

REVIEW



Unscheduled healthcare for children with intellectual disabilities: A systematic scoping review

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Abstract

Background: The provision of unscheduled healthcare for children with intellectual disability is less researched than that focused on hospital settings or for adult services. The aim of the scoping review was to map the evidence base in this area and identify areas for future study.

Method: A five-stage scoping review framework was adopted. CINAHL, PubMed, SCOPUS, PsycINFO, Embase, ProQuest Dissertation & Theses and Google Scholar were searched. Studies published in English after 1/1/2000 were considered eligible for inclusion.

Results: A total of 3158 titles and abstracts were screened, 137 full-text articles were reviewed, and 25 papers met the inclusion criteria. Descriptive themes focused on inequities, needs and experiences of families', poor GP training, and limitations of existing evidence.

Conclusion: Describing trends in healthcare utilisation by this population is valuable for monitoring quality of healthcare, however, addressing observed inequities will require approaches that recognise specific issues within the health system that result in inequities.

KEYWORDS

child, health, intellectual disability, scoping review, unscheduled healthcare

1 | INTRODUCTION

The prevalence of intellectual disability has been estimated at 10.37 per 1000 of population based on a meta-analysis of 52 international studies with higher prevalence rates among children and young people (Maulik et al., 2011). People with intellectual disability typically have poorer health status and greater limitations from long term health conditions compared to people without intellectual disability and this effect is more marked in child populations (Hughes-McCormack et al., 2018). Children with intellectual disability

experience higher rates of conditions that require ongoing specialist medical supervision throughout the lifespan, such as epilepsy, cerebral palsy, obesity and mental health concerns than their peers (Oeseburg et al., 2011; Robertson et al., 2015). Disparities in mortality rates for children with intellectual disability are higher compared to adult samples and for people with mild to moderate intellectual disability (McCarron et al., 2015). Combined with high healthcare utilisation, inequities in healthcare quality outcomes compound the existing inequities in social determinants of health experienced by children with intellectual disability (Emerson & Hatton, 2013).

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Appropriate and timely unscheduled or first contact healthcare is a vital component of any health system with regards to improved public health outcomes (Lennox et al., 2015). Unscheduled healthcare is typically provided in under 24 h notice (O'Cathain et al., 2007) by general practitioners (GPs), in emergency departments (EDs) and in out-of-hours GP services (Nicholson et al., 2020). People with intellectual disability report multiple barriers to accessing healthcare and persistently report poor care quality experiences (Iacono et al., 2014), however, less is known about their experiences with unscheduled health services. Health professionals have reported challenges they face when working with individuals with intellectual disability, such as communication difficulties, inaccessible or incomplete medical history, lack of training, complexity of care, inadequate professional support and fragmentation of disability support and health care (Appelgren et al., 2018; Baxter et al., 2006; Breau et al., 2017; Lennox et al., 1997). Addressing system-level barriers to overcome complex morbidities and early mortality is consequently difficult (Lennox et al., 2015). For example, in Ontario, Canada, people with intellectual disability are up to 13 times more likely to be hospitalised for 'ambulatory care sensitive conditions', of which good primary care should be able to prevent (Balogh et al., 2010).

People with intellectual disability are particularly vulnerable to poor quality and safety in healthcare settings and the extent to which families and caregivers feel listened to can impact health outcomes and mortality for this group (Heslop et al., 2014; Smith et al., 2020). Unplanned admissions for children with intellectual disability can be particularly challenging because plans for reasonable adjustments may be more difficult to put in place (Kenten et al., 2019). From the parents' perspective, assumptions, stereotypes and judgements can affect the quality of care that children with intellectual disability receive in hospital settings, however, the literature pertaining to primary care in this area is limited (Mimmo et al., 2018). Adding to an increasing evidence base, these reviews (Iacono et al., 2014; Mimmo et al., 2018) highlight the consistently poor inpatient experiences of care for children and adults with intellectual disability. Similarly, studies regarding healthcare utilisation and access to primary and preventative care have demonstrated persistent disparities and poor quality care experiences for people with intellectual disability (Bebbington et al., 2013; Glover et al., 2019; Heslop et al., 2014). Furthermore, this population is more likely to be admitted to hospital for conditions that can be routinely managed through primary care services such as asthma and diabetes (Dunn et al., 2018).

Within clinical settings, parents are heavily relied upon as 'experts' about their child and are a valuable resource for healthcare professionals (HCPs), however, over-reliance on parents masks the need for staff to be better educated and informed about children with intellectual disability (Kenten et al., 2019). Indeed, parents of hospitalised children with intellectual disability report being relied on by healthcare staff to be constantly at their child's bedside and attend to all their care needs yet perceive they are not involved in shared-decision making (Mimmo et al., 2019). Less is known about the parental experiences regarding unscheduled healthcare with children with intellectual disability, particularly interactions with health

professionals. Moreover, much of the evidence, including systematic reviews, in this area has focused on adults with intellectual disability or on children in hospital settings rather than in an unscheduled setting, therefore, this review provides a timely addition to the literature.

Scoping reviews are increasingly being used to review and map existing health research evidence on a particular topic (Arksey & O'Malley, 2005). They are most suitable for reviews that do not have a highly specific research question or which seek to incorporate multiple types of research designs (Levac et al., 2010), in which case a systematic review would not be appropriate. The aim of this scoping review was to search and map the evidence base in the area of unscheduled healthcare for children with intellectual disability and identify topics using thematic synthesis that may provide a direction for future areas of study.

2 | METHODS

The scoping review provides an overview of the current evidence relating to unscheduled healthcare for children with intellectual disability. A five-stage scoping review framework was adopted for the review (Arksey & O'Malley, 2005; Levac et al., 2010). The five stages were, (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarising, and reporting the results. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist was followed in conducting and reporting this review (Tricco et al., 2018). Thematic synthesis (Thomas & Harden, 2008) was used to synthesise the data and develop the themes.

The review question was, 'What issues or concerns have been researched in relation to unscheduled healthcare for children with intellectual disabilities?'

2.1 | Identifying relevant studies

A preliminary search of the included databases was conducted to formulate the search terms that were used in the review. Search terms for intellectual disability were derived from previous reviews in this area (Balogh et al., 2016; Robertson et al., 2015). Terms including the word 'impairment' yielded a large number of results pertaining to, for instance, cognitive impairment in older adults and acquired brain injury which were not relevant to the present review. As a result, this term was not included in the final search to increase the sensitivity of the results and maintain a manageable database for screening. A broad search strategy was employed to find data related to all potential stakeholders including children with intellectual disability, parents, and health care providers. Keywords and Boolean operators are outlined in Table 1.

Five databases (CINAHL, PubMed, SCOPUS, PsycINFO and Embase) were selected to capture a wide range of specialities and disciplines. Grey literature databases were also searched including

TABLE 1 Keywords and Boolean operators

Child* OR paediatric OR paediatric
AND
intellect* disab* OR mental* disab* OR development* disab* OR learning* disab* OR intellect* disorder* OR mental* disorder* OR development* disorder* OR learning* disorder* OR intellect* deficien* OR mental* deficien* OR development* deficien* OR learning* deficien* OR retard* OR handicap*
AND
primary care OR general practice OR GP OR family physician OR family doctor OR emergency room OR emergency care OR emergency department OR out of hours OR after hours OR Practitioner Cooperative OR urgent care OR injury unit OR unscheduled health*

ProQuest Dissertations and Theses using the same search terms and Google Scholar using a modified search with the first 10 pages of results screened. Dates searched were between 1 January 2000 and 7 October 2019 to capture more recent literature in this area. The start date of January 2000 reflects the publication of seminal reports highlighting the significance of monitoring healthcare quality and safety indicators (Institute of Medicine Committee on Quality of Health Care et al., 2000). Appendix S1 contains further details on the searches across the five databases and grey literature.

2.2 | Study selection

2.2.1 | Eligibility criteria

Studies were considered eligible for inclusion if they were (1) retrospective or prospective empirical papers that directly explored issues related to children with intellectual disability and unscheduled healthcare, (2) used administrative data reporting on the utilisation of unscheduled health services, and (3) were published in English after 1 January 2000. Different terminology was often used to refer to intellectual disability, however, studies were only included in the review if a population of children with intellectual disability could be identified. The definition of special healthcare needs or chronic medical conditions often included 'behavioural and developmental challenges', but further details were rarely provided and thus, these papers were excluded as data pertaining only to children with intellectual disability could not be extracted. Exclusion criteria included studies reporting on the general population but with no specific data pertaining to children with intellectual disability as a sub-category, studies which focused on autism spectrum disorder (ASD) or attention deficit hyperactive disorder only (included if intellectual disability is considered alongside ASD), intervention studies, studies related to scheduled or specialist healthcare services, studies related to screening for disabilities, studies with adult populations which reported no data specific to children and expert opinion or editorials.

2.2.2 | Screening strategy

Two authors (E. N. and C. C.) independently screened the title and abstracts of search records retrieved against eligibility criteria. Full-text publications of all potentially relevant articles were retrieved and examined for eligibility by two reviewers (E. N. and C. C.). Any disagreements that arose between the reviewers were resolved through consultation with a third reviewer. The reference lists of all identified articles were then searched for additional records. The review management website Covidence™ (Covidence systematic review software, n.d.) was used to manage the screening process, remove duplicates and sort exclusions and inclusions.

2.3 | Charting the data

Data were extracted from included papers into an Excel spreadsheet. The data extracted included authors, year of publication, country of origin, aims/rationale, type of disability under study (if relevant), population, sample size, age, gender, study design, sampling strategy, data collection, data analysis and key findings. Data were extracted by one reviewer (E. N.) and a second reviewer (C. C.) extracted data from 20% of the included studies ($n = 6$) for comparison. Any discrepancies were discussed, and an agreement reached.

2.4 | Risk of bias (quality) assessment

An assessment of the quality of the studies was included to ascertain the nature of the evidence gaps in the literature (Levac et al., 2010). Given the heterogeneity of the study designs that emerged in the review, the Mixed Methods Appraisal Tool (Pluye et al., 2011) was utilised to assess methodological quality of the studies included for full-text review. Papers selected for inclusion were assessed by one reviewer (E. N.) for methodological quality prior to inclusion in the review. A second reviewer (C. C.) assessed 20% of papers ($n = 5$) and the results were compared for consistency. Any disagreements that arose between the reviewers were resolved through discussion. Twelve of the studies were of very high methodological quality (i.e., scored 100%) while 10 scored 83% and three scored 50%. Results of the quality assessment can be found in Appendix S2. Given the small database, no studies were excluded based on the quality assessment.

2.5 | Thematic synthesis

Initial line-by-line coding, where each line of text extracted from the included studies was coded, was carried out by one author (E. N.) and checked for consistency by a second author (S. G.). Descriptive and analytical themes were generated through discussion between both authors and checked against the included papers.

3 | RESULTS

3.1 | Collating, summarising, and reporting the results

A total of 3158 titles and abstracts were screened, with 3021 excluded. One hundred thirty-seven full-text articles were reviewed, and 25 papers met the inclusion criteria and were included in the scoping review. A flow diagram was created to document the search and screening process (see Figure 1). At the full-text review, the most common reason for exclusion was an inability to identify a group or sub-group of children with intellectual disability ($n = 42$) while a number were non-empirical studies ($n = 21$). A large proportion of studies were excluded because they were related to adult populations or where child samples could not be separated from the adult samples ($n = 18$), while the remainder were related to scheduled services, conference proceedings or intervention studies ($n = 31$).

3.2 | Details on the included studies

The majority of the research was carried out in the United States (USA; $n = 13$), with Australia the second most common country ($n = 5$), followed by Canada ($n = 2$) and Taiwan ($n = 2$). One study was included from each of the Netherlands, Norway and the United Kingdom.

Quantitative research designs and methodologies such as retrospective research utilising administrative databases ($n = 11$) and empirical studies using cross-sectional surveys and questionnaires

($n = 11$) were the most frequently utilised sources of data in the included studies. For the studies that used administrative data, data sources included healthcare records such as ED and primary care patient databases, disability service records and health data repositories. The remaining studies utilised newly developed or previously validated surveys and questionnaires ($n = 8$) or conducted secondary analyses of existing national survey data ($n = 3$). Three qualitative studies were included ($n = 3$) which used interviews, focus groups and stakeholder forums to collect data, and thematic analysis used in two of the studies to analyse the qualitative data with note-taking and systemic text condensation used in one study.

3.3 | Thematic synthesis

Thematic synthesis identified four descriptive themes (1) Inequities regarding utilisation of unscheduled health services; (2) needs and experiences of parents' and families' while utilising health services; (3) poor GP training affecting ability to support this population; and (4) limitations of existing evidence: common pitfalls to guide future research, with one overarching analytical theme: Inequity at the systems-level.

3.3.1 | Descriptive theme 1: Inequities regarding utilisation of unscheduled health services

Seventeen of the studies in the review described health service utilisation or hospitalisation of children with intellectual disability and/or compared this utilisation with another group to identify any inequities in service use or need. A common finding across the included studies was that children with intellectual disability were more likely to attend their GP or family physician compared to those without (Boulet et al., 2009; Chien et al., 2017; Gallagher et al., 2002), however, severity was not often an indicator of use (Caicedo, 2016). Children with developmental delays were found to have fewer check-ups with their primary care provider, however, had more medical conditions on record (Nachshen et al., 2009). In relation to out-of-hours services, children with intellectual disability were more likely to request out of hours care compared to those without and their requests were often rated as less urgent (Huetmekers et al., 2017).

Outpatient visits to EDs were also significant for children with intellectual disability, with a twofold increase in ED visits for children with developmental disability compared to those without over an 8-year period (Boulet et al., 2009). Children with intellectual disability had a greater risk of ED attendance for non-traumatic dental conditions (Chi et al., 2014) and had greater attendances for other conditions, including epilepsy (Nachshen et al., 2009) and ambulatory care sensitive (ACS) conditions (Hand et al., 2019a) compared the general population (Chien et al., 2017; Gallagher et al., 2002; Hand et al., 2019a; Hand et al., 2019b; Nachshen et al., 2009). Disability was related to use of the ED in a sample from Taiwan where 30% of children in the sample had attended the ED (Hsu et al., 2009). On

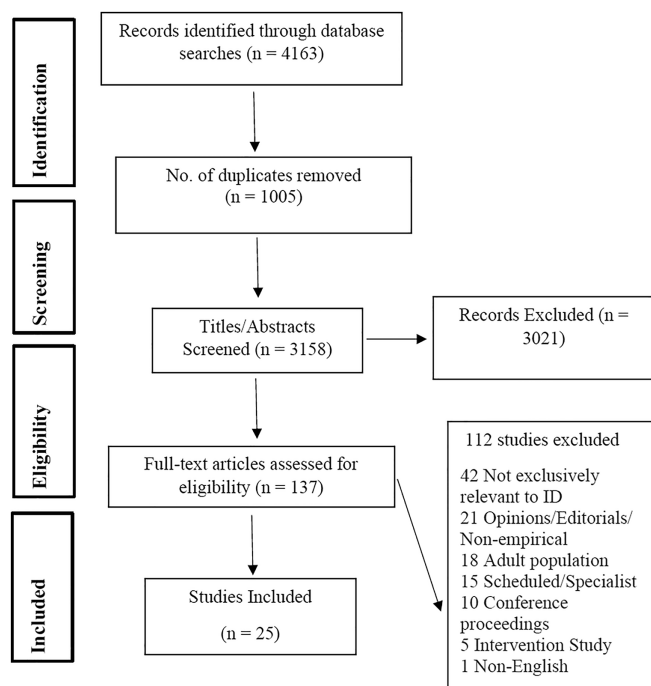


FIGURE 1 Flow diagram outlining the search strategy

balance, a study that linked disability service data with ED records found that those who had received disability services had fewer ED presentations and admissions (Reppermund et al., 2017), however, it should be noted that people who did not receive disability services were not included. Within the medical home model, which is a model for organising primary care to meet a wide range of health needs, (Jackson et al., 2013), fewer ED attendances were linked to having a primary care practitioner who listens to parental concerns, develops meaningful relationships with the families and who takes consideration of cultural values of the families (Lin et al., 2014).

Rates of emergency admittance to hospital was a focus of eight studies and indeed, hospitalisation or admittance for various conditions, including for ACS conditions (Balogh et al., 2010; Hand et al., 2019a) and epilepsy (Nachshen et al., 2009), for children with Down Syndrome (Fitzgerald et al., 2013), including a drop over a 7 year period for Down Syndrome (Thomas et al., 2011) and general intellectual disability (Gallagher et al., 2002). Children with intellectual disability had greater rates of non-emergency surgery admissions in a study from England (Glover et al., 2019) while less hospitalisations among people with intellectual disability were noted in another (Reppermund et al., 2017).

3.3.2 | Descriptive theme 2: Needs and experiences of parents' and families' while utilising health services

Parents and families frequently cited the challenges they faced when seeking and accessing unscheduled healthcare with common issues arising across studies. Four studies included in the review sought to obtain parents' views and experiences regarding primary care for their children. One study used qualitative methods to assess parents' needs regarding primary care for their child (Fereday et al., 2010). Partnership, trust and respect for both parent and the child emerged as key factors that parents wanted from a primary care provider. Regarding more practical considerations around healthcare, other factors included coordinated services, continuity of care, full information and communication and family-centred care. Finally, they wanted GPs to be knowledgeable about their child's disability and the issues facing parents and children and be able to interact with the child (Fereday et al., 2010). In a sample of parents of children with neurodevelopmental disabilities who utilise the medical home model, only a third of parents were satisfied with the primary health care they received (Zajicek-Farber et al., 2015). With regards to Fragile X syndrome, in a sample of well-educated and affluent family caregivers, the majority had a primary care provider (either a family physician or paediatrician), however, 40% noted that their provider could have been more knowledgeable about their children's condition (Wheeler et al., 2019).

Another study explored challenges faced by parents of children with co-morbid behavioural and mental health conditions. Parents had low expectations of their GPs' competence and involvement with their child and typically utilised GP services for everyday problems. In the parents' experiences, GPs were uninterested in their children's

behavioural and mental health issues and did not have the time to adequately address them (Fredheim et al., 2011). In a study from the United States examining parents' satisfaction about primary care, families were happy with their physicians ability to inform them about new care options and that they were sensitive to the child's needs (Liptak et al., 2006). Parents felt that primary care physicians should support them by putting them in touch with other parents in similar situations and felt they could have a greater understanding of the impact of the condition on the family (Liptak et al., 2006).

Two studies referenced social factors that may interact with disability such as socioeconomic status (SES) and immigrant status. Children with intellectual disability from lower SES families had greater use of the emergency department compared to those from higher SES status (Hsu et al., 2009) and children with ASD and certain developmental disabilities from immigrant families were twice as likely to lack a usual source of care (typically primary care) compared to non-immigrant families in the United States (Lin et al., 2012). They also reported that physicians spend less time with the family with poor insurance coverage acting as a barrier to healthcare access (Lin et al., 2012).

3.3.3 | Descriptive theme 3: Poor GP training affecting ability to support this population

The limited research which focused on the viewpoints of practitioners highlighted how a lack of training left them ill-prepared to adequately meet the needs of this population and this was particularly evident when the child had accompanying behavioural challenges. Two studies explored the views of GPs and primary care paediatricians regarding their treatment of children with intellectual disabilities. In line with the concerns of parents discussed above, some providers recognised the challenges faced by families in negotiating complex systems, which can be compounded by the medical complexity of the child and psychosocial concerns (Altman et al., 2018). Additionally, healthcare providers skills and capacity as well as time and availability were key challenges (Altman et al., 2018). Poor communication between healthcare providers was also noted and GPs felt that they were excluded from important communication regarding their patients. A lack of training in developmental and behavioural challenges was identified as a gap in paediatric education in a study from the United States (Freed et al., 2009). Almost half of general paediatricians in the study stated that additional training in developmental and behavioural paediatrics would have been beneficial in their practice.

3.3.4 | Descriptive theme 4: Limitations of existing evidence: Common pitfalls to guide future research

Different terminology was used to describe intellectual disability across the 25 studies, which reflects the broad use of terminology internationally. However, a common reason for exclusion was the lack of a clear definition of intellectual disability provided in the studies or

TABLE 2 Data from the included studies

Study details			Participant details		Methodology and findings from the included studies						
Authors/year	Country of origin	Aims/rationale	Type of disability under study	Sample (sample size)	Age	Gender	Study design	Sampling strategy	Data collection	Data analysis	Key findings
Altman et al., 2018	Australia	Exploring the perceptions and experiences of health care providers	Neurodevelopmental disability typical in sample described (multisystem conditions which did not fit easily into single disease categories)	Health care providers (103)	Not Reported	Not Reported	Qualitative	Purposful	Stakeholder forums, group and individual interviews	Thematic Analysis	Provider concerns regarding family capacity to negotiate the system. This was further impacted by the medical complexity of the children and psychosocial complexity of families. Lack of capacity in terms of skills, time and availability to manage children with complex conditions was also a key problem. Primary health care practitioner reported being left out of communication, not being sent copies of discharge summaries and outpatient letters and some described their authority to request these being challenged.
Balogh et al., 2010	Canada	To examine rates of hospitalisation for ambulatory care sensitive conditions between people with and without Intellectual disability	Intellectual disability	Children (0–9 age group and 10–19 age group) with and without ID were identified through medical codes (0–9, with ID = 10,941; 0–9, without ID = 774,630; 10–19, with ID = 10,799; 10–19, without ID = 831,633)	0–9 and 10–19	Not Reported	Quantitative; Open cohort study	n/a	Manitoba Centre for Health Policy (MCHP) at the University of Manitoba's Faculty of Medicine (Population Health Research Data Repository)	Multiple regression analysis using the GENMOD procedure in SAS software was used to calculate adjusted rate ratios	From 1999–2003, children with ID in both age groups had higher rates of hospitalisation compared to those without ID.
Boulet et al., 2009	USA	Describe health limitations, needs, and service use among children with and without developmental disabilities (DDs) in the USA	Developmental Disabilities (DD)	Parents reporting on children aged 3 to 17 years (95,132)	3–17 years	No DD (48.8% male); ≥1 DD (68.8% male); ≥3 DD (70.1% male)	Quantitative; retrospective analysis	n/a	1997–2005 National Health Interview Survey (NHIS)	Descriptive and inferential statistics	Children with DDs were 2–8 times as likely to have had more than 9 health care visits, and/or emergency department visits. A twofold increase in the number of visits to emergency departments and surgical or medical procedures in the past year for children with a DD compared with children without a DD.
Caicedo, 2016	USA	Describe health care service use of medically complex children by condition severity		Primary caregivers or parents aged 18 years or older who spoke English or Spanish and were responsible for the care of an eligible child (84)	Data extracted from the sample under 18	56% Male	Quantitative; longitudinal descriptive study	Convenience sample	Survey	Descriptive statistics	In the previous 12 months, all of the children had been seen by their primary care physician (PCP). Sixty-three percent of the children (n = 53) were seen for a routine well-child care visit; 30% (n = 25) were seen once; 24% (n = 20) were seen twice; and 9% (n = 8) were seen up to four times. Fifty-three percent of the children (n = 48) were seen by their PCP for an acute care visit; 37% (n = 31) were seen once, 17% (n = 14) were seen twice, and 4% (n = 3) were seen three times for an acute care visit. No differences in routine and acute care PCP office visits were found during the study period across condition severity groups

TABLE 2 (Continued)

Study details			Participant details			Methodology and findings from the included studies					
Authors/year	Country of origin	Aims/rationale	Type of disability under study	Sample (sample size)	Age	Gender	Study design	Sampling strategy	Data collection	Data analysis	Key findings
Chi et al. 2014	USA	Examine whether ED users in the United States with intellectual and developmental disabilities (IDDs) are more likely to be admitted to the ED for a nontraumatic dental condition (NTDD) than individuals without IDDs.	Intellectual and developmental disabilities (IDD)	Administrative data (n = 4,325,309 children, 0.7% had DD)	3–17 years old. Under 3 were excluded because IDD is not typically diagnosed at this age	Not Reported	Quantitative: Cross-sectional analysis	We adopted a diagnosis-based approach of identifying IDDs	2009 National Emergency Department Sample (NEDS) data	Descriptive statistics and odds ratios	Children with IDDs were not significantly more likely to be admitted to the ED for NTDCs than children without IDDs
Chien et al. 2017	USA	Identify number of children with disabilities on Medicaid, quality of primary care, and differences in primary care quality for this group compared to children without disabilities	Medicaid insured children with disabilities (CWD)	2008 Medicaid Analytic eXtract claims data from 9 states (N = 2,671,922. CWD identified 5.3% [n = 141,384] of Medicaid enrolled children from 9 states as CWD)	1–18 years	63.9 Male	Quantitative: Cross-sectional	Children were considered to be CWD if their MAX data contained at least one of the 669 ICD-9 codes in CWDA	2008 Medicaid Analytic eXtract (MAX) claims	Statistical analyses	A significantly greater proportion of CWD had more than one outpatient encounter in the year when compared to the general population and were also significantly more likely than unmatched non-CWD to visit the emergency department (ED) for any reason. CWD received recommended care at rates below 50% on 8 of 12 recommended care measures.
Fereday et al. 2010	Australia	Examine parents'/carers' needs for primary care	Children with disabilities	Parents/caregivers (34)	31–50 years	88% Female	Qualitative, interpretive approach	Not reported	Focus groups and interviews	Thematic Analysis	'Partnership' was an overarching theme. Parents wanted co-ordinated services and care; adequate provision of information; having time; continuity of care; open communication; and family-centred care. Parents identified respect for both the parent and the child as a necessary element in an effective partnership as well as trust. Important that GPs are knowledgeable about the disability and about how to interact with children with a disability more generally, and understand the issues facing parents and children.
Fitzgerald et al. 2013	Australia	Describe hospitalisation patterns for children and young people with Down syndrome	Down Syndrome	Administrative data (405)	Born during the reporting period	57.5% Male	Quantitative: retrospective analysis	Administrative data	Birth records linked to population-based Intellectual disability (IDEA) database	Regression analyses	More children (58.5%) had been admitted for an upper respiratory tract condition than for any other major diagnostic group and accounted for 12.1% of all admissions. Down syndrome: 52% of infectious disease admissions were attributable to otitis media as opposed to 24% in the general population and 30% to chronic tonsillar conditions as opposed to 21% in the general population. Asthma admissions only constituted 2% of the respiratory morbidity in the Down syndrome population as opposed to 48% in the general population. For dental disorders in the Down syndrome group, 57% of admissions were attributable to dental caries as opposed to only 32% in the general population.

(Continues)

TABLE 2 (Continued)

Study details		Participant details			Methodology and findings from the included studies						
Authors/year	Country of origin	Aims/rationale	Type of disability under study	Sample (sample size)	Age	Gender	Study design	Sampling strategy	Data collection	Data analysis	Key findings
Fredheim et al., 2011	Norway	Examine parents' experiences of follow up from GPs of children with intellectual disabilities (ID) who have comorbid behavioural and/or psychological problems	Intellectual disability	Parents/caregivers (9)	Not Reported	Not Reported	Qualitative	Purposive	Interviews	Notes and systematic text condensation	Three clusters of experiences emerged from the analysis: expectations, relationships and actual use. The participants had low expectations of the GPs' competence and involvement with their child, and primarily used the GP for the treatment of simple somatic problems. Only one child regularly visited their GP for general and mental health check-ups. The participants' experience of their GPs was that they did not have time and were not interested in the behavioural and mental problems of these children.
Freed et al., 2009	USA	Determine paediatricians' experiences of their training	Developmental & Behavioural Disabilities	Paediatricians (685)	Not Reported	75% Female	Quantitative	Purposive	Survey	Descriptive Statistics	A large proportion of generalists indicated that they could have used additional training in developmental/behavioural paediatrics (48% [n = 326]).
Gallagher et al., 2002	USA	Establish prevalence of developmental delay (DD) and to determine the role of DD in healthcare use	Developmental Delay	Washington State Medicaid claim records (N = 1242 with DD/N = 5370 without DD)	Children born between 1st November 1990–31st December 1992	With DD: 63.3% Male/Without DD: 51.2% Male	Quantitative	n/a	Administrative Records	Descriptive statistics and regression	Children with isolated developmental delay had more physicians' visits in the first year of life compared to those with no delay or chronic conditions (CC). By the fifth year of life, numbers of physicians visits was similar to children with chronic conditions (without DD) but greater than those with no DD or CC. Children with DD were 1.5 times more likely to visit physician. Children DD and CC had great no. of ED visits compared to other groups in the 3rd and 4th year of life. In the 5th year of life, children with DD and CC had a mean of 1 visit to the ED per year compared to 0.5 visits in the other groups. Children with DD had a slight increase in ED visits in the first 5 years compared to those without DD. DD was also associated with an increased risk of hospitalisations.
Glover et al., 2019	England	Describe frequency and patterns of use for acute, non-psychiatric hospital admitted-patient care by people with intellectual disability	Intellectual disability	GP research database (0–9 years 0.27% of sample; 11–17 years 0.67% of sample)	Data reported for sample aged under 18	Not reported for under 18 sample	Quantitative: retrospective analysis	n/a	Administrative Records	Statistical analyses	Emergency admissions constituted a smaller proportion of the total for children and young people with ID. At this age, rates of emergency surgical admissions were not significantly different between those with and without ID, but rates of nonemergency surgery were much higher for those with ID.

TABLE 2 (Continued)

Study details			Participant details		Methodology and findings from the included studies						
Authors/year	Country of origin	Aims/rationale	Type of disability under study	Sample (sample size)	Age	Gender	Study design	Sampling strategy	Data collection	Data analysis	Key findings
Hand et al., 2019a	USA	Describe emergency department use during adolescence for individuals with intellectual disability and/or autism spectrum disorder	ID-only data reported with comparison to population	Administrative billing data (493)	12–17 years	66.9% male	Quantitative: retrospective analysis	n/a	Administrative Records	Descriptive statistics and regression	After controlling for income and race/ethnicity, individuals in the ID-only group were significantly more likely than the control group to have at least one ED visit during age 12–17 years. Individuals in the ID-only group had 1.2 times more ED visits than the control group.
Hand et al., 2019b	USA	Compare frequency of ambulatory care sensitive admissions among children with autism spectrum disorder (ASD) without intellectual disability, ASD with intellectual disability, ID without ASD, and controls	ID-only data reported with comparison to population	Administrative billing data (N = 1148; ID only (including adults)	Childhood: age 2–10 years; Adolescence: age 11–17 years.	63.3% male	Quantitative: retrospective analysis	n/a	Administrative Records	Descriptive statistics and regression	Controlling for race/ethnicity, birth year, and insurance type, individuals in the ID-only cohort had significantly more frequent ED visit for ACS conditions. The ASD-only and ASD + ID cohorts did not significantly differ from the control cohort on the frequency of ACS ED visits. Number of ACS inpatient hospitalizations indicated that individuals in the ID only cohort and ASD + ID cohort had significantly more frequent ACS inpatient hospitalizations after controlling for sex, race/ ethnicity, birth year, and insurance type. The ASD-only cohort did not significantly differ from the control cohort on the frequency of ACS inpatient hospitalizations.
Huemeckers et al., 2017	The Netherlands	To determine if people with intellectual disability were more likely to seek out-of-hours general practitioner care compared to the general population and level of urgency	ID only data reported	Routine data (70)	0–19 years	Not reported for 0–19 sample. 54.5% male for whole sample	Quantitative: cross-sectional	n/a	Cross-sectional routine data-based study		30.9% of the people with ID requested out-of-hours GP care compared with 18.4% in the general population. The sex and age distribution of people with ID and the general population who requested out-of hours GP care differed with more males in the ID group and less minors and elderly. Requests relating to people with ID were rated as less urgent than requests relating to the general population. The different distribution of urgency level entailed more than 60% of requests made by people with ID categorised as counselling and advice and did not reflect on life threatening requests.
Hsu et al., 2009	Taiwan	Describe factors affecting emergency department visits by disabled children and frequency of use	Disabilities	Parents/caregivers (340)	Under 18	No reported for whole sample	Quantitative	Taiwan National Disability Registration System	Survey	Descriptive and inferential statistics, regression	30.1% had utilised ED. The most common reasons for emergency care use by children with disabilities were fever (34.7%), respiratory symptoms (24.2%), abdominal pain (15.8%), injury (7.4%), and epilepsy seizures (7.4%). ‘Disability level’ was statistically related to utilisation of emergency services. The other factors, including the child’s age, gender, whether the child resided with their own families or in disability welfare institutions, and the onset and diagnosed age of disability did not statistically correlate with emergency department utilisation by children with disabilities.

(Continues)

TABLE 2 (Continued)

Study details			Participant details			Methodology and findings from the included studies					
Authors/year	Country of origin	Aims/rationale	Type of disability under study	Sample (sample size)	Age	Gender	Study design	Sampling strategy	Data collection	Data analysis	Key findings
Lin et al., 2003	Taiwan	Describe patterns of healthcare use and factors influencing healthcare use	Intellectual disability	People with ID in day centres (1390)	1–5 n = 181; 6–10 n = 350; 11–15 n = 293	61.2% male (total sample)	Quantitative	Purposive	Survey	Descriptive and inferential statistics, regression	The children of caregivers, particularly those caregivers who worked as medical professionals, made significantly more outpatient visits than the children of caregivers from other occupational groups. The results show that the group of children with ID used outpatient facilities more often than the children of caregivers from the lowest income group.
Lin et al., 2014	USA	Explore the relationship between ED use and access to appropriate primary care (i.e., medical home)	Down syndrome/mental retardation or developmental delay (DD)	Parents/caregivers (15, 238)	0–17 years	64–69% male (Across EDU categories)	Quantitative	Nationally representative households	National Survey of Children with Special Health Care Needs	Multivariate logistic regression	Compared with children with DD reporting zero ED utilisation, children with 3 or more ED utilisations were less likely to report access to usual health care source. Children with DD who had 3 or more ED utilisations were less likely to have clinicians who listen to parental concerns, demonstrate sensitivity towards family values and customs and build meaningful family partnership.
Lin et al., 2012	USA	Explore the relationship between immigrant status and access to a medical home and health insurance, for children with intellectual disability (ID) and autism spectrum disorder (ASD)	Developmental Delay	Parents/caregivers (N = 413 on-immigrants/N = 5411 on-immigrants)	3–17 years	65–70% male	Quantitative	Nationally representative households	2007 National Survey of Children's Health	Weighted logistic regression	Compared with non-immigrant families, children with ASD and select DD from immigrant families were more than twice as likely to lack usual source of care and report physicians not spending enough time with family. Furthermore, insurance coverage was an important factor in mitigating health care barriers for immigrant families.
Liptak et al., 2006	USA	To outline experiences of primary care for families of children with developmental disabilities	Developmental Disabilities	Parents/caregivers (36)	Mean 6.9 years	88% Female	Quantitative	Patients who currently receive services at the Kirck Developmental Services Center, Golisano Children's Hospital, University of Rochester Medical Center.	Survey	Descriptive and Inferential Statistics	Families rated physicians highest on their ability to keep up with new aspects of care and on their sensitivity to the needs of children. Parents had the lowest ratings for the primary care physicians' ability to put them in touch with other parents, understanding of the impact of the child's condition on the family, ability to answer questions about the child's condition, and information and guidance for prevention. Physicians' knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities ranked worse than neutral. Families with a child with autism rated their primary care physician's ability to answer their questions regarding their child's condition worse than families with children who had physical disabilities or mental retardation.

TABLE 2 (Continued)

Study details			Participant details		Methodology and findings from the included studies						
Authors/year	Country of origin	Aims/rationale	Type of disability under study	Sample (sample size)	Age	Gender	Study design	Sampling strategy	Data collection	Data analysis	Key findings
Nachshen et al., 2009	Canada	Examine the frequency emergency department visits for ambulatory care sensitive conditions to explore whether health disparities for people with delay are observed in childhood	Developmental Delays	Medical billing data (107)	Up to age 18	63% Male	Quantitative	Children were classified as delayed if their medical history included at least one diagnosis of MR or developmental delay, with some children receiving multiple diagnoses	Medical Billing data	ANOVAs	<p><i>Ambulatory care sensitive conditions:</i> Other than children with delays having more ED visits and hospitalizations for epilepsy, there were no differences found between the groups.</p> <p><i>Primary care:</i> In terms of routine general practitioner check-ups, there was a trend indicating that children in the Delay group had fewer check-ups than children in the Non-Delay group. Additionally, children in the Delay group had significantly more total recorded medical problems (multiple visits for the same diagnoses), total number of medical acts, total diagnoses and visits to ophthalmology specialists.</p>
Reppermund et al., 2017	Australia	Examine hospital admissions, presentations to the emergency department (ED) and mortality data for people with intellectual disability	Intellectual disability	Administrative data for emergency department use (not reported for under 15 sample)	Under 15	57–60% male	Quantitative	Data linkage of records of people with ID who have ever received disability services in NSW (<i>n</i> = 73674) and those who have been identified as having ID through diagnosis codes in the APDC and the EDDC in a NSW hospital.	Administrative Records: ED only	Descriptive statistics	<p>0–4 year olds had 2115 (8.7%) ED attendances. 5–14 year olds had 6197 (25.6) ED attendances. Results indicated that those who have ever received disability services have, on average, fewer ED presentations and admissions to hospital than those who have not received disability services.</p>
Thomas et al., 2011	Australia	To compare the prevalence of parent reported medical conditions and health service use in children with Down syndrome	Down Syndrome	Parent/families (146)	Mean: 11.7 years	118 males	Quantitative: cross-sectional surveys	Surveys	Surveys	Descriptive statistics and regression analyses	<p>The rate of GP visits decreased in 2004. Hospitalisation for respiratory conditions was associated with the greatest reduction in 2004, with the average nights in hospital decreasing from approximately 5 in 1997 to 1.6 nights in 2004. When health service utilisation was stratified according to the presence of a cardiac defect, GP services still decreased in those who had had a cardiac defect but actually increased in those who had never had one, although still decreased overall</p>

(Continues)

TABLE 2 (Continued)

Study details			Participant details			Methodology and findings from the included studies					
Authors/year	Country of origin	Aims/rationale	Type of disability under study	Sample (sample size)	Age	Gender	Study design	Sampling strategy	Data collection	Data analysis	Key findings
Wheeler et al., 2019	USA	Examine parent perceptions of access and quality of health care services for children with fragile X syndrome	Fragile X Syndrome	Parent/families (596)	Under 12:27.8% 12–17: 28.2% 18–24: 18.3% 25 and older: 25.7%	90% Female; Fragile X: 83% Male	Quantitative: cross-sectional surveys	Survey registry of families who had a child with FXS.	Survey	Descriptive statistics and regression analyses	Almost half of children (48%) had a paediatrician as their PCP. 38% had a family physician as their PCP. 7% had an internist, and 8% had some other type of provider. Most children (62%) had a caregiver report that their child's PCP was somewhat (40%) or very (22%) knowledgeable of their FXS-related needs. The majority of children had caregivers report that their PCP always explained things in a way that the caregiver could understand (55%), involved them in decisions for that child (81%), and respected their decisions regarding that child (63%). Caregivers of younger children and those with lower family incomes reported greater challenges with health care access. Nearly 40% of caregivers indicated that their child's PCP was not as knowledgeable about FXS-related needs as they would prefer, indicating a possible knowledge gap on the part of providers.
Zajick-Farber et al., 2015	USA	Explore families' experiences of family centred care in primary care for children with neurodevelopmental disabilities	Neurodevelopmental disabilities	Parent/families (122)	75% between 31 and 60 years	88% Female	Quantitative: cross-sectional surveys		Survey	Descriptive statistics	31% satisfied with the primary health care received. 16% had most aspects of a medical home; 64% had some; 20% had none. Strengths: meeting the medical care needs of the child. Weaknesses: needs of families, coordination, follow-up, and support with community resources.

that children with intellectual disability were placed in a larger category of children with special healthcare needs or medical complexity. These were excluded unless there were specific data reported for children with intellectual disability or detailed evidence that intellectual disability was prevalent in the samples. One study included children with Down syndrome only and another included children with Fragile X syndrome only. A variety of terminology was used to describe the disabilities, including intellectual disability, developmental delays, intellectual and developmental disabilities, learning disabilities, and neurodevelopmental disabilities; with one study describing children with multisystem conditions including developmental disabilities but who did not fit into a single disease category. Given the greater prevalence of males within disability populations, there were mostly males reported in the intellectual disability populations sampled in the included studies. For parent studies, female caregivers (mostly mothers) were the most common participants. Health professionals who provided data were typically GPs and general paediatricians.

Three studies did not report the age of the participants, however, in two of these studies the healthcare providers were the participant group and so it was not explicitly relevant to the research question (Altman et al., 2018; Freed et al., 2009). The remaining study was a parent sample (Fredheim et al., 2011). Two studies with parent samples provided an age range of between 31–50 and 31–60 (Fereday et al., 2010; Zajicek-Farber et al., 2015). If the study reported a large sample of children and adults, the data pertaining to the paediatric samples was extracted in these cases. There was some variance in how paediatric samples were defined across studies with ages ranging from under 16 to up to 19 years of age and survey studies often reported a Mean age for the samples. In one study, results for children aged under three were not reported because a diagnosis of intellectual disability is less common in this age group (Chi et al., 2014). A common reason for exclusion ($n = 18$) was reporting adult samples with children included or unable to extract data pertaining to children only. Further details on the participant samples can be found in Table 2.

3.4 | Analytical theme: Inequity at the systems-level

The descriptive themes outlined each focus on different elements and actors within the unscheduled health system and indicate a larger theme of inequity at many levels within the system of unscheduled healthcare. Each element interacts with others in the system such that improvements in one sector may influence and lead to changes and improvements in another. Parents and families identified areas where difficulties often arose such as a lack of coordinated care and little opportunity for their primary care provider to link them in with other services and supports. On balance, primary care providers and paediatricians reported their training in this area was often not sufficient and do not think they have adequate capacity to provide needed supports to parents. GPs also recognised the need for coordinated care between their practice and hospitals and spoke of a need to be

furnished with follow up letters from hospitals regarding, for instance, ED visits. Such coordination may be facilitated by improved coding and synchronisation across administrative systems which often fail to adequately identify children with intellectual disability and creates challenges in monitoring health use and outcomes. Understanding and outlining trends in healthcare utilisation by this population is valuable for monitoring quality of healthcare, however, addressing observed inequities will require approaches that recognise issues within the health system that give rise these inequities.

4 | DISCUSSION

The current scoping review identified 25 papers that explored issues relating to unscheduled healthcare for children with intellectual disability. Seventeen papers utilised administrative databases or national surveys to assess utilisation of unscheduled healthcare services often relative to the general population and/or other disability groups. Eight studies examined parent and healthcare provider's views and experiences regarding children with intellectual disability. One of the marked gaps in the literature was the dearth of research around eliciting children, parents' and families' unscheduled healthcare needs and of the experiences of children with intellectual disability and their parents utilising unscheduled healthcare. Six studies in the current review considered parents' experiences and needs regarding unscheduled health care and the research that emerged from the search strategy largely focused on scheduled healthcare services or specific disability support services and thus, were excluded from the review.

The important role that primary care plays in the lives of families of children with intellectual disability has received little focus in the literature and is an important area for further study. Parents view the GP as a gatekeeper to not only secondary healthcare services but to further supports in their communities, (Fereday et al., 2010), however, GPs do not feel they have adequate capacity or training to provide such support (Altman et al., 2018; Freed et al., 2009). Partnership between parents of children with intellectual disability and healthcare professionals is critical to facilitate shared decision making to reduce parental reliance (Mimmo et al., 2019). Families of children with intellectual disability face unique and additional challenges and are at greater risk of poor physical and mental health due to social disadvantage (Emerson, 2015). Additionally, more vulnerable families, such as lower SES and migrant families, may require greater support to alleviate the additional challenges they face.

The review exclusion process emphasised key limitations in the existing literature, which provide a useful direction for future studies to address. Several papers were excluded from the current review because it was not possible to clearly identify a group of children with intellectual disability as it was common for data pertaining to children with intellectual disability to be included within a larger group of children with special health care needs or chronic illnesses. Therefore, while children with intellectual disability were likely included in the study, it was not possible to identify data related only to this group. This finding is reflective of similar research on the hospital experiences

of parents of children with intellectual disability where the categorisations of intellectual disability within larger special healthcare need groups limited the literature available for review (Mimmo et al., 2018). This issue points to a broader debate around the differentiation of people with intellectual disability within the wider disability community and the need to balance the specific health needs of this population while avoiding labelling and stigma that may arise as a result (Clegg & Bigby, 2017). Additionally, the amalgamation of data pertaining to child and adult populations with intellectual disability was another significant challenge and reason for exclusion in the review. The lack of appropriate data presents a considerable challenge for the organisation of paediatric services for children with intellectual disability as the needs of young adults, including those transitioning to adult services, can be different to children and their families.

Reducing health inequities evident across health systems requires adequate data about the healthcare utilisation of people with intellectual disability and critically, capturing their experiences of healthcare (Emerson & Hatton, 2013). Administrative datasets were widely used to describe healthcare utilisation and/or disparities for this population compared to the general population. Administrative records can be enormously valuable tools for health research as they are cost-effective and less demanding (Huetmekers et al., 2017), however, there are inherent limitations and biases to using such data for research purposes (Emerson & Hatton, 2013). Misclassification, poor coding, and a lack of disclosure by people with intellectual disability and their families are some of the challenges of this approach. Identifying children with intellectual disability based on diagnosis may eliminate children who have not yet received a diagnosis or if medical professionals do not deem it relevant to treatment (Nachshen et al., 2009). Children with mild or moderate intellectual disability that is not associated with a known cause of intellectual disability are also less likely to be identified in hospital data (Bourke et al., 2018). Moreover, data linkage with disability service data precludes children who are not in receipt of such services and severity of intellectual disability are rarely noted (Emerson, 2011). While some health inequities for children with intellectual disability are unavoidable (Ouellette-Kuntz, 2005), describing and understanding healthcare use is a key part of quality and safety and will assist with establishing when certain inequities are unjust and avoidable.

Given the findings of this review regarding the parents' perceptions of the supportive role of GPs, research that examines the training needs of GPs and how they can be facilitated to support this population and their families would be beneficial, with further focus on the experiences of low SES and migrant groups. Quality healthcare for people with intellectual disability relies on appropriate adjustments (Heslop et al., 2014) and research initiatives and funding bodies need to focus research exclusively on this population to highlight, for example, adjustments that need to be made in primary care settings and how they can be implemented, in order for meaningful improvement in the quality and equity of healthcare for children. To truly address the inequities for children with intellectual disability and optimise health care, researchers need to also focus on improving health records for this population and capturing their specific healthcare

experiences through participatory methodologies with children with intellectual disability.

5 | LIMITATIONS

The exclusion criteria employed in the current review may have limited the breadth of studies available and resulted in studies that included children with intellectual disability being excluded from the review. However, these criteria were necessary in order to isolate evidence pertaining to intellectual disability only. On balance, some papers clearly focused on children with intellectual disability, however, it is possible that there were also children with physical disabilities only in the sample. As discussed above, a number of studies were excluded because the cohort under study was referring to people with intellectual disability and not exclusively children with intellectual disability or a further subset were excluded because the focus was children with special health care needs and may have included, but did not provide specific data related to intellectual disability. Moreover, the large number of studies that used administrative data are inherently limited given the issues around disclosure of intellectual disability and poor coding in this area.

6 | CONCLUSION

The present scoping review sought to collate the current literature regarding unscheduled healthcare for children with intellectual disability and subsequently, identify gaps for future research. Improved public health outcomes rely on strong systems of first-contact unscheduled healthcare, which is delivered in a timely and appropriate manner (Lennox et al., 2015). Such health services are critical for families and children with intellectual disability and there is a need to build on the research that has identified and described disparities, by examining modifiable factors that result in health disparities and recognising the multifaceted needs of these children and their families.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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SUPPORTING INFORMATION

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