SSM - Health Systems 6 (2026) 100193

Contents lists available at ScienceDirect

SSM - Health Systems

journal homepage: www.sciencedirect.com/journal/ssm-health-systems

Factors influencing transition from paediatric to adult health care for young people with intellectual disability: A systematic scoping review

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ARTICLE INFO

Keywords:
Intellectual disability
Health care transition
Socio-ecological model
Scoping review

ABSTRACT

Background: Young people with intellectual disability often face sub-optimal transitions from paediatric to adult health care. These transitions are often poorly planned and managed, resulting in delayed access to services and adverse outcomes. No synthesis exists on the factors influencing this process. This scoping review examines the nature and extent of evidence on factors affecting the transition to adult health care for young people with intellectual disability.

Methods: We searched Medline, Embase, CINAHL, and Scopus to identify original research articles published between 2015 and 11 April 2025, using terms 'intellectual disability', 'young people', and 'health care transition'. Two reviewers independently screened full-texts, and 50 % of included publications had data extracted by two independent reviewers. Data were coded and synthesised using a socio-ecological model across five levels – individual, interpersonal, organisational, community, and policy.

Results: Of 15,015 publications identified, 28 met our inclusion criteria, all from eight high-income countries, mainly the United States. Most publications reported the perspectives of carers, health care providers, or both. Factors were identified at each socio-ecological level, most often at the organisational level. Commonly reported factors included dedicated transition roles and pathways, the availability and adaptability of adult health care services, and the knowledge and skills of health care providers.

Conclusion: Our review highlights the predominance of organisational-level influences, the limited inclusion of young people's perspectives, and the lack of evidence on community- and policy-level factors. Future research should address these evidence needs using participatory approaches and broaden the geographic scope beyond high-income settings.

Introduction

Globally, the prevalence of intellectual disability is estimated to be around 1 % (Maulik et al., 2011). With advances in medical care improving life expectancy, most people with intellectual disability now reach adulthood, making the transition from paediatric to adult orientated health care services an increasingly important process (Rubin et al., 2016).Such a transition involves preparation, transfer and integration into adult-centred care (Wood et al., 2016; Fremion et al., 2024). Transition planning commonly begins between the ages 14–18, with the transfer of care typically occurring from 18 to 21 years; however, in some jurisdictions transfer may occur as early as 16 years (Park et al., 2011; Boyle et al., 2011). Health system structures also differ internationally, leading to variation between countries in how transition is

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https://doi.org/10.1016/j.ssmhs.2026.100193
Received 24 September 2025; Received in revised form 10 February 2026; Accepted 16 February 2026
Available online 18 February 2026
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organised, funded and delivered. Given that young people with intellectual disability often have multiple comorbidities and functional impairments, an effective transition to adult care is critical (Knauth et al., 2006). Poor management of the transition process is associated with adverse health outcomes and long delays in accessing appropriate care (Turchi et al., 2024; Young-Southward et al., 2017). Despite increasing recognition that a structured and effective transition process is vital, (Betz, 2023) young people with intellectual disability continue to experience sub-optimal health transitions from paediatric to adult providers with little or no transitional planning (Brown et al., 2019).

Transitioning to adult health care is a complex process, shaped by multiple interacting factors within health systems and the broader social and environmental context (Hamdani et al., 2011). To date, there has been limited evidence on when, where, and how best to support this process (Klein Haneveld et al., 2025a). Developing effective interventions to improve the transition requires an understanding of impacting factors and a holistic view of the dynamic interplay between young people and their environment (Hamdani et al., 2011).

To address this complexity, we employed a socio-ecological model (SEM) to provide a framework for understanding the multi-level interacting factors influencing health transitions. The SEM has been adapted and applied across disciplines, including public health, (Kilanowski, 2017) to improve understanding of the health care transition periods experienced by young people with disability (Hoffman and Kirby, 2022; Fortune et al., 2024; Mirzaian et al., 2024a). It also recognises the dynamic, bi-directional relationship between individuals and their environment. As conceptualised by McLeroy et al. (1988) the SEM comprises five levels – individual, interpersonal, organisational, community, and policy – each of which interacts with the others to shape health behaviours and outcomes (Fig. 1).

Previous studies and reviews have explored the transition to adult health care for young people with intellectual disability (Fremion et al., 2024; Young-Southward et al., 2017; Brown et al., 2019; Kaehne et al., 2019; Varshney et al., 2022; Osako et al., 2023; Lilly et al., 2019; Colliander et al., 2024; Ramachandran et al., 2025). However, to date, a SEM has not been used to explore the multi-level factors that affect this transition. Our review addresses this evidence gap by examining the nature and extent of existing literature on factors influencing the transition from paediatric to adult health care for young people with intellectual disability, using a SEM as the guiding analytical framework. We anticipate that our review findings will contribute to a greater understanding of the factors influencing this transition process and inform both future research and the development of evidence-based interventions.

Methods

We selected a scoping review methodology to comprehensively identify and map the factors influencing the transition from paediatric to adult health care for young people with intellectual disability. Our review followed the methodology based on JBI (formerly Johanna Briggs Institute) guidelines (Peters et al., 2022a) and adhered to a published *a priori* protocol (Folpp et al., 2025). Reporting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). As our aim was to provide a broad overview, rather than to evaluate intervention effectiveness, we did not conduct critical appraisal and risk of bias assessment, in line with JBI scoping review methodology.

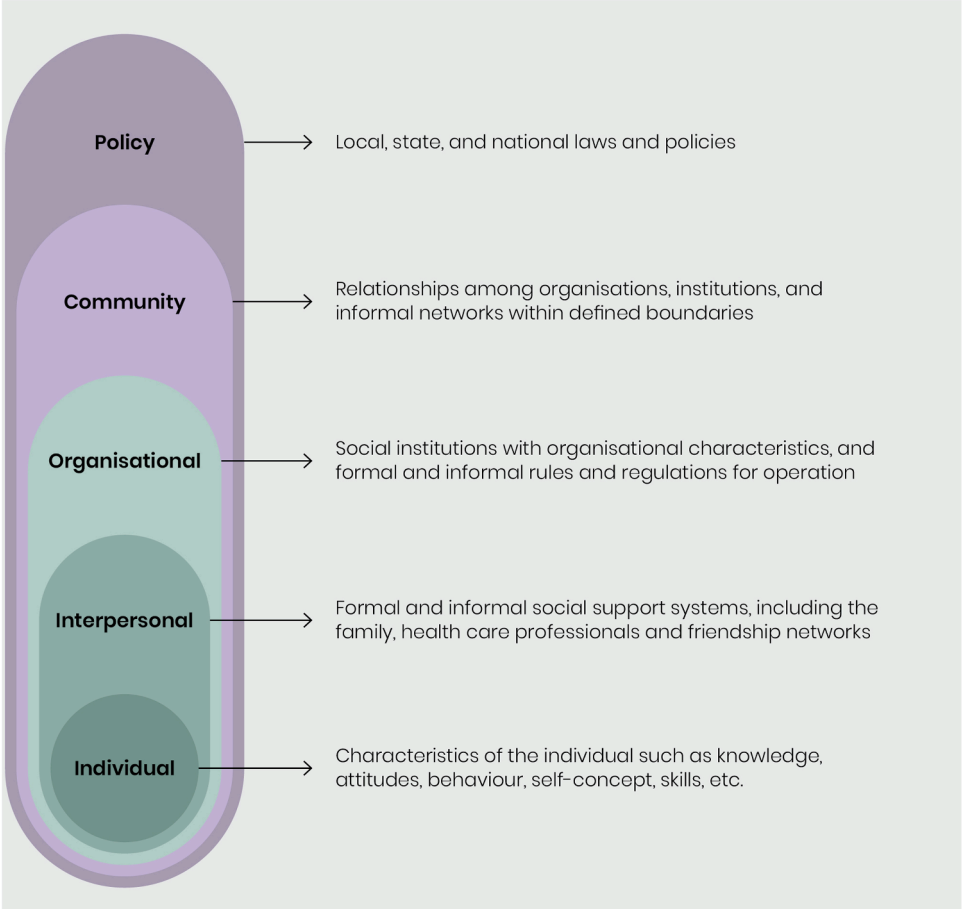

Fig. 1. McLeroy and colleagues' socio-ecological model (McLeroy et al., 1988).

Research question

Our research question was: "*What is the nature and extent of research about the factors influencing the process of transitioning from paediatric to adult health care services for young people with intellectual disability?*"

Inclusion criteria

The scoping review parameters were defined using the "PCC—Population, Concept, Context" framework outlined in the JBI guidelines. The population of interest are people with intellectual disability, defined as having a neurodevelopmental disorder characterised by difficulties in intellectual function and adaptive behaviour, with onset before the age of 18 (Diagnostic and statistical manual of mental disorders, 2013). People with cerebral palsy, spina bifida, autism or other neurodevelopmental disorders were included if they, or at least 70 % of the study cohort, had a documented co-occurring intellectual disability.

The concept of interest for the review was the life-course transition from childhood and adolescence into adulthood, specifically the shift from paediatric to adult-oriented health care services. The review included all forms of health care transition, encompassing primary, secondary and tertiary care. General practice was included, acknowledging its longitudinal role across the lifespan.

The context was all health care contexts including, but not limited to, community and hospital services, in all countries. Empirical, primary, peer-reviewed research with any study design was included. We excluded publications that were not peer-reviewed, including commentaries, perspectives, opinion, editorials, letters to the editor, books, book chapters, conference abstracts and proceedings, case reports, theses, and reviews (such as scoping and systematic reviews). Grey literature sources were excluded. Publications not available in English were excluded.

Literature search strategy

We conducted an initial search in Medline and Google Scholar to identify relevant peer-reviewed publications to inform the development of a comprehensive list of keywords, (for example (Fremion et al., 2024; Young-Southward et al., 2017; Brown et al., 2019; Barrington et al., 2025) in collaboration with an academic librarian (KE) and content experts in intellectual disability and health services research. Search terms related to intellectual disability were further informed by existing peer-reviewed publications previously undertaken by our team (Eveleigh et al., 2025; Shea et al., 2022; Caltabiano et al., 2024). Subsequently, a full Medline search strategy was developed and translated to Embase, CINAHL, and Scopus databases. The index year of 2015 was chosen to capture research relevant to the current health care context, with the search including publications up to 11 April 2025. Given the rapid pace of change in health technologies and systems, this timeframe was considered sufficient to reflect current factors. This approach extends the scope of relatively recent reviews on health care transition for young people with disability (e.g. Young-Southward et al. 2017 up to 2016; Kaehne et al. 2019 1990–2017; Brown et al. 2019 2007–2017; Fremion et al. 2024 2000–2023). Our review builds on this literature by focusing on more recent evidence and applying a SEM framework to examine influences across levels not addressed in earlier reviews. The full search strategy for each of these databases is available in Appendix 1.

Study selection

Citations were uploaded into Covidence (Veritas health innovation,.) and duplicates removed. Following a pilot test, all titles and abstracts were screened by one reviewer (JB) and 5 % screened independently by another (NF). At full-text screening, reviewers (NF, JB, AL) independently assessed publications using predefined inclusion and exclusion criteria. Disagreements between reviewers were resolved through discussion. in the screening process at the title and abstract stage.

During full-text review, we assessed whether at least 70 % of the study population comprised individuals with intellectual disability. This two-step approach enabled potentially relevant publications to be retained at the title and abstract stage, while ensuring that population eligibility was confirmed through detailed review.

Data extraction

A data extraction tool was developed in Covidence, covering variables such as study design, population, methods, and the factors influencing the transition to adult health care. The tool was developed *a priori* and piloted on two randomly selected publications by two independent reviewers (NF, JB) and refined before applying to the rest. Data from 50 % of included publications were extracted independently by two reviewers (NF, JB). Any conflicts that arose during this process were resolved through discussion. Remaining data were extracted by one reviewer (NF) and checked by another (JB).

Data analysis and presentation

Extracted data were exported from Covidence to Excel for analysis, and summary statistics describing publication characteristics were tabulated. Analysis proceeded through an iterative, recursive process of inductive content analysis (Elo and Kyngäs, 2008) to identify factors influencing transition.

To do this, NF and JB read each publication in full, analysing the data line by line and developing initial codes related to factors influencing transition. These factors were then deductively mapped to the SEM. Throughout this process NF, JB, AL and RB regularly discussed, reflected on, and cross-checked the emerging factors and levels of influence to ensure consistency and conceptual clarity.

Coding was guided by an *a priori* codebook (Table 1), which included definitions for each level of the framework and examples of factors aligned with each level. Code definitions were refined iteratively as analysis progressed and new information emerged from the included publications.

Once the data were charted, the information collected in Covidence was exported to Excel, where we coded the data to the levels of influence according to the SEM.

Table 1
Socio-ecological model (McLeroy et al., 1988) and how we conceptualised for this review.

Levels of influence	How we conceptualised for this review
Individual	Individual characteristics that influence a person's ability to effectively transition, including age, developmental age, co-occurring medical diagnoses, knowledge, and cultural and linguistic background.
Interpersonal	The relationships and supports that directly affect an individual, including both formal and informal social networks and social support systems, such as family, caregivers, health care providers and peers.
Organisational	The structures, policies and practices within health care organisations.
Community	The broader social settings with which young people and their families interact, including social norms, collaboration, coordination, relationships between societal sectors, and geographical distribution of services.
Policy	Broader systems-level factors – local, regional and national policies and laws that impact legislation, regulatory guidelines, funding decisions, and standards for service during transition – including both public and private health insurance.

Results

Search results and study selection

The search yielded 15,017 publications. After duplicate removal, title and abstract screening, and full-text review, 28 publications were included (Fig. 2).

Characteristics of included publications

Summary characteristics of the 28 included publications are presented in Table 2. The individual characteristics of each publication can be found in Appendix 2. Twenty-six publications reported on a separate study, with two using findings from the same survey to answer different research questions. The majority of study designs were qualitative (n = 13), followed by quantitative (n = 10), and mixed method (n = 5). Four publications piloted an intervention related to transition, and four were observational, evaluating a pre-existing intervention. More than half of the publications (n = 15) were conducted in the United States of America (USA).

Most publications did not specify the rurality of the study setting, but five included regional or rural perspectives. Most also reported the perspectives of carers (n = 14), health care providers (n = 9), or both (n = 2). Four publications incorporated the views of people with intellectual disability, but none reported their inclusion as research team members.

Factors influencing transition from paediatric to adult health care services

In our review of factors influencing the transition from paediatric to adult health care for people with intellectual disability, data were coded to the following socio-ecological levels: a) individual; b) interpersonal; c) organisational; d) community; and e) policy. The factors identified at each level are presented in Fig. 3 and Appendix 3.

Individual-level factors

Twenty-two publications identified individual-level factors that, in the context of this review, refer to personal characteristics that influence a person's ability to effectively transition (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Fremion et al., 2022; Ishizaki et al., 2022; Nascimento et al., 2023; Nugent et al., 2018; Razon et al., 2019; Szalda et al., 2019; Brown et al., 2020; Kerin et al., 2020; Stehouwer et al., 2021; Malapela et al., 2020; McManus et al., 2024; Marquis et al., 2024; Shanahan et al., 2021; VanZant and McCormick, 2021; Dressler et al., 2018; Franklin et al., 2019; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021).

A major barrier reported at this level was the clinical complexity associated with co-occurring physical and mental health conditions often experienced by people with intellectual disability (Boyce et al., 2020; Fremion et al., 2022; Ishizaki et al., 2022; Nascimento et al., 2023; Nugent et al., 2018; Razon et al., 2019; Szalda et al., 2019; Dressler et al., 2018; Culnane et al., 2021). Syndromic diagnoses such as Down syndrome, (Nugent et al., 2018) Dravet syndrome, (Boyce et al., 2020; Nascimento et al., 2023) and 5p-syndrome (Ishizaki et al., 2022),

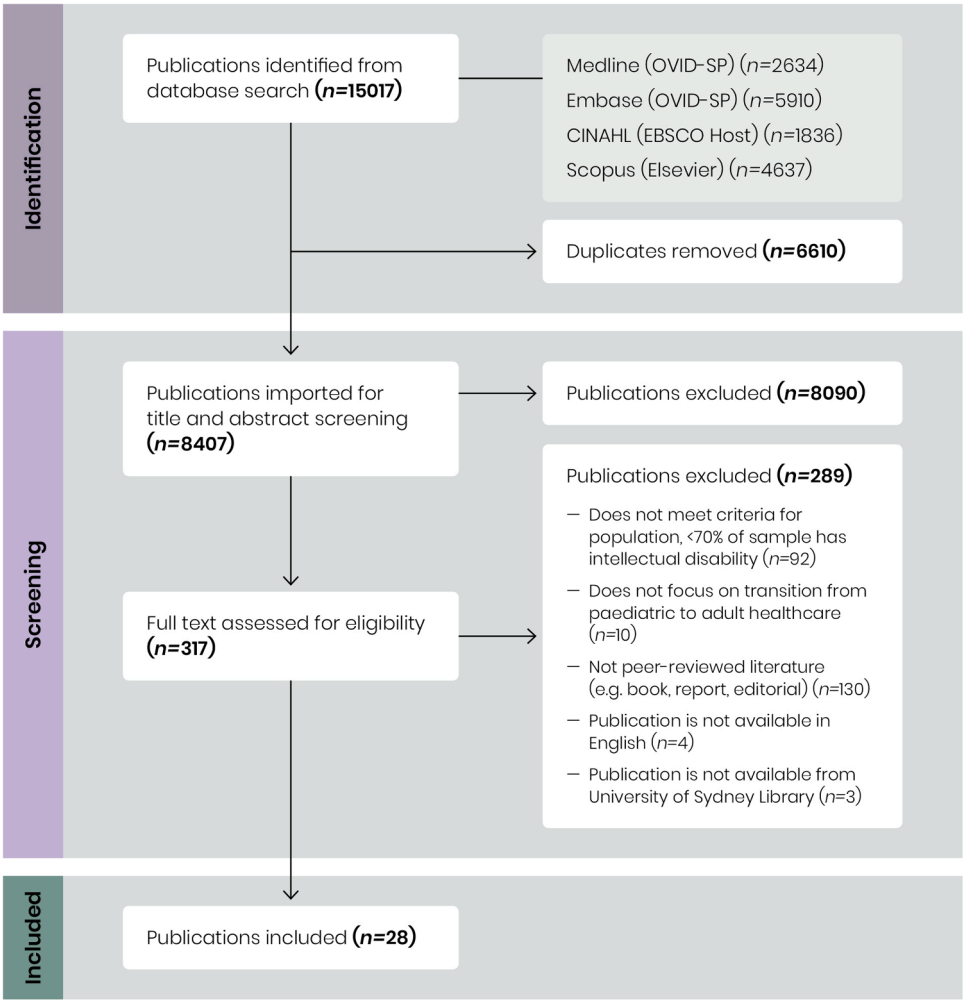

Fig. 2. Preferred Reporting of Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR) flow diagram.

Table 2
Summary characteristics of included publications, 1 January 2015–11 April 2025. n = number of publications.

Characteristics of publications N = 28	
Year of publication	
2018	4
2019	4
2020	3
2021	5
2022	4
2023	3
2024	4
2025	1
Location of study*	
United States of America	15
Canada	4
United Kingdom	3
Australia	3
Japan	1
South Africa	1
Republic of Ireland	1
Netherlands	1
European Countries	1
Study design	
Qualitative	13
Quantitative	10
Mixed-method	5
Participant group*	
Carers	14
People with intellectual disability	4
Health care professionals	9

* Note: Numbers don't add up to 28 as the groups are not mutually exclusive.

frequently involve additional comorbid physical health conditions, resulting in greater medical needs and more intensive engagement with health services, which can complicate transition. The number of co-occurring conditions (Ishizaki et al., 2022; Nugent et al., 2018) and unstable medical conditions (Szalda et al., 2019) further complicated transition, and in some cases, contributed to incomplete or delayed transfers of care.

The degree of health literacy and self-management of the young person with intellectual disability were both described as major influences on the transition process (Boyce et al., 2020; Ishizaki et al., 2022; Kerin et al., 2020; Stehouwer et al., 2021; Culnane et al., 2021). These encompass the ability to understand health information, make informed decisions, manage medications and appointments, and communicate effectively with providers. One publication highlighted that most transition programs target individuals who are capable of functioning relatively independently (Boyce et al., 2020), which may not meet the needs of young people with intellectual disability. This mismatch was a significant barrier, as carers of young adults reported high levels of support and daily care requirements (Culnane et al., 2021), while individuals with intellectual disability raised concerns around managing their own condition and a need for support with independent living (Kerin et al., 2020).

Psychological wellbeing was also reported as influencing young people's transitions, (Kerin et al., 2020; Stehouwer et al., 2021; Malapela et al., 2020; McManus et al., 2024; Marquis et al., 2024; Shanahan et al., 2021; Dressler et al., 2018; Culnane et al., 2021) with many individuals experiencing anxiety (Kerin et al., 2020; Dressler et al., 2018) and stress (Stehouwer et al., 2021; Shanahan et al., 2021) during this period, which was a barrier to successful transition. The transition process could even exacerbate existing mental health issues, (Marquis et al., 2024) with first admissions to adult services often being distressing for people with intellectual disability due to the absence of familiar paediatric providers (Stehouwer et al., 2021). One publication proposed tailored physical, informational, social, and psychological support to enable a more effective process of transition (Malapela et al., 2020). Strategies such as joint telehealth visits between paediatric and adult providers helped reduce anxiety and improve comfort of young adults during transition (McManus et al., 2024).

Ethnic, cultural, and linguistic factors were described as impacting health care transition, particularly for young people with intellectual disability from culturally and linguistically diverse backgrounds (Mirzaian et al., 2024a, 2024b; Fremion et al., 2022; Nugent et al., 2018; Dressler et al., 2018). There was a lack both of accessible health information in languages other than English, (Mirzaian et al., 2024a; Dressler et al., 2018) and of bilingual, culturally competent providers (Mirzaian et al., 2024b). These barriers limited engagement and understanding.

Interpersonal-level factors

Twenty-four publications identified interpersonal-level factors that, in the context of this review, refer to the relationships and supports directly affecting an individual, including both formal and informal social networks and social support systems (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Fremion et al., 2022; Ishizaki et al., 2022; Nascimento et al., 2023; Nugent et al., 2018; Razon et al., 2019; Szalda et al., 2019; Brown et al., 2020, 2022; Kerin et al., 2020; Stehouwer et al., 2021; Malapela et al., 2020; Shanahan et al., 2021; Dressler et al., 2018; Franklin et al., 2019; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021, 2023; Gauthier-Boudreault et al., 2018; Klein Haneveld et al., 2025b; Zulfiqar Ali et al., 2024).

Carers, often parents or families, frequently acted as the coordinator, advocate, and interpreter of medical care (Boyce et al., 2020; Brown et al., 2020; Kerin et al., 2020; Mirzaian et al., 2024b; Shanahan et al., 2021; Dressler et al., 2018; Franklin et al., 2019; Gauthier-Boudreault et al., 2018). They were commonly initiating transition planning, and organising and managing communications across services (Brown et al., 2020; Shanahan et al., 2021; Franklin et al., 2019; Gauthier-Boudreault et al., 2018). This role was reported to facilitate the transition process, particularly if the caregiver's ability to advocate on the young adult's behalf was informed and effective (Boyce et al., 2020; Brown et al., 2020; Kerin et al., 2020). However, the level of carer preparation and access to educational resources about health care transition varied greatly, (Mirzaian et al., 2024a; Boyce et al., 2020; Ishizaki et al., 2022; Szalda et al., 2019; Shanahan et al., 2021; Dressler et al., 2018; Franklin et al., 2019; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021; Zulfiqar Ali et al., 2024) with many carers feeling uninformed and unprepared for their young person's transition (Mirzaian et al., 2024a; Boyce et al., 2020; Shanahan et al., 2021; Franklin et al., 2019; Peters et al., 2022b; Culnane et al., 2021; Zulfiqar Ali et al., 2024). By contrast, carers who reported feeling well prepared and educated about the transition process achieved more positive outcomes, as they were able to arrange appointments and organise services required for an effective transition (Boyce et al., 2020; Ishizaki et al., 2022; Szalda et al., 2019; Dressler et al., 2018; Morton et al., 2021).

It was also identified that if carers and families of people with intellectual disability experienced financial hardship and socio-economic disadvantage, they often had limited access to timely or coordinated health care during the transition (Mirzaian et al., 2024a; Nugent et al., 2018; Shanahan et al., 2021; Franklin et al., 2019). The reasons for this included being unable to fund private services, (Shanahan et al., 2021) a loss of job opportunities due to caregiving responsibilities, (Franklin et al., 2019) and broader financial strain limiting their capacity to engage with and follow up on transition planning (Mirzaian et al., 2024a).

In addition, the isolating and demanding nature of the health care transition process was identified as impacting carers' physical and emotional wellbeing, (Boyce et al., 2020; Brown et al., 2020; Shanahan et al., 2021; Franklin et al., 2019; Culnane et al., 2021; Klein Haneveld et al., 2025b) with limited peer connection and support seen as a gap in transition care (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Ishizaki et al., 2022; Nugent et al., 2018; Razon et al., 2019; Szalda et al., 2019; Kerin et al., 2020). However, informal peer-to-peer support between carers sharing the transition process acted as a vital source of

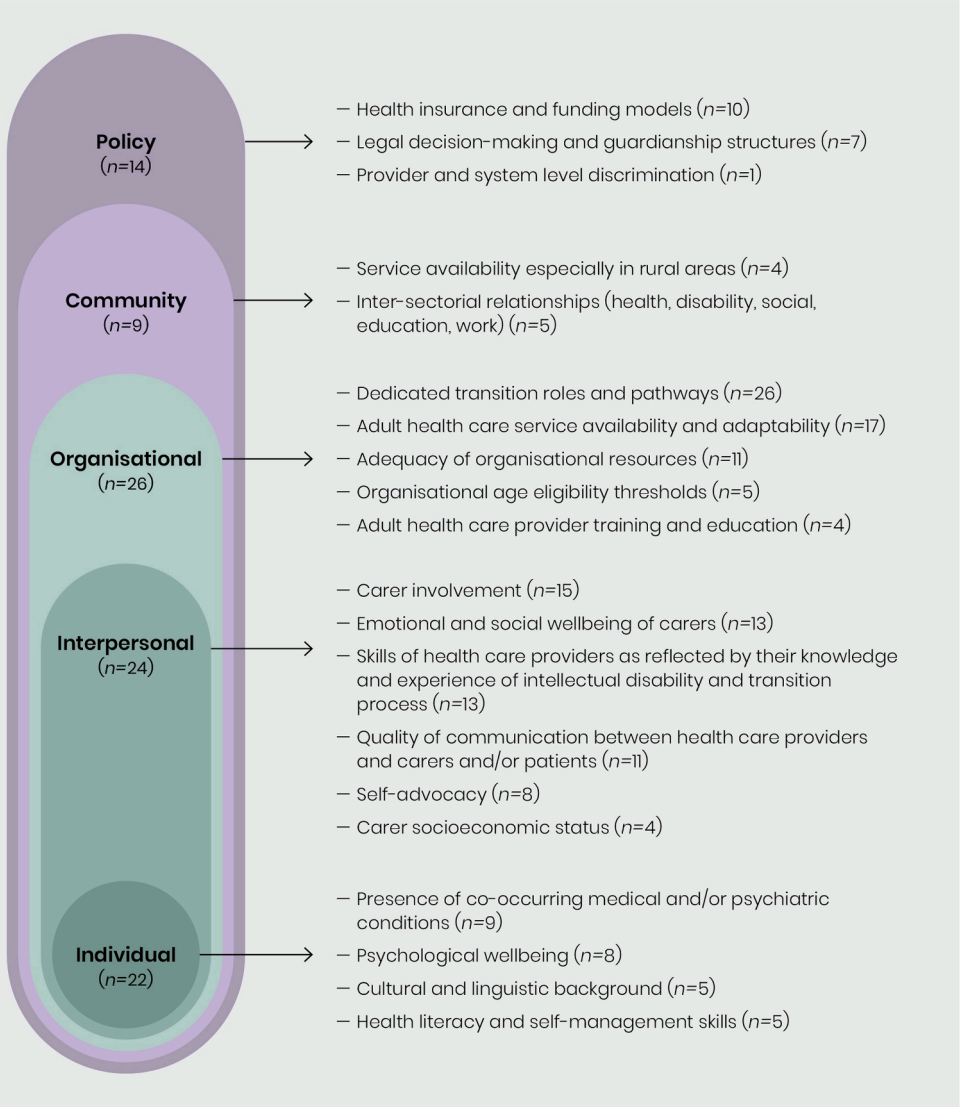

Fig. 3. Factors influencing transition from paediatric to adult health care for people with intellectual disability, by socio-ecological model levels; n = number of publications.

information, (Shanahan et al., 2021; Franklin et al., 2019) hope, and advocacy (Franklin et al., 2019).

Self-advocacy of people with intellectual disability was described as influencing health outcomes in the transition process (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Ishizaki et al., 2022; Nugent et al., 2018; Razon et al., 2019; Szalda et al., 2019; Kerin et al., 2020). Limited encouragement and support for young people with intellectual disability to advocate for themselves was seen as a barrier to an effective transition, (Boyce et al., 2020; Ishizaki et al., 2022; Nugent et al., 2018; Kerin et al., 2020) whereas active promotion of self-advocacy was identified as an enabler (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Razon et al., 2019; Szalda et al., 2019). Although self-advocacy may be considered an individual capacity, in the included publications it was most often described as relationally enabled or constrained through interactions with carers and health professionals, supporting its classification at the interpersonal level.

The skills of the relevant health care providers, as reflected by their knowledge and expertise regarding intellectual disability and transition, were reported to be influential in this process (Mirzaian et al., 2024a; Boyce et al., 2020; Ishizaki et al., 2022; Nascimento et al., 2023; Brown et al., 2020; Kerin et al., 2020; Malapela et al., 2020; Franklin et al., 2019; Culnane et al., 2021; Gauthier-Boudreault et al., 2018). Transitions were perceived to be more challenging when adult health care providers had limited experience and understanding of paediatric care, intellectual disability, and associated comorbidities, and/or lacked familiarity with the transition process (Mirzaian et al., 2024a; Boyce et al., 2020; Ishizaki et al., 2022; Brown et al., 2020; Kerin et al., 2020; Malapela et al., 2020; Culnane et al., 2021; Gauthier-Boudreault et al., 2018). Health care providers with the requisite experience, understanding, and knowledge were more likely to facilitate a young person's transition (Nascimento et al., 2023; Franklin et al., 2019). Several publications highlighted the role and skills of primary care providers in establishing and maintaining continuity of care during transition, reflecting their longer-term relationships with people with intellectual disability and their carers (Brown et al., 2020; Mirzaian et al., 2024b; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021).

Similarly, the quality of communication between health care providers and carers and/or people with intellectual disability was identified as influencing the transition process (Mirzaian et al., 2024a; Boyce et al., 2020; Nascimento et al., 2023; Brown et al., 2020; Kerin et al., 2020; VanZant and McCormick, 2021; Franklin et al., 2019; Peters et al., 2022b; Culnane et al., 2021; Klein Haneveld et al., 2025b; Zulfiqar Ali et al., 2024). When communication was clear and policies were explained, carers reported feeling more comfortable with the process,

(Brown et al., 2020; VanZant and McCormick, 2021) but many described having no prior discussion with their provider (Franklin et al., 2019; Zulfiqar Ali et al., 2024).

In adult health care, experiences were described as being more variable, with providers often failing to involve carers in the management of, and decision making about, the young person (Boyce et al., 2020; Klein Haneveld et al., 2025b). Conversely, some providers were more attentive, (Nascimento et al., 2023) and took interest in the young person beyond their diagnosis, thereby taking a more holistic approach to health and wellbeing and making carers and people with intellectual disability more comfortable and trustful (Peters et al., 2022b; Klein Haneveld et al., 2025b).

Organisational-level factors

Twenty-six publications identified organisational-level factors that, in the context of this review, refer to the structures, policies, and practices within health care organisations (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Fremion et al., 2022; Ishizaki et al., 2022; Nascimento et al., 2023; Razon et al., 2019; Szalda et al., 2019; Brown et al., 2020, 2022; Kerin et al., 2020; Stehouwer et al., 2021; Malapela et al., 2020; McManus et al., 2024; Shanahan et al., 2021; VanZant and McCormick, 2021; Dressler et al., 2018; Franklin et al., 2019; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021, 2023; Gauthier-Boudreault et al., 2018; Klein Haneveld et al., 2025b; Zulfiqar Ali et al., 2024; Son et al., 2019).

Effective coordination, (Ishizaki et al., 2022; Nascimento et al., 2023; Razon et al., 2019; Brown et al., 2020; Stehouwer et al., 2021; Mirzaian et al., 2024b; Malapela et al., 2020; McManus et al., 2024; Dressler et al., 2018; Peters et al., 2022b; Culnane et al., 2021, 2023; Klein Haneveld et al., 2025b; Son et al., 2019) early planning, and continuity of care between paediatric and adult health care providers were reported to facilitate the transition process (Ishizaki et al., 2022; Nascimento et al., 2023; Razon et al., 2019; Brown et al., 2020; Mirzaian et al., 2024b; McManus et al., 2024; Dressler et al., 2018; Peters et al., 2022b; Culnane et al., 2021, 2023; Gauthier-Boudreault et al., 2018; Klein Haneveld et al., 2025b). Dedicated transition clinics, (Fremion et al., 2022; Razon et al., 2019; Stehouwer et al., 2021; Dressler et al., 2018; Morton et al., 2021; Gauthier-Boudreault et al., 2018; Culnane et al., 2023) the availability of formalised transition guidelines (Boyce et al., 2020; Szalda et al., 2019; VanZant and McCormick, 2021; Dressler et al., 2018; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021) and the use of structured clinical assessment tools and medical summaries (Boyce et al., 2020; Szalda et al., 2019; VanZant and McCormick, 2021; Dressler et al., 2018; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021) also helped to ensure continuity of care. Similarly, dedicated transition roles were identified as key to providing support and guidance through the transition process (Mirzaian et al., 2024a, 2024b; Ishizaki et al., 2022; Szalda et al., 2019; Brown et al., 2020, 2022; Stehouwer et al., 2021; Malapela et al., 2020; Peters et al., 2022b; Culnane et al., 2021, 2023; Klein Haneveld et al., 2025b). These roles included care coordinators, (Brown et al., 2020, 2022; Stehouwer et al., 2021; Malapela et al., 2020; Peters et al., 2022b; Culnane et al., 2023) multidisciplinary teams, (Mirzaian et al., 2024b) counselling, (Stehouwer et al., 2021) and central support figures such as nurses (Brown et al., 2020, 2022; Malapela et al., 2020; Klein Haneveld et al., 2025b). Conversely, inadequate planning and coordination often resulted in a poor transition experience (Boyce et al., 2020; Ishizaki et al., 2022; Nascimento et al., 2023; Razon et al., 2019; Brown et al., 2020, 2022; Kerin et al., 2020; McManus et al., 2024; Shanahan et al., 2021; Franklin et al., 2019; Peters et al., 2022b; Culnane et al., 2021; Gauthier-Boudreault et al., 2018; Klein Haneveld et al., 2025b; Zulfiqar Ali et al., 2024).

Organisational resource availability for health care providers was another key factor reported as influencing transition, (Mirzaian et al., 2024a, 2024b; Brown et al., 2020, 2022; Malapela et al., 2020; McManus et al., 2024; Dressler et al., 2018; Franklin et al., 2019; Peters et al., 2022b; Culnane et al., 2021; Son et al., 2019). Inadequate staffing, (Brown et al., 2020) time constraints, (Dressler et al., 2018; Culnane et al., 2021) and financial limitations such as inadequate reimbursement for handovers (Peters et al., 2022b) were barriers to effective transition. Reported enablers included flexible service delivery, (Son et al., 2019) value-based payment models, (McManus et al., 2024) and financial incentives for providers to undergo specific training in intellectual disability (Mirzaian et al., 2024b).

The availability and accessibility of adult health care services were reported as being influential in how the transition process was experienced and managed (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Ishizaki et al., 2022; Nascimento et al., 2023; Razon et al., 2019; Brown et al., 2020; Kerin et al., 2020; McManus et al., 2024; Shanahan et al., 2021; Dressler et al., 2018; Franklin et al., 2019; Culnane et al., 2021, 2023; Gauthier-Boudreault et al., 2018; Zulfiqar Ali et al., 2024; Son et al., 2019). Fragmented adult health care services were perceived by carers and some health care providers as being less accessible and equipped to manage complex needs than team-based paediatric care (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Ishizaki et al., 2022; Razon et al., 2019; Brown et al., 2020; Kerin et al., 2020; Dressler et al., 2018; Franklin et al., 2019; Culnane et al., 2021, 2023; Gauthier-Boudreault et al., 2018; Zulfiqar Ali et al., 2024). In contrast, transitions were more accessible when adult health care services demonstrated flexibility, patience, and a willingness to accommodate behavioural and cognitive needs (Nascimento et al., 2023; McManus et al., 2024; Son et al., 2019).

Adult health care provider training and education was described as influencing transition (Szalda et al., 2019; Brown et al., 2020; Mirzaian et al., 2024b; Culnane et al., 2021). Knowledge gaps among health care providers involved with transition highlighted the need for additional training and professional development (Mirzaian et al., 2024b).

Finally, organisational rules/policies around age limits for patients lead to abrupt, unplanned transitions: (Brown et al., 2020; Franklin et al., 2019; Peters et al., 2022b) as described by one carer “18 and you’re done” (Franklin et al., 2019).

Community-level factors

Nine publications identified community-level factors that, in the context of this review, refer to the broader social settings with which young people and their families interact, including relationships between societal sectors, and the geographical distribution of services (Boyce et al., 2020; Ishizaki et al., 2022; Brown et al., 2020; Kerin et al., 2020; Mirzaian et al., 2024b; Franklin et al., 2019; Culnane et al., 2021; Gauthier-Boudreault et al., 2018; Klein Haneveld et al., 2025b).

The limited availability of health care services were reported as barriers to an effective transition process in rural areas (Boyce et al., 2020; Ishizaki et al., 2022; Kerin et al., 2020; Mirzaian et al., 2024b). The centralisation of these services in metropolitan areas has limited rural patients’ access, especially those who are unable to travel independently (Kerin et al., 2020). Health care providers emphasised the need to improve regional medical networks to facilitate the transition process (Ishizaki et al., 2022).

Effective coordination and multi-agency communication between the health, disability, education, employment, and social care sectors were described as strengthening the transition process (Brown et al., 2020; Franklin et al., 2019; Culnane et al., 2021; Gauthier-Boudreault et al., 2018; Klein Haneveld et al., 2025b). One publication identified that some carers experienced strong coordination and multiagency communication between health and social care, enabling a well-managed transition process (Brown et al., 2020). However, reported barriers included a disconnect between the health and disability sectors, (Culnane et al., 2021) the siloed functioning of the different sectors, (Franklin et al., 2019) and limited information sharing and coordination of care among carers, health providers, educators, social workers, and employers (Klein Haneveld et al., 2025b).

Policy-level factors

Fourteen publications touched on policy-level factors that, in the context of this review, refer to broader systems-level factors, such as local, regional, and national policies and laws (Mirzaian et al., 2024a, 2024b; Boyce et al., 2020; Fremion et al., 2022; Nascimento et al., 2023; Nugent et al., 2018; Razon et al., 2019; Szalda et al., 2019; Brown et al., 2020; Shanahan et al., 2021; Dressler et al., 2018; Franklin et al., 2019; Morton et al., 2021; Culnane et al., 2021).

Legal decision-making arrangements – including guardianship, power of attorney, and proxy decision-making – were reported as shaping the transition process (Boyce et al., 2020; Nascimento et al., 2023; Razon et al., 2019; Brown et al., 2020; Mirzaian et al., 2024b; Franklin et al., 2019; Morton et al., 2021)., with inconsistent recognition of legal guardianship within adult health care systems and inflexible hospital processes creating challenges in facilitating transition (Nascimento et al., 2023; Brown et al., 2020; Mirzaian et al., 2024b).

Health insurance coverage was reported to influence access to transition-related services, particularly in the USA (Boyce et al., 2020; Fremion et al., 2022; Nugent et al., 2018). For many young people with disability, care is primarily funded through public programs such as Medicaid (USA) and Medicare (Australia), although private health insurance at times led to better transition experiences (Fremion et al., 2022). However limited public services sometimes led families to incur high costs for private care (Culnane et al., 2021). Public programs, such as Medicaid in the USA, influenced the transition process due to policy restrictions limiting access to adult care providers, (Boyce et al., 2020; Razon et al., 2019; Szalda et al., 2019; Dressler et al., 2018; Morton et al., 2021) with prolonged waitlists for disability and insurance waivers sometimes extending for 10–20 years (Boyce et al., 2020; Franklin et al., 2019). Publications did not explore how variation in health system organisation - such as the separation of primary, specialist, and hospital care within different policy and funding frameworks - may shape transition experiences.

One publication identified racism and diagnosis-based discrimination as policy-level, system-wide barriers influencing access to care. These barriers were described as operating through service-eligibility rules and how diagnoses were used to decide who could access services, determining how services were organised and delivered. As a result, organisational practices and provider decisions were reported to disproportionately affect young people of colour and those with co-occurring mental health and intellectual disability diagnoses (Mirzaian et al., 2024a).

Discussion

This global scoping review adds to the evidence base by systematically identifying factors reported to influence the transition from paediatric to adult health care for young people with intellectual disability. Influencing factors were identified across all five levels of the SEM, with the most frequently reported occurring at the organisational level. These factors included the presence of dedicated transition roles and pathways, the availability and adaptability of adult health care services, the degree of carer involvement, the knowledge and skills of health care providers, the quality of communication between health care providers and carers and/or patients, and the adequacy of organisational resources.

Frequently reported barriers, in order of frequency, included: lack of clearly defined transition roles and pathways, limited availability and adaptability of adult health care services, poor emotional and social wellbeing of carers, the incidence of co-occurring medical and/or psychiatric conditions, insufficient knowledge and experience of managing people with intellectual disability and the transition process by health care providers, poor communication between carers and health care providers, and limited organisational resources. Conversely, the most frequently reported enablers were having formal transition pathways and services including dedicated positions and roles, active carer involvement and advocacy, and effective communication between carers and/or patients and health care providers.

Several influential factors in our review are consistent with findings from other international reviews on health care transition for young people with intellectual disability (Fremion et al., 2024; Young-Southward et al., 2017; Brown et al., 2019; Varshney et al., 2022; Osako et al., 2023). These include the presence of co-occurring medical conditions, (Fremion et al., 2024; Young-Southward et al., 2017; Brown et al., 2019; Varshney et al., 2022; Osako et al., 2023) the level of carer involvement and advocacy, (Fremion et al., 2024; Brown et al., 2019; Osako et al., 2023) the quality of communication between carers and health care providers, (Fremion et al., 2024; Brown et al., 2019; Osako et al., 2023) and the availability of dedicated transition roles and pathways (Fremion et al., 2024; Brown et al., 2019; Osako et al., 2023). While these factors have been described previously, existing publications predominately present lists of barriers and facilitators without a structured approach to understand how influences operate within and between broader systems (Fremion et al., 2024; Young-Southward et al., 2017; Brown et al., 2019; Osako et al., 2023; Ramachandran et al., 2025).

The McLeroy et al. SEM provided a useful organising framework for synthesising the multi-level factors influencing health care transition and clarifying how influences operate within and across systems. Mapping the evidence to the SEM showed that existing research remains concentrated at the individual and interpersonal levels, with comparatively little attention to organisational, community, and policy environments - levels increasingly recognised as critical to transition success (Ramachandran et al., 2025; Mirzaian et al., 2024b). Importantly, the SEM offers a framework for systems change by supporting the design of interventions that act across multiple, interacting levels rather than isolated strategies. Viewed through this lens, the findings indicate that improving transition outcomes for young people with intellectual disability cannot rely primarily on individual capacity or family advocacy, as self-advocacy and preparedness were consistently shaped by organisational structures, workforce capability, and the availability of coordinated pathways. This provides a clearer line of sight to system-level levers and priorities for strengthening transition experiences.

Our findings underscore the critical role of coordination and continuity of care in supporting effective transitions from paediatric to adult health care for people with intellectual disability. Where dedicated transition roles and structured pathways are in place, care is more seamless: communication between providers is facilitated, families are supported to navigate complex systems, and young people experience greater continuity and preparedness. In contrast, in settings without defined coordination mechanisms, transitions are often fragmented, with families left to assume responsibility for care navigation, resulting in delays, duplication of effort, and preventable gaps in service provision. Dedicated transition coordinators or case managers therefore act as pivotal agents, bridging the divide between paediatric and adult systems (Brown et al., 2019; Ramachandran et al., 2025).

Several publications highlighted the role of primary care providers in maintaining continuity of care throughout the transition process (Brown et al., 2020; Mirzaian et al., 2024b; Morton et al., 2021; Peters et al., 2022b; Culnane et al., 2021). The active engagement of general practitioners is vital as young people transition to the adult health care system (Toulany et al., 2022; Schraeder et al., 2021). As consistent points of contact across the life course, general practitioners are well placed to initiate and sustain discussions about transition (Schraeder et al., 2021). Their ongoing relationship with both the young person and their family positions them to identify emerging health and coordination needs, provide continuity, and facilitate connections with adult health and community services. In many high-income countries, structured annual preventive health assessments in primary care offer a platform for these conversations (Eveleigh et al., 2025). Early engagement during adolescence, particularly between the ages of 12 and 18, provides a crucial

window to introduce the concept of transition, assess readiness, and begin collaborative planning. Embedding a structured prompt within these assessments may support general practitioners to systematically address transition and identify coordination needs.

Families and carers often experience stress and uncertainty as the young people with intellectual disability in their care transition from paediatric to adult health care, (Brown et al., 2019) particularly as it coincides with broader life transitions across education, employment, and legal status (Nugent et al., 2018; Szalda et al., 2019). Managing these intersecting transitions increases the complexity of their role by requiring them to navigate fragmented systems, advocate for support, (Boyce et al., 2020; Brown et al., 2020; Kerin et al., 2020) and coordinate the young person's care, (Brown et al., 2020; Shanahan et al., 2021; Franklin et al., 2019; Gauthier-Boudreault et al., 2018) often in the absence of adequate guidance (Fremion et al., 2024; Brown et al., 2019). Such systemic shortcomings exacerbate carer exhaustion and isolation. Addressing these challenges requires a holistic, family-centred approach that situates health care transition within the broader socio-cultural context and ensures practical, emotional, and informational support.

An important gap in the included literature was the relative silence on the role of ableism and racism in shaping transition experiences. This contrasts with broader health literature identifying ableism and racism as key determinants of access to care, quality of interactions with health services, and health outcomes (Barrington et al., 2025; Shea et al., 2022; Llewellyn et al., 2015; Krnjacki et al., 2018). While not always named explicitly, some factors identified in this review - such as constraints on self-advocacy imposed through relationships or service practices - may reflect underlying ableist dynamics. This suggests that ableism and racism may be operating implicitly within transition processes, even where they are not directly theorised or labelled in the literature.

Although this review was global in scope, all included publications were conducted in high-income countries. With more than half based in the USA, this context may have shaped the factors identified in our review. For example, the prominence of health insurance as a key policy-level factor reflects the insurance mediated nature of the USA's health system, including public programs such as Medicaid. Health care funding and governance arrangements differ substantially across jurisdictions, particularly in how primary, specialist and hospital care are organised and funded, which may contribute to fragmented responsibility for transition. However, these system-level distinctions were rarely examined in the included publications, limiting understanding of how variation in health system organisation shapes transition processes and outcomes. Further research is needed to examine community- and policy-level influences on transition, including the interface between primary, specialist and hospital care.

Crucially, moving the needle toward sustainable change requires centring people with intellectual disability not only as participants but as partners in the design, governance, and evaluation of transition systems. A striking gap across the included publications was the limited inclusion of the perspectives of young people with intellectual disability within the research evidence base itself. This absence risks reinforcing models shaped largely by families and providers, while overlooking the priorities, challenges, and aspirations of those experiencing the process firsthand. More inclusive and accessible research approaches are needed, using adapted methodologies that enable meaningful participation and ensure that young people are heard and represented (Anderson et al., 2025; Bailie et al., 2023; Downs et al., 2025).

While this review focused on the past 10 years of literature to capture factors relevant to the current health care context, somewhat surprisingly, telehealth received little attention despite its rapid expansion during the COVID-19 pandemic (Friedman and VanPuymbrouck, 2021; Desborough et al., 2020). Telehealth services may have the potential to improve access to health care by allowing patients to connect with professionals beyond their local area and while at home, and enabling practitioners to seek second opinions from specialists when necessary, which is helpful for patients with increased care needs and comorbid conditions. Such an approach could be especially valuable in rural and underserved areas, (Osman et al., 2024) and should be a subject of future research.

Based on the findings of this review, we propose several recommendations for future research in transition to adult health care for people with intellectual disability. (Box 1)

Strengths and limitations

The strengths of this review include the use of a published *a priori* protocol, (Folpp et al., 2025) adherence to JBI scoping review methodology (Peters et al., 2022a) and the PRISMA-ScR checklist, (Tricco et al., 2018) and the involvement of two reviewers who independently conducted full-text screening and 50 % of data extraction. These approaches enhanced the rigour, transparency and reliability of the review. However, several limitations should be considered. Relevant evidence may have been missed due to the exclusion of grey literature, non-empirical publications, and publications in languages other than English. Although search terms were cross-checked against those used in recent scoping reviews, some relevant publications may not have been identified due to variation in terminology used to describe intellectual disability or associated health conditions.

Most included publications were conducted in high-income countries, predominantly the USA, which may limit applicability to other contexts. Differences in health system organisation, funding arrangements and integration of primary, specialist and hospital care across jurisdictions were not examined in the included publications, constraining interpretation of their implications for transition outcomes. Title and abstract screening were undertaken by a single reviewer, with 5 % independently screened, potentially introducing selection bias. The comprehensiveness of our review is shaped by the scope of the included publications, many of which did not explicitly investigate multi-level influences on transition. As such, our findings reflect only what has been examined in the existing literature and may therefore provide a partial picture. For example, community- and policy-level influences were reported less frequently, not necessarily because they are unimportant, but likely because these levels were not the focus of the included publications rather than due to any evidence of their limited relevance. A further limitation relates to the analytic approach. In line with JBI guidance, we undertook a qualitative content analysis focused on factors as reported in the included publications. Content analysis does not involve deeper interpretive analysis, and some structural influences - such as ableism or racism - may have been under-recognised where they were not explicitly examined, despite their likely relevance to transition experiences.

Conclusion

Using a widely cited SEM as an organising framework, this scoping review reveals that the current literature on factors influencing the transition from paediatric to adult health care for young people with intellectual disability is dominated by research into organisational-level factors, particularly the presence or absence of dedicated transition roles and pathways, service adaptability, provider knowledge and skills, and quality communication. Further research on the perspectives of young people with intellectual disability, on community and policy level factors and in a wider range of contexts is warranted to ensure a more comprehensive understanding of these multi-level factors.

Ethics approval and consent to participate

No ethics approval was required and consent to participate is not applicable.

Box 1
Recommendations for further research.

- Include the perspectives of people with intellectual disability in future research and research teams, using more inclusive and accessible methods.
- Examine how structural and interpersonal forms of ableism and racism influence transition processes and outcomes.
- Explore the role of health care transition in the context of broader life course research.
- Undertake research to understand the community- and policy-level factors influencing health care transition.
- Examine how interactions between primary, secondary and tertiary care influence transition experiences and outcomes.
- Investigate the role of general practice and how it can be leveraged to support early planning, continuity, and coordination of transition.
- Conduct research in countries not represented in this review to strengthen global understanding.
- Increase research focused on rural and regional contexts.
- Investigate the use of telehealth and digital tools to address accessibility barriers during the transition process.
- Systematic review to assess the effectiveness and quality of transition interventions.

CRediT authorship contribution statement

Noah Folpp: Writing – review & editing, Writing – original draft, Visualization, Validation, Project administration, Methodology, Investigation, Data curation, Conceptualization. **Jodie Bailie:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Alison Laycock:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Methodology, Formal analysis, Data curation. **Kanchana Ekanayake:** Writing – review & editing, Writing – original draft, Resources, Data curation. **Ross Bailie:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Methodology, Formal analysis, Conceptualization. **Nicholas Lennox:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Sally Hall Dykgraaf:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Maddison Eveleigh:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis. **Paul Caltabiano:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis. **Bradley Shea:** Writing – original draft, Methodology, Formal analysis.

Consent for publication

Not applicable.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

Noah Folpp conducted the review as a course requirement for the Doctor of Medicine at The University of Sydney's Faculty of Medicine and Health, under the primary supervision of Dr Jodie Bailie and secondary supervision of Dr Alison Laycock and Professor Ross Bailie. We acknowledge Svetlana Andrienko for the design of the figures and Jane Yule for editing.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ssmhs.2026.100193.

Data availability

Further details on publications included in this scoping review can be retrieved by contracting the corresponding author.

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