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Review Article

Children with Intellectual and Developmental Disabilities in Out-of-Home Care: A Scoping Review

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Children with intellectual and developmental disabilities are often over-represented in child protection and out-of-home care services. Despite this fact, little is known or understood about their experiences with these services. This scoping review seeks to identify the published literature about children with intellectual and developmental disabilities who are engaged with child protection and out-of-home care services. Findings from the 18 studies included in this review show that these children are at increased risk of entering the child protection and out-of-home care system, with outcomes that do not fare as favourably as their nondisabled peers. This is largely due to a lack of support, training, and resources for the children, their families, and carers. Placement failure was a common theme with residential care more likely for children with greater complexity and support needs. These children are understudied, with more research needed to better understand the factors that contribute to their experiences. Greater insights into how a child protection and out-of-home care pathway can be avoided, via the provision of adequate services and supports, are also urgently needed so that fewer children are placed at risk in a system where poor outcomes are common.

1. Introduction

In 2018, 7.6% of children aged 0–14 in Australia had some level of disability, with intellectual and developmental disabilities being the most common (4.5%) [1]. Intellectual disability is defined as having significant limitations in both intellectual functioning and adaptive behaviour before the age of 18 [2]. Intellectual functioning is typically determined by both IQ and adaptive behaviour tests, with the latter a broad concept covering conceptual (e.g., time, self-direction, managing money), social (e.g., interpersonal and communication skills, self-esteem, and ability to understand and follow social rules), and practical (e.g., activities of daily living) skills that enable the person to function in their community. People with intellectual disabilities have greater mortality and morbidity compared to the general population [3] with noted health system pathway barriers and limited understanding and application of reasonable adjustments from within the health system [4, 5]. Developmental disabilities include cerebral palsy, autism, and other developmental disorders that often co-occur with intellectual disability. Children with intellectual and developmental disabilities (IDD) are a particularly vulnerable population with greater caregiving needs and an increased risk of experiencing maltreatment [6]. It is, therefore, not surprising that many children with IDD are reported to have increased engagement with child protection (CP) services and often require placement into out-of-home care (OOHC) [7]. Out-of-home care can be defined as overnight care for children under 18 years of age, provided by authorized carers who are vetted, receive ongoing case management, and are offered financial recompense for the children's expenses [8].

Although specific elements of CP and OOHC services vary between jurisdictions, in most Western countries, these exist to ensure the safety, health, and wellbeing of children who are unable to live with their parents. This is largely based on the United Nations Convention on the Rights of the Child, which emphasizes children's right to an environment conducive to their physical, mental, spiritual, moral, and social development [9]. Decades of research have demonstrated that children fare better in home-based (e.g., foster or kinship care) rather than institution-based OOHC [10]. As such, in Australia (like in many other Western countries), the majority of children requiring OOHC reside in home-based care, with 36% living in foster care, and 54% living in kinship care [8, 11].

On June 30th, 2021, there were 46,200 children residing in OOHC in Australia. The disability status of only 63% (~29,100) of these children was reported. Of these, approximately 30% (>8,730) were reported to have some type of disability [8, 11]. This is more than four times the incidence of children in the general population of Australia. It should be noted there is a disproportionate number of Indigenous children (19,500) in OOHC in Australia [11], and the disability status of these children is not publicly available.

It is well known that children living in OOHC have increased incidence of physical, mental, cognitive, social, emotional, and psychological issues compared to their peers in the general population [12]. Despite this, their disability status is not routinely reported, and there is a dearth of literature specifically addressing the issues related to children with IDD who require OOHC or those of their caregivers. This signifies a significant gap in knowledge of how best to support children with IDD living in OOHC and their carers.

1.1. Aims. The aim of this review was to collate current literature regarding children with IDD requiring child protection and/or out-of-home care services in order to identify gaps in the evidence and map a future program of research.

Research question: What is known about children with IDD engaged with CP and OOHC services?

2. Method

Scoping review methodology was utilised as it provides a framework for searching, assessing, and summarising the available research on a particular area, and identifying the extent of research evidence [13]. Rather than being guided by a focused research question, a scoping review uses a broad exploration of literature to identify all relevant literature regardless of study design (Arksey and O'Malley, 2005). The method adopted for conducting this scoping review was based on Arksey and O'Malley's [14] framework.

2.1. Search Strategy. Databases searched included CINAHL, Medline, ProQuest, PsychInfo, SCOPUS, and PubMed. A preliminary search was conducted in each database to gain familiarity, aid in identifying key terms, and establishing search parameters. Search terms reflected the key concept areas related to the research questions: "Intellectual disability" or "developmental disability" and "out-of-home care" or "child protection." See Table 1 for a full list of search terms. Electronic search results were exported into Mendeley, and duplicates were merged. The inclusion and exclusion criteria are outlined in Table 2. The search was limited to studies published in English and within the date range of January 2010 to May 2021.

Table 1: Search strategy.

Population
Intellectual disability
Developmental disability
Mental retard
Learning disability
Down syndrome
Autistic disorder
Disability
Intellectual impairment
Cognitive disability
Cognitive impairment
Autistic disorder
Autism
Setting
Foster care
Looked after children
Foster home care
Foster home
Foster children
Institutional care
Out-of-homecare
Alternative care
Kinship care
Children in care
Child welfare
Residential care

2.2. Selection Process. Studies were selected in two stages: (a) through title and abstract review and (b) full-article screening, as identified in a Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram (Figure 1). Title and abstract reviewing were conducted by the first author (JS), and full texts were reviewed by the first (JS) and third (SB) authors, with an independent review by the second author (NW) to resolve conflicts.

2.3. Data Collation. Data determined relevant to the aims of the review were extracted and organised into table format using a Microsoft Word document. Data were extracted and summarised within a data summary table in Microsoft Word. Each article was then reread line-by-line and summarised in a word document, and personal thoughts and reflection on the article were also written by the first author (JS), then reviewed, and confirmed by the third author (SB). All authors then met to discuss results and determine the presentation of findings into topic categories and potential discussion points.

3. Findings

After removing duplicates, the initial search generated 2,195 articles. There were 1998 articles removed after the screening

Table 2: Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Population	Involves children (under 18 years) with intellectual disability and/or developmental disability	Older adults with ID/DD
Setting	Out-of-home care, foster care, or residential care Child welfare or child protective services	In the care of biological parents at home
Context	Published peer-reviewed journal articles Written in English	Other publications In languages other than English

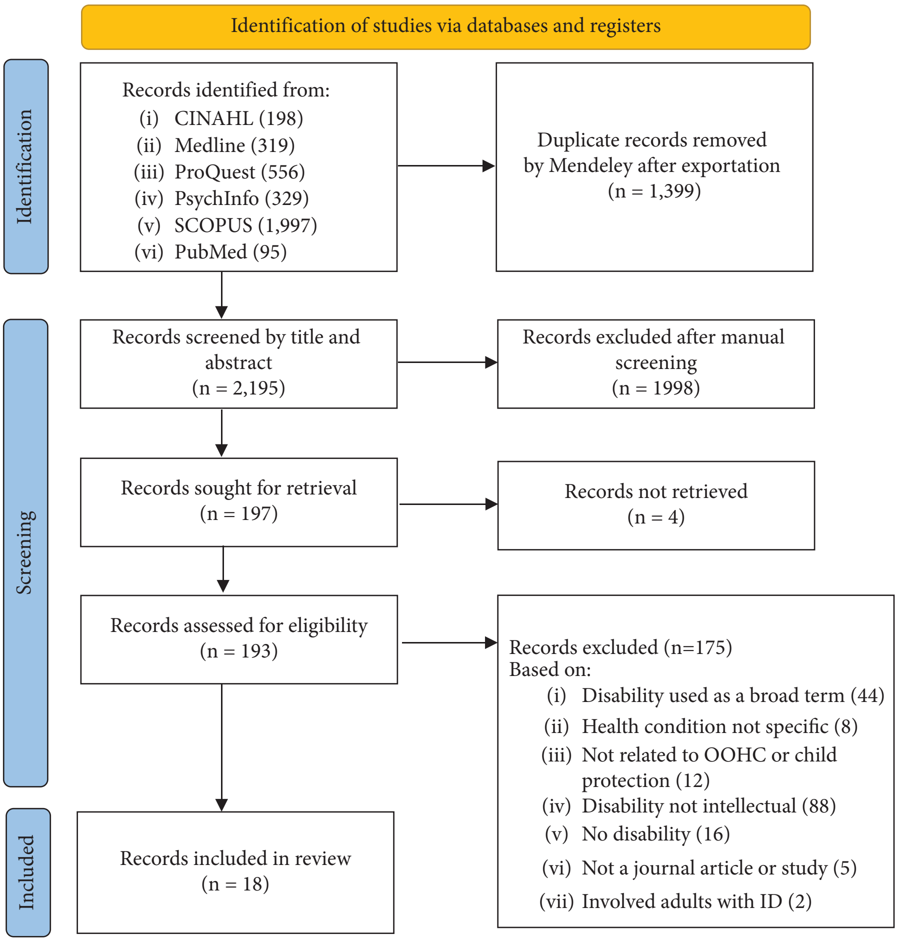

Figure 1: PRISMA flow chart illustrating the selection process.

of titles and abstracts. Full-text review was sought for 197 articles and four texts were unavailable for retrieval, so, therefore, excluded. A further $n = 167$ articles were excluded due to the term "disability" being used to aggregate samples of children with any form of disability ($n = 44$), the ambiguity regarding children's specific disabilities ($n = 8$), the article not relating to CP or OOHC ($n = 12$), the disability not being intellectual ($n = 88$), the children had no disabilities ($n = 16$), the text was not a journal article or study ($n = 5$), or the sample included adults with IDD ($n = 2$). Eighteen articles were subsequently included in the final review (see Figure 1).

Seven articles were from the United States of America (USA), three from the United Kingdom (UK), four from the Netherlands, two from Canada, and one each from Spain, Israel, and India. Five of the included publications focused specifically on children with IDD in residential care, three on children with IDD in foster care, three reported on the prevalence of IDD in different OOHC settings and reasons for children's removal from parents, three focused on maltreatment of children with IDD, two focused specifically on sexual abuse of children with IDD in OOHC, one focused on parents decisions to voluntarily place children in OOHC, and one case study explored the psychotherapy sessions of a young boy with IDD on his journey across many different OOHC settings. Table 3 presents an overview of the findings, which are discussed in detail below.

3.1. *Journey into Care.*

The literature highlights those children with IDD are at increased risk for entering OOHC. A national comparative study in Ireland conducted by McConkey et al. [21] found children with intellectual disabilities were 12 times more likely to be in care compared to children without disabilities. Likewise, a longitudinal study of children receiving special education services in USA schools, found that children with IDD had elevated risks of multisectoral systems involvement, including child welfare, juvenile justice, and mental health systems [25].

3.2. *Maltreatment.*

Children with IDD are overrepresented among substantiated maltreatment cases. A Canadian study by Dion et al. [27] reported prevalence rates of substantiated maltreatment cases to be 10% of children with IDD compared to just 1% of children without IDD. High incidence rates were also found in a USA population-based cohort study by Van Horne et al. [29], who reported that children with Down syndrome were 32% more likely to be maltreated compared to their peers without a genetic syndrome. McDonnell et al. [31] found that children with IDD were

Table 3: Summary of included articles in chronological order.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Strijker and Van De Loo [18], Netherlands	Retrospective longitudinal study	Explore what the risk factors were for placement breakdown specific to children with intellectual disability, and the prevalence of placement breakdown for children with intellectual disability	Children with intellectual disability living in long-term foster care who began a new foster care placement within the study year. The sample included 99 children, with 60% of children were living in nonrelative foster families	For children living in Kinship care, 41.5% had not been placed in foster care before. For children living in family foster care, 44.8% had experienced at least 2 placements prior. Kinship carers underestimated the difficulty of the placement prior to accepting care of the child and this being a contributing factor to placement breakdown (61.5% of kinship carers vs. 38.5% of family foster carers). The probability of placement breakdown moderately correlated to the severity of the child's problem behavior during placement, as well as before entry into the current family. There was also a strong correlation to placement breakdown with the child's age, and a moderate correlation to placement breakdown to the child's placement type of kinship care	Small sample size

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Slayter and Springer [19], USA	Cross-sectional, exploratory study	To explore reasons for child welfare system involvement and the types of out-of-home placements used for children with intellectual disabilities. Two variables were measured – demographics and foster care characteristics demographics measured included: age, gender, race, and Hispanic/Latino/a ethnicity. As well as other comorbid disabilities and other medical conditions. Foster care characteristics included history of child protection services involvement (number of removal episodes, years since first and current removal episode, and age at removal), and placement settings. Also, reasons for the current removal episode were assessed, as well as years since termination of parental rights, history of any previous adoptions, and age at that adoption	A sample of 17,714 children with intellectual disability was compared to a sample of 655,536 children without intellectual disability	2.6% of children in the foster care population were children with intellectual disability. Children with intellectual disability were on average, 2 years older (average age of 11) and more likely to be male. Children with intellectual disability were between 4 and 20 times more likely to have a comorbid disability or medical condition, compared to the comparison group. Children with intellectual disability were more likely to have had a previous adoption. Children with intellectual disability were more likely to be placed with child protective services voluntarily, compared to children without intellectual disability. Children with intellectual disability were also more likely to have court-ordered removals. Neglect was the most common reason for removal for both groups, however children with intellectual disability had a greater percentage of removal for neglect compared with the comparison group. Reasons for removal of children with intellectual disability was also more likely due to relinquishment, parental death, their disability, sexual abuse, or physical abuse – compared to the comparison group. Girls with intellectual disability were twice as likely to be removed due to sexual abuse, compared to girls without intellectual disability. Although both girls and boys with intellectual disability experienced the same rates of physical abuse, boys with intellectual disability were 15% more likely to be removed due to reasons of physical abuse compared to boys in the comparison group. Children with intellectual disability were twice as likely to be placed into an institutional setting compared to the comparison group. Children in the comparison group were more likely to be living in kinship care settings, or at home in a family trial, compared to children with intellectual disability. Children with intellectual disability experienced a greater number of placement settings compared to the comparison group	Not stated

TABLE 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Russell, [17], UK	Single case study	To contribute to a growing understanding of the potential of psychoanalytic psychotherapy as an intervention for children and young people with severe learning disabilities	A boy with foetal alcohol spectrum disorder (FASD) in the UK in OOHC. Written from the perspective of his psychologist	The psychologist saw progress with the boy in his understanding of his own internal feelings but was also unsure if the therapy helped or hindered, as prior to therapy the boy was in a state of ignorant bliss to cope with trauma, and the process of confronting trauma was challenging for the boy	Not stated
Brown et al. [18], UK	Qualitative	To explore the perceptions of family life for parents prior to child's admission to residential school/care and after admission to the school/care facility. To explore parents' perceptions of child behaviour prior to admission and after admission	In the sample of 23 children, there were a substantial number (17 of the 23) diagnosed as having an intellectual disability. There were 16 children with autism spectrum disorder, two of whom had Asperger syndrome. Three children had Down syndrome, two of whom also had a diagnosis of autism spectrum disorder. Three children had diagnosed psychiatric disorders, including obsessive compulsive disorder (OCD). There were single cases, each of attention-deficit hyperactivity disorder (ADHD), CHARGE syndrome, fragile *X*, foetal alcohol syndrome, Pallister–Killian syndrome and Rett syndrome. Most of the children in the study were in full-time residential care at Camphill school Aberdeen and received active, full-time day programmes. Altogether 19 parents (17 families) were involved in the 1 : 1 interview. In two cases, both parents were interviewed. There were 12 mothers and seven fathers. The above included one foster and one adoptive mother. Seven other parents participated in the focus group. The parents represented six children and five families. Two sets of mothers and fathers were present. One family had two children with major disabilities attending the residential school/care facility	The parents described life with the child prior to placement as being extremely difficult, mostly due to challenging behaviours of the children. Experiences included impacts and restrictions to parental employment/work, having visitors to the house, and choosing outings. Impacts to siblings, difficulties accessing respite, and challenging behaviours and discontent in the child. Parents saw improvements in child's behaviours, including their social interactions and their independence. They also saw an improvement in their health: Sleeping and eating better. When children returned home for visits, parents described experiencing enjoyment when their child with disability visited, and improved quality time eased feelings of guilt associated with placement	It was recognised that the study was primarily directed to the potential effects of major changes to the facilities with the planning of a major roadway close to the school/care facility's group homes and other facilities
Tenenbaum et al. [19], Israel	Use of a questionnaire developed by the office of the medical director, Ministry of Social Affairs and Social Services	To examine trends in the number of children with intellectual disability in residential care centers in Israel	6,872 persons with intellectual disability in residential centers in 2007	The percentage of residents that were children (aged under 19 years) has been trending down since 1999, from 18.07% to 12.6% in 2007	Not stated

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Sainero et al. [20] Spain	Descriptive study used questionnaires completed by child's key residential worker	To profile the state of health and wellbeing of a group of children with intellectual disability living in a residential care facility in Spain and compare these results to their nondisabled counterparts	A sample of 264 children aged between 6 and 18 years living in a residential care facility in Spain were used as the sample for this study. Forty-eight individuals in this sample had intellectual disability	The study found that the children in the sample who had intellectual disability were more likely to have experienced physical abuse and multiple forms of abuse compared to children without a disability. Children with intellectual disability had also experienced more placement instability prior to their placement in the residential care facility. More than a quarter of the children with intellectual disability presented with major physical illnesses compared to only 7.4% of children without a disability in the studies sample. There was significant difference in the utilization of mental health services between the two groups, with a little more than a quarter of the entire sample receiving mental health treatment, 45.8% of the children with intellectual disability were receiving treatment compared to just 21.3% of the children without a disability. Similarly, the use of psychotropic medication was disproportionately prescribed, with 86.4% of the children receiving mental health treatment with intellectual disability taking them compared to just 50% of the children without a disability receiving mental health treatment. Children with intellectual disability had higher scores for clinical range of all mental disorders; however, they were only statistically significantly higher for social problems and total behavior problems compared to the children without a disability	Exploratory and descriptive study conducted in a single autonomous community of Spain that may not represent the generality of cases in the country. The number of children meeting the criterion for diagnosis of intellectual disability was relatively small. The potential sample of children with disability in residential homes might be even higher than that recognised here

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
McConkey et al. [21] UK	Comparative study	To monitor the living arrangements of children with intellectual disability from the Republic of Ireland over a ten-year period	700 children with intellectual disability living in out-of-home care settings. Data came from the national intellectual disability database. Children's placements between 1999 and 2009 were monitored	Children with intellectual disability were 12 times more likely to be in care compared to children without disability. Male children without disability were only slightly more prevalent than female children without disability (50.6% compared to 49.4%), whereas male children with intellectual disability were more prevalent in care compared to female children with intellectual disability (64.8% compared to 35.2%). Children without disability had only a slight difference in percentages between the 2 age ranges of 0–9 years, and 10–19 years, with 54.2% of the population in the 10–19 years age group compared with 45.8% of children aged 0–9 years. However, children with intellectual disability in the 10–19 years aged group had a significantly higher proportion of children in care compared with children with intellectual disability in the 0–9 years aged group (83.7% compared 16.3%). Most children without disability were in foster or boarded out settings, whereas most children with intellectual disability were in residential settings	The National Database in the Republic of Ireland contains no information regarding the reasons as to why children were placed in care. No details were available on the children's behaviour or health needs which might influence their care arrangements. It is possible, that children experienced different placements over the ten-year period within the same form of care arrangements that would not have been reflected in the analysis, as only two time points were selected for comparison
Joshi and Joshi [22] India	Descriptive study	To describe the menstrual pattern of girls with disabilities	30 adolescent girls with disabilities living in a residential home. Disabilities included intellectual disability (21), locomotor disability (3), visual impairment (1), hearing impairment (2), and multiple disabilities (3)	Of the 30 girls, 15 had started menstruating. Seven girls with intellectual disability had attained menarche beyond 14 years of age, and 2 girls with intellectual disability had not yet attained menarche by the age of 15 years. Disobedience in girls with intellectual disability peaked in the premenstrual phase of their cycles. Girls with mild intellectual disability were independent with menstrual hygiene, girls with moderate intellectual disability required supervision, and girls with severe intellectual disability were fully dependent. The authors claim that the study demonstrates that girls with moderate intellectual disability could become independent with menstrual hygiene with the right education. However, some behavioral modifications and psychotherapeutic drugs may be needed to promote this. Dysmenorrhea may be under reported in girls with intellectual disability	Sample size is limited. Dysmenorrhea could have been underreported due to communication skills of participants

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
McConnell et al. [23] Canada	Multimethod study spanning across 3 years using annual surveys and in-depth interviews – this article presents the surveys for the first year	To identify factors that may explain why some families, and not others, seriously consider out-of- home placement as an option for their child	538 families raising children with disabilities in Alberta, Canada disabilities of children included intellectual disability (48%), autism spectrum disorder (36%), cerebral palsy (15%), Down syndrome (11%)	The findings of this study suggest that if parents shared responsibilities for keeping the family running, had sufficient services that meet the needs of the family, with flexible working conditions, and satisfactory childcare options, the sustainability of the family was achievable despite child characteristics (e.g., activity limitations, complex behaviour, and healthcare needs)	Generalizability may be limited to only families within the same state of the study population. Relies on parent carer view and other family members may have other views
Euser et al. [24] The Netherlands	Used a questionnaire	To examine the year 2010 prevalence of child sexual abuse in Dutch residential and foster care for children with a mild intellectual disability	A sample of 104 professionals from 18 different facilities was used. Each professional reported on a different group of children with intellectual disability for which they supported care of during the study period. There were 1650 children overall in out-of-home care. There were 955 children in residential care, and 695 children in foster care in the study period	In total, 16 cases of sexual abuse were reported, creating an overall year prevalence estimate of 9.7 per 1000. This was significantly higher compared to the study of children without intellectual disability in the same study period residing in out-of-home care, whose prevalence risk was 3.5 per 1000. The sexual abuse risk prevalence of children with a mild intellectual disability residing in residential care was initially higher compared to children with a mild intellectual disability in foster care settings. However, children residing in foster care were significantly younger (31% of children in foster care were over 12, compared to 84% of children in residential care). To prevent an age effect on the prevalence risk, these risk scores were recalculated for estimates of risk prevalence in children aged over 12. This resulted in an overall risk rating for children in residential care with intellectual disability to be 9.9 per 1000, compared with children in foster care at 9.3 per 1000	Sentinel reports to assess sexual abuse were used. Meta-analytic evidence indicates that prevalence rates of sexual abuse based on self-report are considerably higher than prevalence rates based on sentinel studies

TABLE 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Slayter [7] USA	Cross-sectional, exploratory study	Establish the prevalence of disrupted adoptions of children with intellectual disability in foster care; establish the demographic differences of foster children with intellectual disability who discharge from foster care compared to those who remain; explore case outcomes for foster children with and without intellectual disability; and explore case outcomes of foster children with and without intellectual disability who are ageing/transitioning out of foster care	Taken from data from the adoption and foster care analysis and reporting system (AFCARS) – sample included 11,420 children with intellectual disability and 359,353 children without intellectual disability or any other disability	Children with intellectual disability constituted 3.2% of the foster care population for which a confirmed disability diagnosis was recorded. The data found that 6.7% of children with intellectual disability had had a previous failed adoption, compared to just 1.9% of children without a disability. Foster children with intellectual disability were 46% less likely to exit foster care compared to their nondisabled counterparts. Foster children with intellectual disability were 48% less likely to experience reunification with their family compared to their nondisabled counterparts. Foster care children at transitional age (18+) with intellectual disability were 28% less likely to exit foster care compared to their nondisabled counterparts	The definition of "mental retardation" used by the adoption and foster care analysis and reporting system (AFCARS) is limited in that it does not allow for specification of findings by level of intellectual disability. This measure may also include diagnoses other than intellectual disability. Prevalence data derived from the use of this variable are likely to be an undercount of the actual prevalence of intellectual disability, as child welfare case workers who enter data about their clients might not enter this diagnostic condition for all their clients
Chen et al. [25] USA	Longitudinal study	To examine the prevalent types, varying degrees, and predictive patterns of multisector involvement in out-of-home settings for students with disabilities in different special education classifications	This study examined a sample of early adolescents in grades 7, 8, and 9 receiving special education in a large urban school district. Out of 58,000 youth, 10,911 (18.8%) were enrolled in special education programs (7, 028 with learning disabilities, 1,247 with serious emotional disturbance, 1245 with intellectual disability, 804 with speech and language impairments, and 587 with other disabilities)	For students with disabilities receiving special education services, nearly 10% were involved in at least one form of out-of-home care system (either child welfare, juvenile justice, or mental health), and more than 3% were involved across 2 or more systems. Students with serious emotional disturbance were most at risk with 21.2% of students involved in at least 1 system of out-of-home placement. Of the students with learning disabilities, 9.1% had at least one system involvement, and 3% had more than one system involvement. For children with intellectual disability, 6.8% had one system involvement, and 1.5% had more than one system involvement. Less than 3% of students with speech and language, and other disabilities were involved in at least one system and nearly 1% experienced more than one system involvement. Looking specifically at the children with intellectual disability, 8.2% had any amount of system involvement. Of those children with intellectual disability involved in out-of-home care systems ($n = 102$), 47.1% were involved in child welfare, 49% were involved in juvenile justice, and 23.5% were involved in mental health	The study sample, though sufficient in size, is from an urban school district that disproportionately serves minority, low-income students in the northeast. The findings for multisector involvement for students with disabilities are limited to out-of-home placements

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Wissink et al. [26] Netherlands	A retrospective file analysis design	To determine what the characteristics of the reported cases of sexual abuse in children with intellectual disability, and whether there were differences in the cases of sexual abuse of children with intellectual disability compared to children without intellectual disability	In the period under study, a total of 176 reports of sexual abuse were received. Of these reports, 128 involved a child with intellectual disability	Of the 128 reports of sexual abuse of children with intellectual disability, 85% ($n = 109$) of the reported cases involved a child placed in residential care, compared with 15% ($n = 19$) receiving ambulant care. In terms of frequency of abuse, 56% of reported cases occurred only once, and 44% had occurred repeatedly. Most reports came directly from the child (66%, $n = 85$) who disclosed the incident by telling another person of the incident, whereas 24% ($n = 31$) were flagged by other individuals involved with the child (such as family members or care providers), and in 9% ($n = 11$) of cases, the perpetrator was caught in the act. Victim characteristics explored included gender, age, child protection measures, previous victimization, IQ level, and ethnicity. Most cases involved victims who were female (71%, $n = 91$). Reports involved children of all ages; however, most were adolescents between 12 and 17 ($n = 85$). A small percentage (30%, $n = 38$) of victims were aged 6–11, and 4% ($n = 5$) aged 1–5 years old. Of the 128 reported cases, 99 (77%) of the children were under a provisional family supervision order	Data are not conclusive regarding whether there are more incidents of sexual abuse in these residential institutions or whether these residential institutions report the abuse more often than ambulant care institutions. The information found in the examined files of the inspectorates was not consistent or uniform

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Dion et al., [27] Canada	Incidence study	To determine what the differences are in characteristics of children with substantiated maltreatment reports who have intellectual disability, compared with children without intellectual disability	Sample included 5,797 investigations of substantiated child maltreatment, 656 (11.3%) involved children with intellectual disability	Children with intellectual disability are overrepresented among maltreatment cases. The studies general population of children with intellectual disability is around 1%. However, the percentage of the maltreatment cases for children with intellectual disability was 10%. Children with intellectual disability were more likely than children without intellectual disability to be slightly older, boys, and have attention deficit disorder/attention deficit hyperactive disorder, attachment issues, aggressive behavior, inappropriate sexualized behaviors, and physical disability. Primary caregivers of children with intellectual disability were slightly more likely to have a source of income that was not from full-time work and have fewer social supports. Children with intellectual disability were more likely to have had a case previously opened, compared to families of other children. They were also more likely to have their case remain open for ongoing child protection services, and more likely to be referred to as “beyond the parameters of child protection services.” Children with intellectual disability were also more likely to be formally placed into care, including foster/kinship care, group homes, or therapeutic residential treatment centers	The data represent a limited timeframe/snapshot, which reduces the generalizability of the findings. As this design did not allow the identification of causal relationships, prospective studies are needed. The child’s intellectual disability status was identified by practitioners who completed the file and it included intellectual disability strongly suspected or confirmed by a diagnosis. In the current analysis, only substantiated cases were included
Cidav et al. [28] USA	Retrospective cohort study	To estimate the prevalence of foster care involvement among Medicaid children with autism spectrum disorder, children with intellectual disability, and typically developing children; and determine the risk of entry to foster care	Children were excluded from the study if they were already in foster care at the start of the study period (January 2001). The entire sample consisted of 39,422,498 children, 220,271 had autism spectrum disorder; 286,344 had intellectual disability; and 63,703 had autism spectrum disorder and intellectual disability	The prevalence of foster care involvement for autism spectrum disorder increased from 73 per 1000 in the years 2001–2004 to around 98 per 1000 for the years 2004–2007. For all other groups the prevalence did not change over the study period. The prevalence for foster care involvement for children with intellectual disability was 77 per 1000, for children with ASD and intellectual disability it was 68 per 1000, and for typically developing children it was 36 per 1000. The rate of entry for children across the study period included 8.1% for children with autism spectrum disorder, 5.7% for children with intellectual disability, 5.3% for children with autism spectrum disorder and intellectual disability, and 2.6% for typically developing children	The accuracy of the autism spectrum disorder diagnosis in Medicaid claims is unknown. The authors relied solely on a sample of children enrolled in Medicaid for the analysis, and the results may not be generalizable to other populations. Data came from older claims data and did not examine subtypes of autism spectrum disorder

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
Van Horne et al. [29], USA,	Population-based cohort study	This study was conducted to determine whether the risk and predictors of maltreatment in children 2 to 10 years of age differ between those without and with specific birth defects: Down syndrome, cleft lip with/without cleft palate, and spina bifida	The sample consisted of 2,902,385 children, which included 2,895,319 children without birth defects, 3503 children with Down syndrome, 2670 children with cleft lip with/without cleft palate, and 893 children with spina bifida	The age specific prevalence for maltreatment peaked at age three for all groups and declined after this. However, the group without birth defects had a steadier decline as the child aged compared with the birth defect groups who had peaks and troughs across age strata. There were no new substantiated maltreatment reports for children with Down syndrome after the age of 9. Neglectful supervision was the most prevalent maltreatment type across all groups. The birth defect groups were significantly more likely to have a substantiated report for medical neglect compared to the group without birth defects. For children with Down syndrome, compared to the unaffected group – the perpetrator of maltreatment was significantly less likely to be a nonparental relative. Children with Down syndrome were more likely to be born to older, more educated, and married parents which are protective factors for maltreatment. However, when data were adjusted for these factors, children with Down syndrome were 32% more likely to be maltreated compared to the group without birth defects. This study also highlights the risk for children both with and without birth defects, born into families with fewer socioeconomic resources. Mothers' education level, parity, and lack of private insurance were found as risk factors for maltreatment	Due to state statutes on record retention, only data for substantiated cases and not all alleged or investigated cases were provided for these analyses. As the substantiation decision process may be influenced by multiple external factors (e.g., reporter identity, recovery of physical evidence) and maltreatment is generally underreported, this study likely underestimated the true prevalence of maltreatment in its population. Additionally, family mobility (out of Texas) was not taken into account. Consequently, children moving out of state were not censored and substantiated maltreatment reports from other states were not available for these analyses
Lindley [30] USA	Multivariate regression analyses	To determine if children in residential care with intellectual disability were more likely to utilize hospice care during their end-of-life stage. This study sought to measure hospice enrollment and hospice length of stay	The study used a sample of 1538 children, who died at under 21 years of age from a life-limiting, or chronic condition. 289 of those children had intellectual disability	Only 164 children had enrolled in hospice care out of the sample of 1538 children. The average length of stay for those who enrolled in hospice care was 27 days. The odds of children with intellectual disability in residential care enrolling in hospice care was 3 times higher than their counterparts in their last year of life. There was no relationship with length of stay in hospice care. This study indicates that residential care may improve enrollments into hospice care for children with intellectual disability approaching end-of-life	Findings of the study may not be generalized to non-Medicaid population outside of California. Children who reside in other states or have private insurance may experience different outcomes

Table 3: Continued.

Authors, country	Design	Objective	Population	Key findings	Reported limitations
McDonnell et al. [31], USA	Prevalence study	To assess lifetime maltreatment experiences across children with autism spectrum disorder, intellectual disability, both autism spectrum disorder, and intellectual disability, in comparison to children in the general population	316 children with autism spectrum disorder-only; 291 children with autism spectrum disorder and intellectual disability; 1,280 children with intellectual disability-only; and a population control sample of 3,101 children	Children with intellectual disability-only were more likely to have substantiated reports of sexual abuse, physical abuse, and emotional abuse, compared with all other groups. For physical neglect, all groups (autism spectrum disorder-only, autism spectrum disorder and intellectual disability, and intellectual disability-only) were more likely to have substantiated reports than the control group. Children with autism spectrum disorder-only and intellectual disability-only had significantly more cases of alleged physical abuse and physical neglect then the control group. The autism spectrum disorder and intellectual disability group, and intellectual disability-only group were more likely to have multiple perpetrators reported across cases, compared with the control group. The intellectual disability-only group were more likely to have a perpetrator that was an immediate family member, compared to the control group	The study design could not identify bidirectional relationships between autism spectrum disorder and maltreatment. The control group was not re-evaluated for late autism spectrum disorder diagnosis after age 8, which may have underidentified children with subtle autism spectrum disorder presentations and potentially led to misclassification. Maltreatment data from state social services only reflect cases that were formally reported, which may underestimate the true prevalence of maltreatment and noncaregiver perpetrated-maltreatment

more likely to experience severe forms of maltreatment, from multiple perpetrators, including their caregivers.

Slayter and Springer [19] found the prevalence rates for the different types of maltreatment that lead to placement into OOHC differed, with children with IDD experiencing an increased incidence of neglect compared to other children. McConkey et al. [21] also found children with IDD in the UK are more likely to experience neglect as a reason for removal.

In Slayter and Springer's [19] study, children with IDD were less likely to be removed due to parental drug abuse or child drug abuse compared to the comparison group. They also reported that females with IDD were twice as likely to be removed due to sexual abuse, compared to those without IDD. Although both males and females with IDD were found to experience the same rates of physical abuse, males with IDD were 15% more likely to be removed from parental care due to physical abuse compared to boys in the comparison group.

3.3. Voluntary Placement. Children with IDD often have additional complexities, such as multiple chronicity, and require an increased level of care [21]. Subsequently, they are also more likely to be voluntarily placed into OOHC settings compared to nondisabled children [19, 21]. A survey exploration of parental decision-making found 1 in 6 parents of children with IDD had considered placing their child in OOHC, and 1 in 10 were actively pursuing OOHC placement due to the increased care needs, lack of resources to provide care, and pervasive impact on the entire family [23].

A qualitative study by Brown et al. [18] used interviews to explore families' perspectives on life prior to choosing to place their child with IDD into a residential care facility. The parents described life with the child prior to placement as being extremely difficult, mostly due to challenging behaviours of the children. Experiences included impacts and restrictions to parental employment/work, having visitors to the house and choosing outings, impacts to siblings, difficulties accessing respite, and challenging behaviours and discontent in the child.

3.4. Placement Settings in OOHC: Home-Based Care Vs. Residential Care. Like maltreatment types, the patterns of OOHC settings differ for children with IDD compared to other children. Given children with IDD are at much higher risk for maltreatment and voluntary relinquishment from parents, it is not surprising that a retrospective cohort study, conducted in the USA by Cidav et al. [28], found that children with IDD enter foster care at higher prevalence rates compared to the general population of children. The reported rates of entry into foster care for children with IDD were 5.7% compared to 2.6% for typically developing children.

Generally, following their placement into OOHC, the goal of child protective services is to support families to create a safe environment for the child to return to their care. However, Slayter [7] found that children with IDD are more likely to remain in foster care and are less likely to return to their primary caregivers or be placed with kinship carers, compared to other children in foster care. Slayter [7] also found that children with IDD are more likely to experience a failed adoption compared to other children, with 6.7% of children with IDD having had a previous failed adoption, compared to just 1.9% of children without a disability.

Slayter and Springer's [19] cross-sectional, exploratory study conducted in the USA found that 2.6% of children in the foster care population were children with IDD. In terms of characteristics, children with IDD were on average, two years older (average age of 11), more likely to be male, and were between 4 and 20 times more likely to have a comorbid disability or medical condition, compared to the comparison group. Children with IDD had only a very slightly higher number of lifetime removals and were only slightly older at the age of first removal compared to the comparison group. Children with IDD were also more likely to have had a previous adoption.

Children with IDD are more likely to be placed in institutional or residential care settings. Slayter and Springer [19] found children with IDD requiring OOHC in the USA were twice as likely to be placed into an institutional setting compared to a comparison group of children without a disability.

A longitudinal study conducted in Israel identified a downward trend in the percentage of children with IDD living in residential facilities between the periods 1999 (18.07%) and 2007 (12.6%) [19]. The authors proposed that this decrease was likely related to policy shifts toward deinstitutionalization and not related to increased support for families. The authors argued that in the Israeli context, residential care was often the better option for children with IDD due to their increased needs which necessitated nursing care and various medical and mental health supports, which could not be provided in the home, due to the lack of public health support for families with a child with IDD [19].

A mixed-methods study of 99 Dutch children with IDD in long-term foster placements reported that 28.3% experienced early termination of their placement [18]. The study identified a correlation between the severity of troublesome behaviours of children with IDD and the experience of multiple placements. A comparative study by McConkey et al. [21] found the type of placement was dependent on the child's level of disability. Specifically, they found children with mild disabilities were more likely to be in foster care settings, whereas children with more severe disabilities were more likely to be in congregate care arrangements.

When comparing children with IDD living in residential care to their nondisabled counterparts, Sainero et al. [20] found that the care needs of children with IDD were greater. More than 25% of the children with IDD presented with major physical illnesses compared to only 7.4% of children without a disability in the study sample. Overall, children with IDD had higher care needs due to additional physical and mental comorbidities and behavioural needs. Children with IDD were more likely to have experienced severe maltreatment and previous placement instability prior to their placement into residential care.

Enhanced care support is also reported for adolescent females with IDD in residential care. In a study of menstrual patterns in adolescent females with disabilities living in a residential facility ($n = 15$), females with mild intellectual disabilities were found to be independent with menstrual hygiene. However, females with moderate IDD required supervision, and those with severe IDD were fully dependent on assistance from others to manage their menstrual hygiene [22]. Behavioural problems in females with IDD were reported to peak during the premenstrual phase of their cycles. The authors suggested dysmenorrhea may be underreported in adolescent females with IDD and may contribute to the reported increase in behavioural issues [22].

The comorbidities of children with IDD, which often necessitate higher care requirements, may also result in premature death. Using a multivariate regression analysis (2018) found that the odds of children with IDD in residential care enrolling in hospice care were three times higher than their counterparts in their last year of life.

3.5. Sexual Abuse in OOHC. Two studies on the sexual abuse of children with IDD in OOHC settings were found in the review of the literature [24, 26]. One study conducted in the Netherlands reported children with mild IDD to be at increased risk for sexual abuse in OOHC settings compared to children without IDD. The overall year prevalence estimates of sexual abuse for children living in OOHC with IDD were significantly higher (9.7 per 1000) when compared to children without IDD (3.5 per 1000) [24].

Euser et al. [24] reported the overall risk rating for children with IDD to be similar whether residing in residential care (9.9 per 1000) or foster care (9.3 per 1000). Conversely, Wissink et al. [26] found children with and without a disability had an increased risk of sexual abuse in residential care compared to other OOHC settings. However, children with IDD in OOHC settings that were not residential care were seven times more likely to be the victim of sexual abuse compared to children without IDD in OOHC settings that were not residential care [26].

4. Discussion

The aim of this study was to summarise what is known about children with IDD who engage with CP and OOHC services. The small sample of articles included in this review suggests that children with IDD engaging with CP and OOHC services are an understudied population despite the finding that the prevalence of children with IDD engaged with CP and OOHC services exceeds that of the general population. This review highlights the journey into and through OOHC differs for children with IDD, with their disability directly impacting their entry to care, placement stability, the context of care, and the likelihood of experiencing further maltreatment.

It is clear from the literature that children with IDD have increased care needs which are often further compounded by additional complexities, such as challenging behaviour and multiple chronicity, causing increased levels of stress for parents [32], a known risk for child maltreatment [33]. When families are well supported, parental stress can be moderated, thereby reducing the risk of child maltreatment. Unfortunately, this review suggests when families are not well-supported, children with IDD are either removed from parental care for their own safety or voluntarily placed into OOHC by their overwhelmed parents. While the former is a common reason for placement into OOHC, the latter is less so.

Voluntary placement into OOHC is not well understood or universally available but appears to be more common for children with disabilities. In a comparative review of state statutes in the USA, Jones et al. [34] found a lack of clarity and consistency related to voluntary OOHC placement. An exploratory study by Hill [35] found 3.4% (21,966) of the children in OOHC in the USA in 2013 were voluntarily relinquished by their parents. Of these, 41.1% had a disability diagnosis. Hill [35] also reported that children who are voluntarily placed into OOHC experience higher numbers of placements, spend longer overall time in OOHC, and are more likely to be placed into congregate care settings compared to children who are not voluntarily relinquished to OOHC.

Irrespective of their entry pathway, compared to their nondisabled peers, the OOHC experience of children with IDD differs. Whilst in care, they are more likely to experience multiple foster carers and less likely to be placed in kinship care. This is likely due to the difficulties which foster carers' experience trying to meet the increased needs, in particular increased healthcare needs of children with IDD. Not unlike the biological parents, foster carers have been found to experience financial, social, and healthcare system-related challenges when providing care to children with IDD [36]. Whether foster carers of children with IDD are consistently provided with additional supports or training to assist them in their caregiving role is largely unknown, but not likely given the plethora of literature indicating foster carers are poorly supported in their caregiving role (e.g., [37–40]).

Previous research has identified that carers do not receive adequate training for the children in their care. For example, a recent Australian study found foster carers of infants were provided no training related to basic infant care such as feeding, sleeping, settling, vaccination schedules, or developmental outcomes [41]. A mixed-methods study in New Zealand identified a "mismatch" between the level of support and training offered to foster carers and the burden of care related to the children's complex needs [39]. Carers in this study expressed an urgent need for training regarding the etiology of children's challenging behaviours and practical skills for effective behaviour management. Foster carers' requests for training and support related to behaviour management have been consistently reported in the literature for at least half a century (e.g. [40, 42–47]), indicating such training has either not been provided or is not effective. In this context, given that some children with IDD are known to manifest complex and challenging behaviours [48], it is not surprising that foster carers struggle to provide care for children with IDD.

Children's complex care needs coupled with poorly supported foster carers result in multiple foster care placements and eventual placement into residential care facilities, where they are at greater risk of further physical and/or sexual maltreatment compared to children without disabilities [24, 26]. Further, while residential care settings may be better equipped to cater to the specific physical care needs of children with IDD, such as complex health supports, they can reduce the likelihood of children forming healthy attachment relationships. Attachment theory purports the quality of children's attachment with their primary caregiver plays a pivotal role in their social and emotional development [49, 50]. Institutional care is known to inhibit attachment; this understanding likely underpins the reported decrease in the institutionalization of children with IDD in Israel [19]. Nevertheless, without services to support either biological parents or foster carers in the community, children with IDD will continue to be at an increased risk of placement into residential care facilities and subsequent maltreatment. This suggests the need for a well-integrated multisystem approach to support children with IDD and their families (biological and/or foster) to enable them to reside in a home with individuals who can provide both the physical and emotional care they need.

Biological parents relinquish care for multiple reasons, including a lack of support and resources to provide adequate care for children with IDD in their homes or a lack of funds to secure quality residential care [23]. This review suggests that foster carers also relinquish care, as many children with IDD experience multiple foster carer placements prior to residing in residential care. If this pattern is consistent, it is possible that their initial placement into foster care is merely delaying the inevitable placement into residential care. Tenebaum et al. [19] argued that residential care is the preferable form of OOHC for children with disabilities, due to the lack of support available in the community. This perspective is not without controversy, for a range of reasons. The question that arises, however, is whether the risk of multiple foster care placements and broken attachments outweighs the benefits that come from residential care despite the limited opportunities to form attachments to a primary carer. Surely, the answer is to better support families in the first instance, thereby reducing the incidence of placement, voluntary or not, into the OOHC system.

When a child is diagnosed with IDD, parents' responses can be quite varied [51]. For some, diagnosis may bring affirmation or relief, while others experience grief and must deal with the loss of the dreams and ambitions they held for their child. Conversely, many foster carers are made aware of children's diagnoses prior to their placement into care. As such, these carers make a conscious decision to provide care for children with IDD. However, this review suggests carers are not always able to make informed decisions as the information provided to carers does not accurately reflects children's needs [18]. When this occurs, carers may find themselves unable to provide the care required. This has negative implications for both the children (as previously discussed) and the carers. Research has previously demonstrated the termination of a placement, planned or unplanned, has a significant emotional impact on carers [52, 53], often contributing to foster carer attrition [54].

Not only should foster carers be provided adequate information to make informed decisions regarding their capacity to provide care to children with IDD but also that they should be supported to provide optimal care. Of note is that this review found no literature indicating foster carers of children with IDD were routinely provided training related to the children's care. It should be noted that in the USA, however, a small minority of children with complex needs are placed into medical foster care, with carers who receive a higher level of financial compensation and support. Unfortunately, these specialized medical foster carers have also reported feeling inadequately prepared to provide care for children with medical complexity [55], as they often receive fragmented and inaccurate information regarding the children's needs [56]. Statistics regarding how many of these children are diagnosed with IDD are not known. What is clear is that the supports (or not) currently in place for carers of children with IDD in out-of-home care are greatly lacking. Urgent attention is needed to reduce potential foster carer attrition and increase the likelihood that children achieve optimal physical and emotional outcomes.

It is important to highlight that most articles included in this review came from the USA, UK, and the Netherlands with a small number from Canada, Spain, Israel, and India. As such, conclusions drawn from this review may have limited transferability to different cultural contexts. None of the articles came from Australia, demonstrating a major gap in the Australian literature for children with IDD in OOHC.

5. Conclusion

This review is the first to focus on the published literature related to children with IDD who are engaged with CP and OOHC services. Of note is the overwhelming quantum of data that reports added problems for these children at every stage of the CP and OOHC journey. The most significant finding is the reported lack of adequate support, training, and resources for the child with IDD, their families, and their carers in the OOHC system. Future research needs to identify those children with IDD who are either not let down by the system or who thrive within the system to better understand the factors that are required to improve outcomes. The added complexity of many children with IDD, whether from challenging behaviours or multiple chronicity, is an area that perhaps requires specialized input that is both targeted and timely from appropriately trained health professionals.

Additional Points

The following is known about this topic: (i) children with intellectual and developmental disabilities have increased caregiving needs and are at greater risk of neglect and abuse or voluntary placement into out-of-home care. (ii) As a result, there is a disproportionate number of children with intellectual and developmental disabilities engaging with child protection and out-of-home care services. This paper adds the following: (i) children with intellectual and developmental disabilities who engage with child protection and out-of-home care services are an understudied population. (ii) Their journey into and through care differs from their nondisabled peers, characterized by increased placement instability while in foster care and increased likelihood of placement in residential care facilities. (iii) There is little known about what training or supports are provided to foster carers regarding the care of children with intellectual and developmental disabilities.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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