualitative interviews	$n = 4$ mothers
Pytlowana and Kroese (2021)	England	Psychology	Experience of fathers when child(ren) removed from care	Inclusive methods throughout: Consultation and collaboration with adult male coresearcher with intellectual disability	Qualitative interviews	$n = 5$ fathers
Shewan et al. (2014)	UK	Psychology	Identities of parents with intellectual disability	Participant feedback sought to validate accurate representation of findings	Qualitative interviews	$n = 8$ parents (5 fathers, 3 mothers)
Starke (2010)	Sweden	Social Work	Experiences of relationships and support	n/a	Qualitative interviews	$n = 21$ (15 mothers, 6 fathers)* representing 15 families
Starke (2022)	Sweden	Social Work	Views and experiences of mothers encounters with service providers	n/a	Qualitative interviews	$n = 7$ mothers
Strnadova et al. (2019)	Czech Republic	Education	Experiences becoming a mother	Interview protocol piloted with a mother with intellectual disability. Participant feedback sought to	Qualitative interviews	$n = 19$ mothers

(Continues)

TABLE 1 | (Continued)

First author (year)	Location of study	First author discipline	Focus of study	Inclusive methods	Data collection methods	Sample size and parent role (total $N = 405$)
				validate and verify emerging findings		
Strnadova et al. (2019)	Australia	Education	Parents experiences with peer support	Inclusive methods throughout: Coresearcher and coauthor with intellectual disability	Qualitative interviews	$n = 26$ parents (20 mothers, 6 fathers)
Symonds et al. (2021)	England	Social Work/ Policy Studies	Experiences being a father	Consultation with 4 fathers with intellectual disability at each stage of study	Qualitative interviews	$n = 8$ fathers
Tarleton and Ward (2007)	UK	Policy Studies/ Social Work	Experiences of parenting with support	Inclusive methods throughout: Group of 13 participants also contributed as consultants across each stage of study	Qualitative interviews and consultation group interviews	$n = 30$ parents (25 mothers, 5 fathers)
Theodore et al. (2018)	UK	Psychology	Experiences of parenting	Inclusive methods throughout: Project emerged directly from community group who commissioned researchers for analysis and dissemination	Qualitative interviews	$n = 8$ parents (5 mothers, 3 fathers)
Wilson et al. (2013)	Scotland	Psychology	Postnatal support needs of mothers	n/a	Qualitative interviews	$n = 6$ mothers

*Manuscripts may include other focuses of study, methods, and/or samples beyond relevance to our research question.

and Dodd 2014; Heifetz et al. 2019; More and Tarleton 2022; Pacheco and McConnell 2017).

While participants in one study noted the benefits of the internet as an empowering source of information (Heifetz et al. 2019), many others spoke about the inaccessibility of generalised information about sex, contraception, pregnancy and parenting (Conder et al. 2011; Guay et al. 2017; Starke 2022; Strnadová et al. 2019a; Symonds et al. 2021). Some noted the value of access to information for parenting-adjacent matters such as independent living, employment, finances, mental health, and housing (Symonds et al. 2021; Tarleton and Ward 2007).

3.2.1.2 | Child Welfare Systems. Child welfare systems were specifically highlighted as a key source of institutional ableism. Participants described child welfare processes as discriminatory, inaccessible, and distressing. These experiences evoked intense and persistent negative feelings such as fear, humiliation, grief, despair, anger and suicidal ideation (Aunos et al. 2008; Baum and Burns 2007; Booth and Booth 2005; Conder et al. 2011; Franklin et al. 2022; Gould and Dodd 2014; Heifetz et al. 2019; MacIntyre and Stewart 2012; Mayes and Llewellyn 2012; More and Tarleton 2022; Pytlowana and Kroese 2021; Strnadová et al. 2019a; Tarleton and Ward 2007; Theodore et al. 2018). A common belief was shared that stigma about intellectual disabilities was a key reason for child apprehension (Baum and Burns 2007; Conder et al. 2011; Gould and Dodd 2014; Pacheco and McConnell 2017; Pytlowana and Kroese 2021; Strnadová et al. 2019a; Tarleton and Ward 2007; Theodore et al. 2018).

Many identified a lack of transparency and accessible communication about child welfare assessment and decision-making (Baum and Burns 2007; Booth and Booth 2005; Conder et al. 2011; Franklin et al. 2022; Gould and Dodd 2014; MacIntyre and Stewart 2012; More and Tarleton 2022; Pytlowana and Kroese 2021). The child welfare court process was identified as particularly inaccessible and discriminatory. Many felt anger and powerlessness facing a lack of transparency as well as a need to defend their competence as parents against ableist assumptions (Baum and Burns 2007; Booth and Booth 2005; Conder et al. 2011; Franklin et al. 2022; Gould and Dodd 2014; Heifetz et al. 2019; MacIntyre and Stewart 2012; Mayes and Llewellyn 2012; More and Tarleton 2022; Pytlowana and Kroese 2021; Strnadová et al. 2019a; Tarleton and Ward 2007; Theodore et al. 2018).

Very few participants had been advised of their legal rights or resources associated with navigating court processes; including legal, advocacy, guidance, plain language information and/or emotional support (Booth and Booth 2005; Gould and Dodd 2014; Pytlowana and Kroese 2021). Some shared that their needs as a parent were overlooked or dismissed by child welfare teams (Baum and Burns 2007; MacIntyre and Stewart 2012; Pytlowana and Kroese 2021), and very few had a support person available to them during court procedures (Booth and Booth 2005; Gould and Dodd 2014; MacIntyre and Stewart 2012; Pytlowana and Kroese 2021).

Many noted that it was rare for child welfare and legal professionals to have knowledge or experience with parents with intellectual disabilities (MacIntyre and Stewart 2012; Strnadová et al. 2019; Tarleton and Ward 2007). Some shared the value of professionals who did have knowledge and balanced attitudes about intellectual disabilities in translating information and/or supporting them to create healthy environments for their child (Pytlowana and Kroese 2021; Strnadová et al. 2019). Independent advocates and informal supporters were identified as valuable for emotions support and mediation of communication during court proceedings (MacIntyre and Stewart 2012; Pytlowana and Kroese 2021; Tarleton and Ward 2007).

3.2.2 | Interpersonal: Formal and Informal Supports

The essential nature of formal and informal supports was highlighted across studies (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Ćwirynkało et al. 2022; Forslund et al. 2022; Franklin et al. 2022; Heifetz et al. 2019; MacIntyre and Stewart 2012; MacLeod et al. 2022; Starke 2022; Symonds et al. 2021; Tarleton and Ward 2007; Wilson et al. 2013). When interpersonal supports held ableist beliefs about intellectual disabilities and parenting, this could have serious negative consequences for parents as well as for their child(ren) (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Ćwirynkało et al. 2022; Franklin et al. 2022; Gould and Dodd 2014; Heifetz et al. 2019; MacLeod et al. 2022; More and Tarleton 2022; Theodore et al. 2018; Wilson et al. 2013). Some fathers noted compounding discrimination from support people who underestimated or dismissed their parenting abilities not only due to their intellectual disabilities but also due to their role as fathers rather than mothers (Ćwirynkało and Parchomiuk 2022; More and Tarleton 2022; Symonds et al. 2021; Theodore et al. 2018).

3.2.2.1 | Formal Supports. Participants identified ways in which formal supports were inadequate due to ableist beliefs and/or processes, evoking feelings of mistrust, anger, shame and feeling ignored, disempowered, and patronised (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Franklin et al. 2022; Gould and Dodd 2014; Heifetz et al. 2019; MacIntyre and Stewart 2012; MacLeod et al. 2022; More and Tarleton 2022; Pytlowana and Kroese 2021; Starke 2010, 2022; Strnadová et al. 2019; Theodore et al. 2018; Wilson et al. 2013). Many had explicitly requested support with one or more aspects of parenting, but it was not provided or accessible (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Franklin et al. 2022; Gould and Dodd 2014; Pytlowana and Kroese 2021; Starke 2022; Strnadová et al. 2019; Theodore et al. 2018). Some noted that without early access to support, difficulties escalated resulting in crisis including restrictions or child apprehension (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Franklin et al. 2022; MacIntyre and Stewart 2012; MacLeod et al. 2022; Starke 2010; Tarleton and Ward 2007; Strnadová et al. 2019). Others noted feeling disempowered by pressure to engage in unnecessary interventions under threat of the apprehension of their child (Ćwirynkało and Parchomiuk 2022; Franklin et al. 2022; Gould and Dodd 2014; Theodore et al. 2018; Wilson et al. 2013).

Many noted that a focus on the well-being and development of the child was prioritised over the parents' needs for support or identifying strengths-based opportunities to enhance parental thriving (Aunos et al. 2008; Franklin et al. 2022; Gould and Dodd 2014; Wilson et al. 2013). If their disabilities were known, many shared needing to regularly defend themselves against providers' ableist scrutiny (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; Franklin et al. 2022; Gould and Dodd 2014; More and Tarleton 2022; Starke 2010, 2022; Theodore et al. 2018; Wilson et al. 2013). Participants in two studies noted being actively discouraged from becoming parents by professionals who believed that parenthood was an unattainable goal for someone with intellectual disabilities (Franklin et al. 2022; More and Tarleton 2022).

Characteristics of helpful formal supports included those who understood intellectual disabilities and believed in their capacity to parent, were non-judgemental and collaborative, focused interventions on the unique strengths and needs of the parent, were easily accessible and present in interactions, mediated communication between parents and child and family services, and provided practical help or modelled/taught skills (Aunos et al. 2008; Booth and Booth 2005; Conder et al. 2011; Ćwirynkało and Parchomiuk 2022; Guay et al. 2017; Heifetz et al. 2019; MacLeod et al. 2022; More and Tarleton 2022; Potvin et al. 2016; Starke 2010, 2022; Strnadová et al. 2019; Symonds et al. 2021; Tarleton and Ward 2007; Theodore et al. 2018; Wilson et al. 2013).

3.2.2.2 | Informal Supports. Family members (including intimate partners and co-parents) were identified as the key providers of informal support (Aunos et al. 2008; Ćwirynkało and Parchomiuk 2022; Ćwirynkało et al. 2022; Forslund et al. 2022; Franklin et al. 2022; Heifetz et al. 2019; McConnell et al. 2022; Potvin et al. 2016; Starke 2010; Strnadová et al. 2019; Symonds et al. 2021; Wilson et al. 2013). Many participants noted having limited peer connections due to their intellectual disabilities (Aunos et al. 2008; Baum and Burns 2007; Franklin et al. 2022; Gould and Dodd 2014; MacLeod et al. 2022; McConnell et al. 2022; More and Tarleton 2022; Potvin et al. 2016; Starke 2022; Strnadová et al. 2019).

Informal supports were often described as infantilizing, invalidating, and controlling (Ćwirynkało and Parchomiuk 2022; Heifetz et al. 2019; McConnell et al. 2022; More and Tarleton 2022; Pacheco and McConnell 2017; Starke 2010; Strnadová et al. 2019; Symonds et al. 2021). Several noted that ableist beliefs contributed to unmet emotional and practical needs before and during parenthood, inciting feelings of anger, shame, and being dismissed or abandoned (Baum and Burns 2007; Ćwirynkało and Parchomiuk 2022; McConnell et al. 2022; Starke 2010; Strnadová et al. 2019).

Participants who shared positive experiences with informal supports noted benefits for themselves as well as their children (Aunos et al. 2008; Franklin et al. 2022; Heifetz et al. 2019; More and Tarleton 2022). Helpful characteristics of informal supports included those who responded positively from the offset of pregnancy; respected and advocated for them as a person and parent; demonstrated interest in their needs and goals; and were reliable and available for emotional, financial, informational, instrumental, and practical support (Conder et al. 2011; Ćwirynkało and Parchomiuk 2022; Ćwirynkało et al. 2022; Potvin et al. 2016; Starke 2022; Strnadová et al. 2019; Symonds et al. 2021; Wilson et al. 2013). Many spoke about the unique benefits of peer and mutual supports, resulting in feeling heard and validated, connected to and trusting of others, and empowered as parents (Ćwirynkało and Parchomiuk 2022; Franklin et al. 2022; Heifetz et al. 2019; Potvin et al. 2016; Symonds et al. 2021; Tarleton and Ward 2007). Two studies found that parents who had larger, secure, and more positive informal support networks were also less likely to have undergone a parenting assessment (Franklin et al. 2022), and more likely to have their child still in their care (More and Tarleton 2022).

3.2.3 | Internalised: Identity as a Parent

Internalised ableism influenced parental identity (Baum and Burns 2007; More and Tarleton 2022; Pacheco and McConnell 2017; Strnadová et al. 2019; Symonds et al. 2021). Some shared doubts about their desire and competency to parent because of their intellectual disabilities (Baum and Burns 2007; More and Tarleton 2022; Theodore et al. 2018). Conversely, some identified motivation to resist internalised ableism by increasing independence, self-determination, and resilience; forming an identity not defined by others or their disabilities; and actively challenging ableist beliefs (Ćwirynkało et al. 2022; Franklin et al. 2022; Gould and Dodd 2014; Guay et al. 2017; Heifetz et al. 2019; MacLeod et al. 2022; McConnell et al. 2022; Pacheco and McConnell 2017; Strnadová et al. 2019; Symonds et al. 2021). Some noted becoming a parent in itself was an act of resistance, and a way to shift their primary identity to that of 'parent' rather than as an infantilized and stigmatised person (Gould and Dodd 2014; More and Tarleton 2022; Pacheco and McConnell 2017; Pytlowana and Kroese 2021; Shewan et al. 2014; Symonds et al. 2021; Theodore et al. 2018).

Physical closeness and direct care of children were identified as key components informing parental identity (More and Tarleton 2022; Pytlowana and Kroese 2021; Strnadová et al. 2019a; Symonds et al. 2021). Accordingly, some noted a significant loss or shift in their parental identity following removal of their child(ren) (Baum and Burns 2007; Booth and Booth 2005; Mayes and Llewellyn 2012; More and Tarleton 2022; Pacheco and McConnell 2017; Pytlowana and Kroese 2021).

Of the few participants who noted ways their intellectual disabilities could create or exacerbate parenting challenges, reasons included difficulty processing abstract and inconsistent information; limitations in problem solving and decision making; and/or managing complex child health or behaviours (Baum and Burns 2007; Forslund et al. 2022; Franklin et al. 2022; Heifetz et al. 2019; Mayes and Llewellyn 2012; Pacheco and McConnell 2017; Strnadová et al. 2019). Some noted the value of being able to acknowledge challenges faced and needs they had, alongside embracing the joys of parenting (Franklin et al. 2022; Heifetz et al. 2019; Pacheco and McConnell 2017; MacLeod et al. 2022; Shewan et al. 2014; Strnadová et al. 2019; Tarleton and Ward 2007; Theodore et al. 2018).

4 | Discussion

This scoping review shares a thematic analysis of the experiences of parents with intellectual disabilities as shared in the research over the last two decades. By centreing the direct and lived experience of parents with intellectual disabilities the findings align with the goals of CLBC self-advocates to capture what is known to date about parental experiences and identify systemic gaps and opportunities to enhance services and supports based on the expertise of the recipients of these supports.

While this review intended to highlight broad themes related to experiences of parenting, the inclusion of only studies with parent participants offered a more in-depth understanding of the nuances of these experiences than research to date centreing external perspectives has offered. Unique to this review, a recurring theme of ableism was found to be deeply interwoven. Ableism has been defined as "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human" (Campbell 2001, 44).

Ableism may be forestalling the provision of adequate education, information, and resources about sex, contraception, pregnancy, and parenting to and for people with intellectual disabilities (Hole et al. 2022). The finding that many of the participants have undergone an assessment of parenting and/or apprehension of child(ren) reinforces the claim that parents with intellectual disabilities may be at higher risk of intrusive child protection interventions than parents without intellectual disabilities (Burch et al. 2024; Feldman and Aunos 2020; LaLiberte et al. 2024). While not specifically explored in this review, a study out of the United Kingdom noted that when babies of parents with intellectual disabilities are subject to care proceedings, the identified concern is not typically the parental intellectual disabilities per se, but instead a co-occurring risk such as parental mental health, substance misuse, and/or domestic violence (Burch et al. 2024). This may obfuscate the influence of ableism on creating and exacerbating conditions rendering people with intellectual disabilities vulnerable to these co-occurring risks and subsequent increased likelihood of involvement with child protection. Additionally, while child protection involvement can be distressing for any parent, this study showed that unique to parents with intellectual disabilities are challenges associated with inaccessibility of processes, including lack of transparency, collaboration, and plain language communication or materials.

This review highlights a crucial need for a multi-systemic approach that shifts away from the notion that a person's intellectual disabilities automatically precludes them from participating equitably in society, including the opportunity to thrive in a parenting role. The broader society subtheme in this study draws attention to ways in which lifelong experiences of ableism (including lack of accessible information about sex, pregnancy, and parenting) may greatly influence confidence, independence, and self-determination in the parental role.

Services and supports should prioritise individualised, person-centred, collaborative, rights-based, strengths-based, wrap-around/holistic, community-based, and culturally relevant models (Hole et al. 2022; Morris et al. 2024; Burch et al. 2024; Zeitlin and Augsberger 2024). Service providers who work alongside parents could benefit from more information and training that is designed to directly challenge and address ableist stereotypes (Albert and Powell 2021; Retzer et al. 2020). Informational materials should be distributed via diverse accessible formats including plain language, visual, and/or active and experiential opportunities (Hole et al. 2022; Albert and Powell 2021).

Collaboration with informal and community-based support networks as early as possible could increase opportunities for thriving among parents with intellectual disabilities (Burch et al. 2024; Carnemolla et al. 2021; Esteban et al. 2021; Harrison et al. 2021). For example, person-centred planning models have demonstrated beneficial outcomes including social and community inclusion and enhanced quality of life; and have been noted to empower adults with intellectual disabilities in decision making around their own lives (Morris et al. 2024; Lightfoot and DeZelar 2020). Additionally, natural supports could be prioritised including through peer mentorship and/or social or group-based connections with other parents (Harrison et al. 2021).

5 | Limitations

Scoping reviews do not include an analysis of methodological rigour (Pham et al. 2014). While this study may be limited by this, scoping reviews have been noted for their value in offering a helpful summary of information to inform later systematic reviews that do conduct this methodological analysis (Munn et al. 2018).

The findings may also be limited by some of the homogenising features of the studies. For example, included studies only represented a few countries (mainly the UK and Canada), most recruitment was done through service agencies (meaning that participants were already connected to supports), and most utilised qualitative interviews as the primary method of data collection.

5.1 | Implications for Research

Future research should examine more in-depth qualitative information from the experiences of parents, especially with regard to ableism as well as before or with no child welfare involvement. For example, deeper exploration into the potential link between lifelong experiences of societal ableism and parenting confidence and competence could identify unique opportunities to increase independence, well-being, and thriving among people with intellectual disabilities and reduce the need for individualised parenting-specific interventions for those who become parents. Additionally, a closer examination of the role of technology and the internet across different global contexts, for example through a jurisdictional scan, may be warranted.

Future researchers should consider addressing homogeneity of studies to date, for example by diversifying recruitment and data collection methods and by broadening diversity of parental type and exploring intersectional identities to identify how systemic inequalities may be compounded for parents with multiple marginalised identities, for example indigenous or racialized parents (Collings et al. 2018; Zeitlin and Augsberger 2024).

The use of qualitative interviews as the dominant mode of data collection may have systemically excluded certain groups of adults with intellectual disabilities from contributing to the knowledge to date, for example those who may be primarily non-verbal or prefer non-verbal methods of communication (Dreyfus 2022). Of note, almost half (46%) of the studies in this review noted the use of inclusive research design or processes. A methodological analysis of research to date or a meta-synthesis review including only studies incorporating inclusive design (see e.g., Morris et al. 2025) could glean valuable information. Future research in this area should prioritise diverse and inclusive methodologies, recognising that inclusive research requires a thoughtful and reflexive approach to ensure that it is conducted ethically and authentically, prioritising social justice and the best interests of participants with intellectual disabilities (Hole and Schnellert 2024).

Author Contributions

Rae Morris led analysis and interpretation of data, and led drafting of the manuscript. Lizzy Walsh co-led literature search and screen, and contributed to analysis and interpretation of data, and drafting of the manuscript. Michelle Goos led study conception and design, and contributed to analysis and interpretation of data, and manuscript review. Arielle Lomness co-led literature search, ran final searches and exports, managed Covidence, and contributed to drafting of the manuscript. Rachelle Hole oversaw study conception and design, analysis and interpretation of data, and contributed to drafting of the manuscript.

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Conflicts of Interest

The authors declare no conflicts of interest.

Ethics Statement

Ethics review was completed and approved by the University of British Columbia Behavioural Research Ethics Board (#H23-03650).

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.
Parenting Experiences Among Adults with ID - Appendix A.