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Title:
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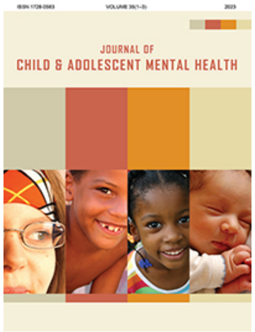
Date:
2024

Citation:
Dimov, S., Shields, M., Dickinson, H., Kavanagh, A. M., White, B. & Sutherland, G. (2024). Mental health and post-school transitions for young people with Intellectual and Developmental Disabilities (IDD): A scoping review. Journal of Child and Adolescent Mental Health, 36 (2), pp.207-236. https://doi.org/10.2989/17280583.2024.2424198.

Persistent Link:
https://hdl.handle.net/11343/357209



Journal of Child & Adolescent Mental Health

ISSN: 1728-0583 (Print) 1728-0591 (Online) Journal homepage: www.tandfonline.com/journals/rcmh20

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To cite this article: Stefanie Dimov, Marissa Shields, Helen Dickinson, Anne M Kavanagh, Bella White & Georgina Sutherland (26 Nov 2024): Mental health and post-school transitions for young people with Intellectual and Developmental Disabilities (IDD): A scoping review, Journal of Child & Adolescent Mental Health, DOI: 10.2989/17280583.2024.2424198

To link to this article: https://doi.org/10.2989/17280583.2024.2424198

Journal of Child & Adolescent Mental Health 2024, xx(x): xx–xx
This is the final version of the article that is published ahead of the print and online issue.

JOURNAL OF
CHILD & ADOLESCENT MENTAL HEALTH
ISSN 1728-0583 EISSN 1728-0591
https://doi.org/10.2989/17280583.2024.2393839

Review Article

Mental health and post-school transitions for young people with Intellectual and Developmental Disabilities (IDD): A scoping review

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Background: **Young people with an Intellectual and Developmental Disability (IDD) often face ineffective and exclusionary post-school transition practices, leading to poor mental health in early adulthood.**
Objective: **This scoping review aimed to map existing literature on mental health for young people with IDD during the post-school transition period including how IDD and mental health are characterised in this context and the extent to which community members with lived experience are included in the design and/or production of research.**
Methods: **In collaboration with a co-researcher, we used the JBI framework and PRISMA guidelines in accordance with a published protocol. A tiered search was conducted in PsycINFO, Medline, ERIC, Web of Science, and Family and Society Studies Worldwide.**
Findings: **The search identified 28 articles that met the inclusion criteria. Articles were published between 2011 and 2023 and conducted across four countries. Thirteen applied a quantitative study design, eight were qualitative, three used a mixed-methods design, and the remaining were reviews. Most articles focused on autism. The majority discussed mental health in terms of its impact on transitioning from school or as a co-occurring condition.**
Conclusions: **There is a growing body of literature highlighting the challenges young people with disabilities face when transitioning from high school. However, there is a notable gap in the representation of diverse IDD populations and mental health emerged variably, often as an incidental finding rather than a primary focus.**

Keywords: intellectual and developmental disability, mental health, post-school transitions, scoping review, young people

Background

The post-school transition period is an important milestone for all young people on the pathway from adolescence to adulthood and is decisive for many later life outcomes (Heckhausen, 2002). For the purpose of this scoping review, post-school transition refers to the phase in a young person's life immediately prior-to or after they complete formal education, typically after graduating from high school. It encompasses the time when individuals transition from an educational setting to the next stage of their lives, such as entering the workforce, pursuing higher education, vocational training, or other post-secondary options. Poor experiences of post-school transition (i.e., low education attainment, unemployment) is known to increase the risk of social exclusion and poor financial, social, and health outcomes (Barham et al., 2009).

Post-school transition is not without its challenges for all young people. However, young people with intellectual or developmental disabilities (IDD) face particular and complex difficulties (Carter et al., 2012; Wei et al., 2014). In this paper, we will primarily use person-first language while acknowledging that some individuals may prefer identity-first language; we will also occasionally use diagnostic terms, or the terminology employed by the original authors. IDDs are a wide and diverse category that includes lifelong conditions that manifest during early childhood that can be cognitive, physical, or both (e.g., autism spectrum disorder, cerebral palsy, Down syndrome, intellectual disability, or spina bifida) (Carulla et al., 2011). Research indicated that young people with IDD can face ineffective, narrow, and exclusionary school policies and strategies that fall short of meeting their needs (Children with Disability Australia, 2015). Furthermore, compared to young people without disability, young people with IDD report experiencing more difficulties in accessing tertiary education (O'Brien et al., 2019), are underrepresented in the labour force (Scott et al., 2015; Wilson & Campain, 2020), and find it difficult to gain and maintain employment (Meltzer et al., 2016).

Research evidence suggests that negative post-school transitions for young people with disability may also lead to poor mental health in early adulthood (Centre for Equity & Innovation in Early Childhood [CEIEC], 2008; Winn & Hay, 2009). Although evidence about post-school experiences for young people with IDD is limited, it is generally assumed to be worse given their systemic exclusion from school-based processes that shape transition possibilities (Australian Human Rights Commission, n.d.). There are several additional reasons why navigating the post-school transition period may be particularly complex for young people with IDD with potential impacts for mental health. The post-school transition period is a critical phase in the lives of young people with IDD, often marked by significant changes and challenges that can impact mental health (Winn & Hay, 2009). This transition, encompassing the move from structured school environments to adult roles and services, and is associated with increased vulnerability to mental health issues, including anxiety and depression (Hsieh et al., 2020; King et al., 2020; Nucifora et al., 2024). Contemporary research highlights that young people with IDD are at a heightened risk of poor mental health outcomes during this period due to factors such as loss of routine, social isolation (Gur & Bina, 2023; Santiago Perez & Crowe, 2021), and limited access to appropriate support services (Greenwald et al., 2024; Sanderson et al., 2020). This lack of routine can lead to anxiety and difficulty in managing daily tasks, further exacerbating mental health challenges.

Social isolation is another major concern during this period. School environments often provide social networks and opportunities for peer interaction, which are crucial for the mental well-being of young people with IDD (Boyle et al., 2023). However, after leaving school, these social connections can diminish, leading to increased feelings of loneliness and isolation (Gur & Bina, 2023; Santiago Perez & Crowe, 2021). The reduction in social engagement not only impacts mental health directly but also reduces the availability of informal support systems that can help mitigate the effects of stress and anxiety.

As summarised by the World Health Organization (WHO) International Classification of Diseases (ICD) Working Group on the Classification of Intellectual Disabilities (Carulla et al., 2011), people with IDDs have a high comorbidity with other mental disorders and are frequently misdiagnosed due to limited access to health care services and negative biases held by clinicians (Hallyburton, 2022). In addition to the mental health challenges faced by young people with IDD during the post-school transition period, the broader social and systemic factors further complicate their experiences. The transition period often involves navigating a complex and fragmented service landscape, where support systems are not always equipped to address the unique needs of this population (Winn & Hay, 2009). Limited access to educational and employment opportunities, inadequate social support networks, and financial strain, significantly contribute to the mental health challenges faced by individuals with IDD during the post-school transition period (Zisman-Ilani, 2022). Research indicates that young people with IDD frequently encounter barriers such as limited access to mental health services, lack of coordinated care, and inadequate preparation for adulthood (Benson et al., 2021; Carter et al., 2023; Casale et al., 2021; Malik-Soni et al., 2022; Mirzaian et al., 2024; Shady et al., 2024). These barriers can exacerbate feelings of anxiety, isolation, and uncertainty, making the transition even more challenging.

Furthermore, experiences of stigma, discrimination, and social exclusion exacerbate the vulnerability of young people with IDD to mental health issues (Jansen-van Vuuren & Aldersey, 2020). The societal stigma associated with both disability and mental health issues can discourage help-seeking behaviours, leaving many young people without the support they need during this critical period (Sahu & Banerjee, 2016; Schnyder et al., 2017). The intersectionality of disability, mental health, and societal expectations underscores the importance of adopting a holistic approach to support young people with IDD through tailored interventions that address their mental health needs, promote social inclusion, and ensure continuity of care as they transition into adulthood. These systemic barriers and societal attitudes hinder access to appropriate mental health care and perpetuate negative stereotypes and self-perceptions, leading to increased psychological distress and diminished well-being among individuals with IDD (O'Byrne & Muldoon, 2017; Shifrer, 2013).

Despite broad acknowledgement in the literature that young people with IDD face particularly complex challenges navigating educational transitions (Šiška et al., 2024), research that specifically focuses on mental health in this context is sparse. Moreover, the extent of involvement of young people with IDD in building the evidence base to support better transition pathways is largely unknown. Engaging people with lived experience in research can improve the evidence base that impacts outcomes and service delivery, facilitating not only the translation of research into practice but the dissemination and uptake of results by intended audiences (Domecq et al., 2014; Wang et al., 2023). However, there is a limited understanding of the extent to which community members and young people with disability are engaged in the design or production of research investigating post-school transitions and mental health.

Scoping review aims and objectives

We conducted a scoping review to systematically map the existing literature on mental health for young people with IDD during the post-school transition period, including how these constructs are defined and the extent to which community members with lived experience are involved in the research process. The specific objectives were to:

(i) Analyse the characterisation of IDD in the literature focusing on mental health and the post-school transition period.
(ii) Assess how post-school transitions are defined and studied in the included articles.
(iii) Evaluate the conceptualisation of mental health and methodologies utilised in defining and studying mental health within the context of post-school transitions for young people with IDD.
(iv) Assess the extent to which community members with lived experiences of IDD are included in the design and/or production of research concerning their post-school transition experiences and mental health outcomes.

Methodology

A scoping review methodology was chosen as it is the most appropriate methodology for synthesising a body of evidence that has yet to be comprehensively reviewed (Munn et al., 2018). Additionally, a scoping review methodology is acknowledged as an appropriate method to identify concepts or characteristics in the literature (Munn et al., 2018), such as the characteristics of post-school transitions or definitions of IDD. This scoping review followed the Joanna Briggs Institute (JBI) methodology for scoping reviews (Aromataris et al., 2024) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR: Tricco et al., 2018). A preliminary search of PsycINFO, the Cochrane Database of Systematic Reviews, and JBI Evidence Synthesis conducted in June 2023 identified no current or in-progress systematic reviews or scoping reviews on the topic.

A protocol was registered with the Open Science Framework (https://osf.io/79rsc). There were two deviations from the protocol. One was the exclusion of grey literature from the search strategy. This decision was made to prioritise the inclusion of peer-reviewed literature, which typically undergoes rigorous quality assessment and peer-review processes. By focusing exclusively on peer-reviewed studies, the review aimed to provide a more consistent and high-quality evidence base, reducing any potential variability and bias (Colquhoun et al., 2014). Additionally, the exclusion of grey literature allowed for a more streamlined and focused analysis. The second was with regards to the age limit. We replaced the specific age range of 15-25 with the term “transition-aged youth” to be more inclusive.

Knowledge user engagement

A collaborative approach was adopted to ensure the research was both comprehensive and inclusive (Pollock et al., 2022). A co-researcher, who is a young person with a developmental disability, was engaged throughout the process. From the outset, we were committed to ensuring that their involvement was meaningful. To achieve this, we provided the co-researcher with training and support to actively contribute to all phases of the review, including the development of research questions, refinement of search terms, and interpretation of findings. Regular meetings were held to discuss progress and incorporate their insights, ensuring that their lived experience informed key decisions. Their contributions were not only valued but also integral to shaping the direction of the review. This approach fostered an environment of mutual respect and partnership, where the co-researcher’s perspectives were recognised as essential to the authenticity and relevance of the research. The co-researcher provided suggestions on relevant search terms, ensuring that the search strategy was reflective of the real-world context of individuals with IDD. Additionally, they were involved in interpreting the findings and commenting on the final manuscript. The initial themes were reviewed by the co-researcher – they read several of the included papers and provided insights into the interpretation of those papers and the corresponding themes. The co-researcher reviewed the final manuscript providing suggestions for edits.

Search strategy

Five electronic databases were searched: PsycINFO, Medline, ERIC, Web of Science and Family, and Society Studies Worldwide. Databases were searched on 26 May 2023 and the search was updated on 10 June 2024, and by a rapid review for entries to 9 June 2024. Variants and combinations of search terms were used relating to intellectual and developmental disability, mental health, and post-school transitions. MeSH terms were also used to capture relevant terms, particularly in relation to IDD which may include several different conditions (see Supplementary 1). The terms were determined after an initial search of the literature and advice from a librarian. The reference list of all identified articles was also hand-searched for additional articles that met the inclusion criteria to locate additional relevant publications not identified during the database searches.

Inclusion and exclusion criteria

Publication format was limited to peer reviewed journal articles, including all types of review publications. The rationale for including previous reviews was that scoping reviews are designed to identify key themes and trends in the literature (Colquhoun et al., 2014) as opposed to extracting data for meta analysis, and previous reviews are valuable sources of such themes. Publications were deemed eligible for inclusion if they examined post-school transitions for young people with an IDD and addressed mental health. The review examined literature that included a focus on transition-aged young people with IDD (diagnosed or self-identified).

Given the heterogeneous nature of IDD, this review considered articles that encompassed a wide range of intellectual or developmental conditions such as autism, Down syndrome, Prader-Willi syndrome, cerebral palsy, and others. A rigid classification system for IDD during the operationalisation of the search strategy was not employed to ensure the broadest possible scope by using keyword searches that encompassed a wide array of terms related to IDD. This approach was intentional to capture the full breadth of relevant literature without imposing constraints that could unintentionally narrow the scope. This inclusive approach ensured that the literature examined captured the diverse experiences and needs of transition-aged young people across the IDD spectrum, regardless of their specific diagnosis or self-identification.

There was no restriction on age, as long as the publication focused on transition aged youth, reflecting the unique developmental trajectory of young people with IDD. By not imposing a strict age limit, we aimed to ensure an inclusive age range that accounts for the varying timelines young people with IDD may experience during this critical phase. The review considered all articles that investigated post-school transitions, and excluded those that did not, such as broad transitions to adulthood (with no focus on school) or healthcare transitions.

Finally, this review considered articles that addressed mental health, mental illness, or well-being and there were no predefined restrictions on the extent to which the publications addressed mental health (e.g., either as an exposure or an outcome). Articles published before 2000 were excluded to ensure contemporality and articles not published in English were excluded due to resource constraints (see Table 1).

Article selection

Search results were imported into Covidence (Veritas Health Innovation, 2023) and duplicates were removed. Titles and abstracts of records were screened for relevance by two researchers (SD and MS), with conflicts resolved through discussion. The full texts of selected records were obtained and assessed against the review criteria by one researcher (SD), with 25% assessed by a second researcher (MS). The kappa statistic (ScienceDirect, n.d.) for agreement on article inclusion at both stages was calculated to determine consistency in the screening process. In instances when the full text of potentially relevant publications could not be located, two attempts were made to contact the author(s) via email to request a copy.

Data extraction and synthesis

A data extraction form was developed in Covidence for all published articles and relevant information was summarised. A narrative synthesis was conducted, where we investigated the similarities and differences between studies to provide a summary of knowledge related to four key research questions (see Table 2). Data from the studies were extracted and imported into Nvivo (Lumivero, 2023), where the data were mapped on to the narrative synthesis questions and thematic analysis was conducted to identify and extract key themes (Mak & Thomas, 2022).

Table 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Population: - Transition aged - Diagnosed or self-diagnosed IDD	Population: - Disability type other than IDD
Concept: - Mental health - Mental illness - Well-being	Concept: - Addresses broader domains like ‘life satisfaction’ which may be related to mental health but outside the scope of this review
Context: - Post-school transitions - Transitions out of high school - Preparation to transition out of high school	Context: - Transitions other than out of high school (e.g., healthcare) - Focus on ‘transition age’ but do not explicitly focus on the school transition itself
	Limits: - Non-English language articles - Papers published pre-2000

Results

Article inclusion and characteristics

The search generated 1 444 articles (1 398 from the original database search, 46 from the rapid update, and 16 from other sources: see Figure 1), of which 1 208 remained after duplicates were removed. A further 963 articles were removed after title and abstract screening. The full texts of the remaining 245 articles were screened and 217 were excluded (see Figure 1), leading to 28 articles

Table 2. Narrative synthesis questions

Question
How is IDD characterised in the literature on mental health for young people with IDD during the post-school transition period?
How are post-school transitions defined and studied and are these transitions examined in relation to mental health?
How is mental health defined and studied during the post-school transition period?
To what extent are community members with lived experience included in the design or production of the research?

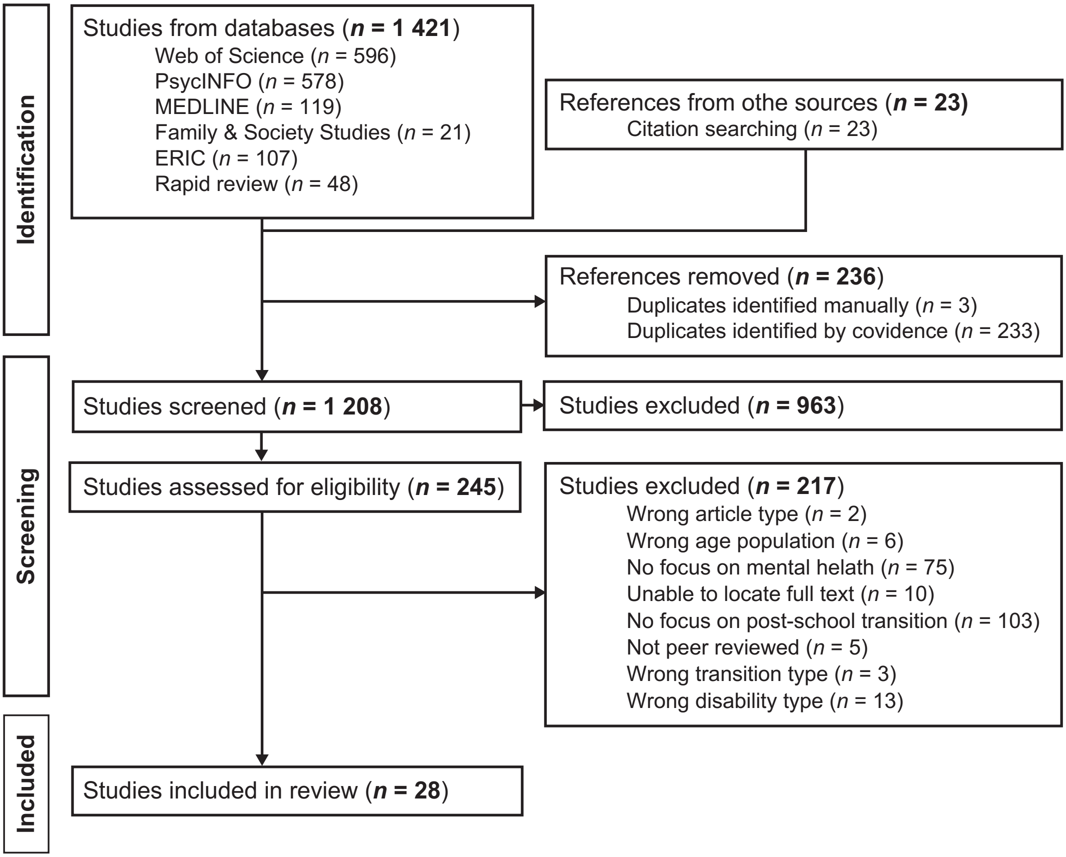

Figure 1. PRISMA diagram outlining search results and article selection and inclusion process

that met the review criteria and were included in the final review including primary research articles (*n* = 24) and reviews (*n* = 4). Inter-rater reliability between the screening authors revealed a Cohen's kappa score of 0.65 for the title and abstract screening and 0.93 for the full-text screening. The characteristics of the included articles (aim, country, year of publication, study population, diagnosis, setting/context, methods and design) are presented in Table 3.

Across the 28 included articles, the most common disability type addressed was autism (referred to in the articles as either autism, Autism Spectrum Disorder (ASD), Asperger's Syndrome, or high functioning ASD). Articles were published between 2011 and 2023. The following countries were represented in the included articles: United States (*n* = 13), UK (*n* = 6), Canada (*n* = 5), and Australia (*n* = 4). Of the included articles that collected data, 19 were conducted with young adults (students, transition program members); three were conducted with young people and their parents/guardians; one was conducted with young people, their parents/guardians and professionals; and one with parents/guardians only. Thirteen articles used a quantitative approach (descriptive, cross-sectional, longitudinal), eight articles applied a qualitative study design (using semi-structured interviews, focus group interviews, photovoice, and/or observations), and three articles used a mixed methods design.

Review findings

Based on JBI scoping review guidelines, findings are presented according to the data interrogation questions that guided the synthesis (see Table 2).

How is IDD characterised in the literature on mental health for young people with IDD during the post-school transition period?

Most included articles (*n* = 20) focused on autism (Anderson & Butt, 2017; Bell et al., 2017; Bennett et al., 2018; Cheak-Zamora et al., 2015; Cribb et al., 2019; Di Rezze et al., 2023; Elias et al., 2023; Giarelli & Fisher, 2013; Hatfield et al., 2017, 2018; Hughes et al., 2024; Hughes, Kirby, et al., 2023; Hughes, Shaw, et al., 2023; Kirby et al., 2020; Lam et al., 2020; Lei et al., 2020; Pillay et al., 2022; Senland & Higgins-D'Alessandro, 2016; Tesfaye et al., 2023; White et al., 2021). Among these, four studies excluded participants with co-occurring ID or participants with intelligence quotients (IQs) below a certain score (Hatfield et al., 2017; Kirby et al., 2020; Pillay et al., 2022; Senland & Higgins-D'Alessandro, 2016; White et al., 2021). Four articles focused on intellectual disability (Forte et al., 2011; Young et al., 2016; Young-Southward, Cooper, et al., 2017; Young-Southward, Philo, et al., 2017), two focused on learning disability (Dubois et al., 2023; Thapa et al., 2023), and two on Foetal Alcohol Syndrome Disorder (Coons-Harding et al., 2019; Gault et al., 2023). None of the included articles specifically used IDD terminology, instead referencing specific diagnoses.

Overall, there was a lack of diversity among study participants in terms of their cognitive and or communication functioning and their schooling environment. Most articles, for example, did not explicitly include young people with complex support and/or communication needs. Further, all the included articles (except for a study conducted by Lam et al. (2020) who used a photovoice approach) adopted more conventional approaches to data collection (such as interviews and surveys), which often exclude young people with more complex needs or who used alternative forms of communication (Mietola et al., 2017). Some articles (*n* = 6) explicitly excluded participants with co-occurring ID and/or based eligibility on intellectual functioning (e.g., IQ score). There was also a lack of diversity regarding experiences of mainstream and specialist education. In most articles participants were either in one setting or the other. Few articles addressed how experiences may differ across educational settings.

How are post-school transitions defined and studied and are these transitions examined in relation to mental health?

The scoping review identified a diverse range of definitions and approaches used to conceptualise and study post-school transitions for young people with IDD, particularly in relation to mental health. Post-school transitions were primarily characterised (*n* = 10) as transitions to adulthood

Table 3.Characteristics of included articles

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Anderson (2017) USA	Investigate outcomes for young adults with ASD, including achievement at college	Young adults with ASD Families with a young adult with ASD who had left high school in the last 15 years. *n* = 18	Qualitative study Unstructured interviews with adults with ASD and their families. Interviews were mostly led by participants and what was important to them with regards to leaving high school.	Families and young adults with ASD shared diverse experiences related to postsecondary education and varying levels of education. Four main themes relating to how well a student was able to cope and perform at college emerged from participant varied narratives: Preparation Beyond Academics, Student/College Fit, Campus Supports, and Family Supports.
Bell (2017) UK	Explore how young people with ASD experienced transition at two separate time points: (i) pre-transition, and (ii) post-transition.	High school students with ASD. Subset of students with ASD taken from larger study investigating Special Education Needs (SEN). *n* = 6 at follow-up	Qualitative study. Semi-structured interviews pre- and post- transition phase. Asked questions about initial transition experience; academic engagement with post-secondary education setting; social engagement with post-secondary education setting; participant sense of belonging in the new setting; their own health and well-being; perceived effectiveness of supports provided; and perceived barriers to participation.	Students had a variety of ambitions regarding post-secondary education varying outcomes. All had positive relationships with support staff and said career guidance was appreciated. However, some lacked specific knowledge needed to support transition pathways. Students reported facing heightened pressures related to examinations and feelings of apprehension.
Bennett (2018) USA	Discuss common issues surrounding transition to adulthood in youth with ASD.	Focused on transition-aged youth with ASD.	Narrative review and opinion article. Review recent evidence on co-occurring medical and mental health conditions and topics of education and employment, sexuality and relationships, independent living, and financial support.	Psychiatric conditions are prevalent in ASD, with increased suicide risk. College attendance for ASD individuals is low, and employment rates are poor, especially for those with severe impairments or comorbidities. Transition narratives highlight anxiety due to limited services. Socialisation programs are crucial, with high school experiences mixed.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Cheak-Zamora et al. (2015) USA	Explore the perspectives of adolescents with ASD and their caregivers by examining their social, education and vocational needs.	Youth with ASD and their caregivers. Young people were predominately male, and caregivers were predominately female and lived in the same home. *n* = 13 (youth, 15 to 22 years) *N* = 19 (caregivers *n* = 1, *n* = 18 parents)	Qualitative study. Focus groups. Questions regarding service needs, barriers and coordination, as well as general issues around youth and transition to adulthood.	Both groups felt fear and anxiety about the transition process and had unmet needs, leading to caregivers struggling to bridge these gaps. Many caregivers and youth noted a lack of personalised services. Caregivers found it challenging to motivate youth and provide educational and employment opportunities. While the youth had future aspirations, they were unsure of how to achieve them and were reluctant to discuss their plans with their caregivers.
Coons-Harding et al. (2019) Canada	Review the literature on transition planning processes for youth with FASD across Canada as well as to identify and gather existing transition planning tools.	Reviewed instruments and guidelines available across Canadian states.	Narrative Review. Peer reviewed literature and grey literature.	The study identified common themes/factors for successful transition to adulthood for young people with FASD including planning, starting early, having a timeline, having a designated transition plan coordinator and including the voices of young people themselves in the planning. The review showed commonality between tools with regards to factors included, but they placed different emphasis on various aspects of the youth's life (e.g., biological, psychosocial), and have very limited agreement on who bears the responsibility for the transition planning process.
Cribb et al. (2019) Australia	Explore people's subjective experiences of growing up autistic and their aspirations for the future.	Youth with ASD and their parents Participants were part of an existing longitudinal study. Young people were majority male (*n* = 26) *n* = 28 (young people, 16 to 20 years)	Qualitative study. Young people and parents were interviewed separately. Young people were asked questions about experiences of school and goals for the future. Parents were asked about their perspective on their child's experience of school, their ambitions for their child's future and the extent to which they felt being autistic impacted on their child's current and future lives.	Young people highlighted school stress and the need to address mental health in transitioning. They valued deep connections but noted reduced social networks after high school. Parents struggled to access support, citing low school aspirations and rigid systems, identifying mental health as a major challenge in their children's transition to adulthood.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
DiRezze (2022) Canada	Describe and evaluate the Job-Train Program (JTP), a vocational program for autistic high school students	High school students with ASD. Primary inclusion criteria were a diagnosis of autism, absence of aggressive behaviour, ability to manage the curriculum, and sufficient independence in self-care to participate in the group. Majority of participants were male with an average IQ. *n* = 12 (15 to 18 years)	Mixed-methods study. Quantitative measures were collected using a pre–post design. Qualitative data were collected post program to examine the perspectives on program delivery and variables impacting skill acquisition. The primary quantitative measure was the Canadian Occupational Performance Measure (COPM) – measure of an individual's change in self-perceived performance for specific tasks. Parents independently completed the Child Behaviour Problems Checklist pre–post to examine any changes in mental health state while involved in the program. Qualitative data were collected from youth, parents, job coaches, and employers approximately 2 weeks post program using varied data collection methods.	Positive changes in youth in terms of their self-esteem and independence after participating in the job program. There were also improvements in social communication skills and understanding of the world of work. The peer support group and family support were also helpful. Employer education about the strengths, abilities, and learning styles of autistic youth in combination with first-hand experience of youth themselves enhanced workplace capacity. Youth experienced a modest mean decrease in internalising and externalising symptoms.
Dubois et al. (2022) Canada	Test the role of autonomy support and motivation in predicting transition status and well-being among youth with LD.	Participants were in the last year of a work-study program. *n* = 218 (15 to 21 years)	Quantitative study. Participants were surveyed at the end of the school year and 1 year later. Transition Status was a dichotomised variable ('not transited' or 'transited') based on their main occupation. Those who reported employment as their main occupation were classified as transited. Those who had no occupation, who were studying, volunteering, or searching for work, fell into the 'not transitioned' category. Mental health was measured using the Warwick-Edinburgh Mental Well-being Scale.	Two structural equation models were tested: One with the transition status as the outcome and one with well-being. Analyses revealed that autonomy support from fathers was positively associated with autonomous motivation in both models, as was autonomy support from friends in the transition status model. Autonomous motivation positively predicted both outcomes, while controlled motivation negatively predicted them.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Elias et al. (2023) USA	Describe the development and initial psychometric testing of the Transition Readiness Scale (TRS), which was developed to assess autistic students' academic and psychosocial preparedness for transition to postsecondary education.	Students with ASD. Participants in a randomised controlled trial. All participants were 'cognitively able'. *n* = 23 (mean age = 17.18 years)	Quantitative study. Completed assessment materials as part of their participation in a randomised controlled trial. The TRS was designed to assess thoughts, feelings, and behaviours related to transition readiness. Mental health was measured using the Beck Depression Inventory-II and Beck Anxiety Inventory	Results provide preliminary psychometric data indicating that the measure is appropriate for an autistic population. Findings also showed that the instrument functions independently of intellectual ability, self-report autistic presentation, and self-report psychiatric co-occurring presenting problems.
Forte et al. (2011) UK	Examine worries experienced by young people with mild ID during transition to adulthood.	Students with mild to moderate ID Participants attended a Further Education college. *N* = 26 (ID) (mean age = 18.23 years; *n* = 16 male) *n* = 26 (TD) (mean age = 18.07 years; *n* = 15 male)	Mixed methods study. Semi-structured interviews to establish a dialogue about these young people's worries, and then to ask them to identify their four most salient worries. Mental health measured using the Glasgow Anxiety Scale-ID (GAS-ID).	Most salient worries for the ID group (e.g., being bullied) were largely different from their non-disabled peers (e.g., getting a job) at this stage of transition. Not only was there a difference in worries expressed, but the intellectually disabled group also reported ruminating significantly more about their worries and being more distressed by them.
Gault et al. (2023) Canada	Review the literature that examined strategies, programs, and/or supports for youth with FASD entering adulthood	*N* = 21 papers.	Scoping review. Inclusion criteria: published in English, 2005 to 2020, youth aged 15 to 30, full-text available, focus on FASD, formal support.	The review included 21 peer-reviewed sources, focusing on three main areas: (i) programs supporting youth with FASD and their families, (ii) lived experiences during the transition to adulthood, and (iii) preventing adverse outcomes. Recommendations emphasised the need for programs that understand FASD and prioritise relationship-building, the benefits of obtaining an FASD diagnosis, the significant service gap for adults with FASD, and the importance of consistent advocates for youth with FASD.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Giarelli and Fisher (2013) USA	Describe the phenomenon of transition from secondary school to community among adolescents and young adults with AS.	High school students with AS. Participants were in the last year of secondary school or within 8 months graduated. *n* = 13 (adolescents) *n* = 13 (parents) *n* = 10 (teachers and employers)	Qualitative study. Grounded theory study. Interviews were audiotaped with parents, adolescents and teachers. Data generated on self-determination, identification and pursuit of goals, perception of problems, barriers and feelings associated with TC. Teachers and employers described their experiences with employees on the autism spectrum. Data were analysed using constant comparison including theoretical sampling.	The core psychosocial problem of transition to community is to stay steadfast and have a predictable and 'steady' lifestyle and routine. Adolescents, with the support of parents, teachers and sympathetic employers solved this problem by using three psychosocial processes of structuring (e.g., planned reorganisation of situational factors to positively influence the adolescent's ability to transition), anchoring (e.g., attachment to another person as the source of security), and embarking (e.g., making way or moving under one's own power in the direction of a self-identified, realistic goal).
Hatfield et al. (2017) Australia	Determine the effectiveness of the BOOST-A in improving self-determination among adolescents on the autism spectrum. The secondary aim was to determine the program's impact on quality of life; access to environmental supports; career planning and exploration; and domain-specific self-determination among adolescents on the autism spectrum.	Adolescents on the autism spectrum. Adolescents participating in an RCT assessing BOOST-A (an online program that aims to support adolescents on the autism spectrum with their transition from high school). Participants had to be enrolled in years 8 to 11 at school and could write at a year 5 reading level and possess basic computer skills. Were ineligible if they had a co-occurring diagnosis of ID. *n* = 49 (intervention) *n* = 45 (control)	Quantitative study. Career planning and exploration was measured by the Career Development Inventory - Australia - Short Form (CDI-A). Transition Planning Objectives Scale was designed for this trial to evaluate the transition planning objectives identified in the needs assessment. Quality of life was measured by the Personal Well-being Index-School Children (PWI-SC).	The BOOST-A led to a significant increase in career awareness among participants. There were no significant differences between the intervention and control groups for the primary outcome of overall self-determination. No significant differences were found in career planning, which is the amount of planning that has been completed. For both groups, adolescent quality of life decreased, whilst happiness with life increased. The overall reduction in quality of life during adolescence is consistent with a decrease in quality of life that is seen in mid to late adolescence for the general population. Overall quality of life for both groups was below the normative range for Australia, which is between 73.4 and 76.4 points out of 100.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Hatfield et al. (2018) Australia	Conduct a needs assessment to determine the predisposing, reinforcing and enabling factors that impact on successful transition for adolescents on the autism spectrum. A secondary aim was to link these factors to perceptions of current and ideal transition planning processes.	Adolescents or young adults on the autism spectrum without ID. Participants were in years 9 to 12 in high school or who had finished high school in the past 5 years; parents/carers of adolescents who fit the above criteria; and professionals who worked with adolescents on the autism spectrum in transition planning. *n* = 26 (adolescents) *n* = 83 (parents) *n* = 53 (professionals)	Quantitative study. Participants answered questions about their experiences with transition planning and what they would prefer to happen. Participants were asked about the following aspects of transition planning: the school year that transition planning starts; composition of the transition planning team; team coordinator; transition planning assessment; frequency of transition planning meetings; documentation of the transition plan and transition planning activities.	Factors for successful transition planning included coordination, strengths-based approaches, team support, and skill development. Most participants desired earlier planning and preferred the same coordinator. Training priorities varied, with professionals and parents wanting more frequent meetings and a different format for the plan. Motivation, insight, and anxiety were key considerations alongside autism-specific needs.
Hughes et al. (2023) USA	Describe the health status and educational transition plans of adolescents with ASD.	Young people with ASD. Participants were children born in 2002 whose health and education records were reviewed for ASD surveillance in the 2010 Autism and Developmental Disabilities Monitoring (ADDM) Network. *n* = 1 846 children identified in the community.	Quantitative study. Data was taken from the ADDM which included IEPs. Select data was analysed from IEPs from ages 9 to 16 years, including whether a child ever had a transition plan, an assessment of transition needs, a course of study to meet post-secondary goal(s), and postsecondary goals for education/training, career/ employment, and independent living skills/ daily living skills/community participation. Mental health was measured using ADDM Network staff clinicians' documentation of whether children had ever been diagnosed with anxiety, depression, or obsessive-compulsive disorder or had documentation of self-injurious or aggressive behaviour.	The prevalence of neuropsychological conditions increased significantly from age 8 to 16 in children with ASD, with anxiety, depression, and epilepsy more common in females by age 16. ADHD and anxiety were the most prevalent conditions. Transition plans were associated with IEP for 94.3% of participants, with fewer plans for those with intellectual disability (ID). Goals varied, with fewer focusing on independent living skills for those without ID.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Hughes et al. (2023) USA	The study aimed to analyse the contents of IEPs for adolescents with autism spectrum disorder (ASD). It focused on examining postsecondary transition goals, services provided, and changes in special education classification over time.	Population-based surveillance cohort from the Autism Developmental Disabilities Monitoring Network from 2002 to 2018 in 3 catchment areas in the United States. Participants were adolescents who were born in 2002, identified with ASD, and had an IEP available for review at ages 15 to 16 years. *n* = 322	Quantitative study. Data elements were collected from IEPs including whether a transition plan section was included in the records and free-text responses describing post-secondary goals for education/training, employment/career, and independent living skills/daily living skills/ community participation. Anticipated job positions for adolescents listed by IEP teams based on an assessment or knowledge of the adolescent's goals or interests were also collected. Data was also collected (from the IEP) on mental health school services offered through school.	The study found that 92% of adolescents with ASD had an IEP with a transition plan. Those without intellectual disability (ID) were more likely to have goals related to higher education and competitive employment. 41% had a goal for post-secondary living arrangements. While 28% received school-based mental health services, none were Black; 15% of those with ID received mental health services compared to 34% without ID. The percentage of adolescents served under an autism classification increased from 44% at age 8 to 62% by age 16.
Hughes et al. (2024) USA	Describe the frequency of selected co-occurring health conditions and IEP services and post-high school transition planning for adolescents with autism spectrum disorder	Population-based surveillance cohort from the Autism Developmental Disabilities Monitoring Network. Participants were adolescents who were born in 2004, identified with ASD. *n* = 1 787	Quantitative study. Data from a student's most recent IEP from ages 15 and 16 years. From the transition plan section of the IEP, additional information was collected, including whether (i) a transition plan was completed, (ii) there was an assessment of transition needs, (iii) there was a course of study to reach post-secondary goal(s), and (iv) post-secondary goals were stated for education, employment, and independent living skills (includes daily living skills and community participation). The anticipated high school diploma type was collected (regular or alternate). Collected historical and current diagnoses of the selected co-occurring conditions (including mental illness).	ADHD (47%) and anxiety (39%) were the most common co-occurring conditions among adolescents with autism. Those without intellectual disability (ID) were more likely to be diagnosed with ADHD, anxiety, depression, or have documented suicidal behaviour or ideation. Among students aged 15 to 16 receiving special education services (*n* = 482), 69% were served under autism eligibility. Those with ID were more likely to receive extended school year services and therapies (speech, occupational, physical), but less likely to receive mental health services. Most students (94%) had a transition plan in their latest IEP, with over 90% including assessments of transition needs, courses of study, and postsecondary goals for education and employment. There was a decline in the number of IEPs completed in March, April, and December 2020 compared to the same months from 2013-2019, likely due to the pandemic and virtual schooling.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Kirby et al. (2020) USA	Expand understanding of transition preparation and the role and influence of parental factors.	Parents of youth with ASD who were still in high school and did not have an intellectual disability. *n* = 236 (mothers) *n* = 23 (fathers) *n* = 6 (other primary caregivers)	Quantitative study. The Transition Preparation Activities Measure (T-PAM) was a 6-item measure developed by the researchers. It included 14 questions about the frequency of various activities that the respondent and/or the youth have engaged in over the past month (such as receiving transition-related school services, working towards goals for the future). The Adulthood Expectations Questionnaire (AEQ) is a 12-item measure developed by the research team and includes questions about parent perspectives on the likelihood that youth will achieve various adult outcomes. The Perceived Stress Scale (PSS-10) is a widely used and well-validated measure of psychological stress.	The T-PAM identified parent-youth discussions and youth chores as common transition preparation activities. Parents with higher self-efficacy and expectations engaged more in preparation activities, particularly as youth aged. Factors predicting greater readiness included parent expectations, transition activities, and youth age without anxiety diagnosis or social challenges. Parents expressed concerns about their child's independence, social skills, career prospects, financial management, safety, and health, including mental well-being.
Lam et al. (2020) UK	Understand well-being as perceived and defined by young adults with autism.	Young adults with ASD. Participants were part of a transition program designed for young adults with ASD between the ages of 18 and 25. *n* = 14	Qualitative study. The primary design of the study involved the methodology of Photovoice.	Three main themes were identified: self and personal growth (e.g., self-identify, interests); close relationships (e.g., family); and community connections.
Lei et al. (2020) UK	Describe the short-term outcomes of a pre-transitional program in the form of a summer school for autistic students wishing to attend University.	Autistic students. Students involved in the Autism Summer School - for autistic students (16 to 19 years) who are wanting to attend/apply to university. *n* = 122	Quantitative study. Evaluation of a summer school program designed to prepare autistic students for university life and promote self-care and well-being when at university. The evaluation was a survey that included the Transition to University Questionnaire (TUQ) - a 26-item self-report questionnaire.	Participants reported an average of 15.14 worries (SD = 5.34) and a mean total concern score of 65.92 (SD = 25.55). Seven subscales were derived through factor analysis, covering micro and macro social concerns, leaving home, academic challenges, daily living skills, and time management. The autism summer school was highly enjoyable and helpful, while attitudes towards university were somewhat positive across all years.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Pillay et al. (2022) Australia	Understand the transition journey over time for autistic young adults and examine the potential risk and protective factors associated with both successful and unsuccessful transition during this time.	Young adults with autism. Participants were young adults diagnosed with autism living in Australia. Participants were excluded if they have intellectual disability. They were aged between 19 to 25 years. Most participants were female. *n* = 9	Quantitative study. Participants completed an online survey at two time points. Self-report evaluations of transition planning and intervention received at high school, engagement in post-secondary education, access to employment, living circumstances, and social support. The QoLQ is a 40-item self-report scale designed to measure the QoL of autistic individuals and those with a disability.	Social support appeared as a common protective factor for those participants who were unemployed during transition. With regards to risk factors associated with poorer transition, functional independence and unemployment were evident for many as was mental health problems, however, the type of mental health problem differed between participants.
Senland et al. (2016) USA	Investigate sociomoral reasoning, empathy, and challenging and supportive factors during the transition to adulthood in emerging adults (18-27-years-old) with ASD to better understand how these variables facilitated positive developmental outcomes.	Emerging adults (18 to 27-years-old) with ASD. Participants were part of a larger study including young adults with nonverbal learning disability. *n* = 22 (ASD) *n* = 22 (TD)	Mixed methods study. An adapted version of a developmental outcomes measure examined participants' ability to meet developmental tasks associated with young adulthood in three domains: education and employment, friendships, and independence. Difficult Real-Life Sociomoral Situations Interview-Expanded Version (DRLSSI-EV) - asked participants to recall a personal challenging sociomoral situation and to identify and describe factors that were most helpful and that were least helpful as they moved into young adulthood. Interpersonal Reactivity Index (IRI) – measures cognitive and affective empathy. The personal distress (PD) subscale measures anxiety in stressful emotional situations.	The TD group exhibited better developmental outcomes than the ASD group, who faced more challenges with social conflict, isolation, and bullying. Both groups valued informal support during the transition, but the ASD group highlighted the role of transitional living programs in developing skills. TD individuals emphasised personal qualities aiding transition, while both groups faced challenges from peers, family, and support programs, with ASD individuals also encountering pressure from service providers and extended support networks.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Tesfaye et al. (2023) Canada	Understand the factors that help or hinder autistic youth in various environments and social relationships, as well as their future aspirations and hopes. The insights gathered will provide a deeper understanding of what is important to autistic youth and how to better support them during adolescence and transitional periods.	Participants were part of the Pathways to Better Outcomes in ASD study, a longitudinal Canadian inception cohort with a group of autistic youth with various language and cognitive abilities. *n* = 31 (6 female and 26 male; aged 11-18 years)	Qualitative study. Data taken from the Autism Voices interviews that were conducted as part of the Pathways to Better Outcomes in ASD study. Semi-structured interview with pre-determined activities and topics to explore. The interview included an ordering activity wherein the participant was asked to order four topics (family, friends, future, and school) according to what worried them from most to least. These topics were then discussed from the most to least worrisome. Participants were also queried about their experience with various emotions such as sadness, anger, happiness, and stress.	Based on a thematic analysis, six themes emerged: (i) autistic identities (conveyed that they were “OK” with their autism diagnosis, but desired greater accessibility and reduced stigma in their environments), (ii) thinking about the future (future is a significant concern for the participants, but their perspectives and strategies for navigating it vary widely), (iii) seeking social connection on their own terms, (iv) seeking autonomy (desire for more autonomy and independent decision-making, but also recognised the need for ongoing support), (v) school as both a stressor and social facilitator, and (vi) experiences of stress and anxiety (School and the future were identified as primary stressors, but manifestations of anxiety and stress were evident across all subjects).
Thapa et al. (2023) USA	Investigate internal and external factors that influence the post high school success of young adults with learning disabilities.	Students with LD. Participants were graduates of a specialised school for students with learning disabilities. *n* = 36 (23 to 30 years; *n* = 20 female).	Qualitative study. Interviews occurred between 5 and 10 years after their high school graduation. The interview included questions regarding educational achievement, employment attainment and accomplishments, social and familial relationships, and life satisfaction. Participants were asked to describe components of school life that improved their experience within the school and to share their suggestions for what might have improved their experience.	Success among participants wasn’t linked to psychological or socio-emotional difficulties but to seeking treatment and support. Optimism and clear goals distinguished more successful individuals, who sought help when needed and saw their learning disability as part of their identity. Less successful participants struggled with relationships and felt hindered by their disability. Successful participants found fulfilling careers, were confident in facing challenges, and valued school support but suggested improvements in curriculum, college preparation, and life skills training.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
White et al. (2021) USA	RCT to evaluate the feasibility and preliminary efficacy of the Stepped Transition in Education Program for Students with ASD (STEPS).	Students with ASD in the STEPS program. Participants were excluded if they had intellectual disability. *n* = 59 (16 to 25 years)	Quantitative study. Student Adaptation to College Questionnaire (SACQ) - a self-report measure designed to examine postsecondary student adjustment in the academic, social, personal-emotional, and goal commitment domains. Transition Readiness Scale (TRS) - a 30-item measure available in student, parent, and educator formats. Mental health was measured using the Anxiety Disorders Interview Schedule for DSM-5 (ADIS-5) or the Anxiety Disorders Interview Schedule for DSM-5-Child and Parent Versions (ADIS-5-C/P).	Comorbidity was prevalent, with most participants exhibiting at least one secondary psychiatric disorder. High school students who underwent STEP 1 showed enhanced transition readiness, while STEP 2 recipients, post-secondary, improved college adjustment. Mental health issues hindered response to STEP 2, but self-determination predicted retention of gains. ASD severity predicted a decline in adjustment post-program. Addressing mental health alongside core ASD symptoms may optimise transition service effectiveness.
Young et al. (2016) UK	Explore the content of the worry of adolescents with IDs and their non-intellectually disabled peers to identify if there were differences between the groups.	Students with ID. Participants were young people with ID aged 15 and 18 years. Participants attended special education schools and had IQ scores that fell within the mild to moderate learning disability range. *n* =25 (ID) *n* = 27 (non-ID)	Mixed methods study. The interview was used to gather information on the participants most salient worries and the extent of the distress and frequency of rumination caused by these worries. It used a semi-structured format and pictorial representations of carefully identified ‘worry topics’ to establish a dialogue about the participants’ worries. The worry topics covered the following areas: school, further education, family, friendship, relationships, bullying, loneliness, work, money, home, appearance, health, decisions, failure and death.	At the time of transition from school, the adolescents with IDs were more concerned about death, relationships, bullying and decisions than those without. The adolescents with IDs specified that they worried about what college courses to pick or what college to go to. There was a significant positive association between distress and anxiety for the ID group: rs = 0.54, $p < 0.01$ indicating a large effect size.

Author, Year & Country of origin	Aim	Description of sample/ articles (if review)	Design/methodology	Key findings
Young-Southward et al. (2017) UK	Describe how transition from school to adulthood affects the health and well-being of individuals with ID.	Young people aged 18-35 with intellectual disability or their parents. *n* = 17 (ID) *n* = 23 (parents)	Mixed method study. The interview guide covered aspects of health and well-being and transition. Mental health was measured using the Strengths and Difficulties Questionnaire (SDQ).	Interview themes encompassed school-to-adulthood transition, health, relationships, support, and growing up. Many youths showed signs of mental health issues, with concerns heightened during transition, affecting both youths and parents. Youths felt underprepared for post-school life and perceived a lack of practical preparation in school. Accessing employment was challenging, contributing to mental health difficulties post-school. Independence was seen as vital but complex.
Young-Southward et al. (2017) UK	Investigate the effect transition has on the health and well-being of young people with intellectual disabilities	17 studies met the inclusion criteria.	Systematic review. Inclusion criteria: the age of participants was within the range 13 to 24 years; participants had intellectual disabilities; both transition and health or well-being were discussed. Published in English and all study methodologies were included.	The review suggests transition can negatively impact health and well-being, though findings are mixed. Five studies highlighted high rates of emotional and behavioural issues persisting into adulthood but not worsening post-transition. Quality of life, assessed in four studies, was notably lower for youths with autism or intellectual disabilities, as reported by parents, across physical, psychological, and social domains compared to normative samples.

Note. ASD = Autism Spectrum Disorder, FASD = Foetal Alcohol Syndrome, LD = Learning Disorder, ID = Intellectual Disability, AS = Asperger Syndrome, RCT = Randomised Control Trial, IEP = Individualised Education Plan, TD = Typical Development.

(Bennett et al., 2018; Cheak-Zamora et al., 2015; Coons-Harding et al., 2019; Forte et al., 2011; Lam et al., 2020; Pillay et al., 2022; Senland & Higgins-D'Alessandro, 2016; Tesfaye et al., 2023; Young-Southward, Cooper, et al., 2017; Young-Southward, Philo, et al., 2017). These articles not only highlighted experiences of leaving high school but also extended to the broader context of adult life, including relationships, health, and independent living, which are crucial aspects linked to mental health outcomes. The transition to adulthood was often portrayed as a pivotal juncture where individuals move from the structured environment of school or family life into a less predictable adult landscape, impacting mental health through the loss of familiar routines, increased independence, and the need to navigate new social and health-related challenges. This shift entailed not only navigating educational or vocational pathways but also negotiating social relationships, managing health and well-being, and establishing a sense of autonomy and independence.

Five articles focused on transition out of high school (Cribb et al., 2019; Giarelli & Fisher, 2013; Hatfield et al., 2018; Thapa et al., 2023; Young et al., 2016), which included aspirations for the future and factors that influence post-school success. These articles addressed not only educational and vocational pathways but also mental health factors, such as participant worries about leaving school and how these worries contribute to anxiety and stress. Four articles focused on transition to higher education (Anderson & Butt, 2017; Bell et al., 2017; Elias et al., 2023; Lei et al., 2020) including preparing students for higher education, assessing what high schools and/or tertiary institutions can do to improve student transitions, or investigating worries about leaving high school and moving into higher education. Two articles concentrated on post-school transition programs (Hatfield et al., 2017; White et al., 2021), both of which were for youth with autism. Hatfield et al. (2017) assessed the effectiveness of an online transition planning program to improve transitions through career planning and self-determination. White et al. (2021) evaluated a program to support students' development of transition readiness. Four articles focused on transition planning (Hughes et al., 2024; Hughes, Kirby, et al., 2023; Hughes, Shaw, et al., 2023; Kirby et al., 2020) which included assessing the number of students with a transition plan in place and effectiveness of this plan, as well as preparation activities (e.g., discussions with parents about leaving school). Two articles focused on transition from school to work, describing a vocational program to increase skills, responsibility and independence (Di Rezze et al., 2023), and the impact of motivation to work (Dubois et al., 2023).

While some of the included articles did address the facilitators to successful transitions for students with IDD (n = 8), there was a scarcity of articles adopting a strengths-based approach to identify effective strategies and interventions that capitalise on the abilities and resources of students with IDD, rather than solely focusing on deficits and barriers. More frequently, articles acknowledged that young people with IDD face barriers in post-school transitions and common themes in relation to barriers emerged in only a small subset of articles (n = 3). Identified barriers encompassed individual barriers (e.g., matters of disability, lack of confidence and self-esteem); interpersonal barriers (e.g., lack of social support or community integration); and systemic barriers (e.g., issues with supports and services; lack of good jobs/post-school environments). In most instances, barriers were raised in relation to post-school transition success.

The studies that addressed individual barriers (n = 5) described a wide range of disability-related factors that may impact post-school transitions; however, difficulties with social skills were the most common. For example, Thapa et al. (2023) discussed successful transitions for young people with learning disability, highlighting that participants who were less successful in post-school transitions felt that their learning disabilities affected all aspects of their lives, including their success at school and confidence in social relationships. Three other articles described individual barriers related to a lack of confidence, self-esteem, and autonomy (Cheak-Zamora et al., 2015; Giarelli & Fisher, 2013; Pillay et al., 2022). Three articles described interpersonal barriers to post-school transitions in their social relationships and integration with the community through the transition period (Giarelli & Fisher, 2013; Pillay et al., 2022; Thapa et al., 2023). Severa; articles discussed systemic barriers to successful post-school transitions (n = 6) including issues with limited services and a lack of appropriate transition plans (Bell et al., 2017; Bennett et al., 2018; Cheak-Zamora et al., 2015; Giarelli & Fisher, 2013; Hughes, Shaw, et al., 2023; Thapa et al., 2023). For example, Cheak-Zamora et al. (2015) interviewed caregivers who described poor services and long waiting lists and that their children went from "being in school all day to waiting for services" (p. 551). Finally, two articles discussed the negative effects of difficulties accessing suitable employment as well as not finding a fulfilling job (Cheak-Zamora et al., 2015; Thapa et al., 2023). A mismatch between employment goals and feasibility (as identified by caregivers) was also noted. For example, Cheak-Zamora et al. (2015) reported that caregivers worried that their youth were interested in jobs that were not achievable, which was a barrier to gaining and maintaining employment.

Barriers to successful transitions frequently intersected with mental health concerns, as many articles identified individual, interpersonal, and systemic factors that contribute to psychological distress during this period. For instance, the lack of confidence, self-esteem, and difficulties with social skills – commonly noted as barriers – were often directly linked to poor mental health outcomes, highlighting the cyclical nature of these challenges (Cheak-Zamora et al., 2015; Giarelli & Fisher, 2013; Pillay et al., 2022; Thapa et al., 2023). Articles also noted that systemic barriers, such as inadequate services and support structures, could exacerbate mental health issues, since young people often find themselves navigating critical life transitions without adequate resources (Bell et al., 2017; Cheak-Zamora et al., 2015).

In summary, the literature on post-school transitions for young people with IDD provides a multifaceted understanding of this critical phase of life. Defined primarily in the literature as the transition to adulthood, encompassing movements from high school to various post-school settings and the preparation for adult life, the literature highlights the complexities and challenges faced by individuals with IDD during this period. There was limited exploration of the intersectionality between post-school transitions and mental health outcomes, as well as a need for more comprehensive examinations of the barriers and facilitators involved in successful transitions for individuals with IDD in navigating the transition to adulthood.

How is mental health defined and studied during the post-school transition period?

An explicit focus on the mental health of young people with IDD transitioning from high school was largely absent from the literature. Mental health was rarely prioritised as a primary aim or thoroughly examined in planned analyses. Instead, it was often addressed tangentially, such as when reported as a co-occurring condition, as a means of describing the sample (i.e., reporting proportions of young people with depression, or depressive symptoms) (Bennett et al., 2018; Elias et al., 2023; Hughes, Shaw, et al., 2023; Kirby et al., 2020; Pillay et al., 2022; White et al., 2021), or as a covariate. In two studies mental health was measured as an intervention outcome (Hatfield et al., 2017; Lei et al., 2020). Mental health was also included as a difficulty in post-school transition success, such as anxiety and worry around leaving school, which was often raised as impacting mental health (Dubois et al., 2023; Forte et al., 2011; Hatfield et al., 2018; Lam et al., 2020; Senland & Higgins-D'Alessandro, 2016; Tesfaye et al., 2023; Thapa et al., 2023; Young et al., 2016). The remaining articles addressed mental health in the results as part of review findings (Coons-Harding et al., 2019) or when raised spontaneously (i.e., without any prompting) by interview participants (Anderson & Butt, 2017; Bell et al., 2017; Cheak-Zamora et al., 2015; Cribb et al., 2019; Di Rezze et al., 2023; Giarelli & Fisher, 2013).

Only three articles explicitly focused on mental health in the context of the post-school transition period, and while there were other papers that addressed mental health, these were the only ones that did so directly as an a-priori focus. Young-Southward, Philo, et al. (2017) conducted a systematic review of 17 articles to investigate the effect transition to adulthood has on the health and well-being of young people with ID and noted that obesity and sexual health issues were the most commonly reported concern for young people with ID during the transition to adulthood. They also reported negative experiences (such as not having social contacts or vocational opportunities) during the transition, and they reasoned this could result in poor health and well-being outcomes for young adults in this population. The second article, published shortly after, was a mixed-methods study (Young-Southward, Cooper, et al., 2017), which aimed to explore the transition experiences of individuals with ID with a specific focus on identifying the health or well-being implications of these transitions. Findings from semi-structured interviews with 17 young people with mild, moderate, and severe ID, aged 16 to 27 years, revealed that participants experienced heightened anxiety during the transition period. Key themes contributing to this anxiety included a lack of meaningful activity following school exit, inadequate support during the transition, and the difficulties associated with growing up. Finally, Tesfaye et al. (2023) primarily focused on worry, conducting interviews with 31 participants (6 female and 26 male) from the Pathways to Better Outcomes in ASD study, a longitudinal Canadian inception cohort. The interviews included an ordering activity where participants were asked to rank four topics (family, friends, future, and school) based on what worried them the most to the least. Participants were also questioned about their experiences with various emotions, such as sadness, anger, happiness, and stress. Findings indicated that stress and anxiety were pervasive among participants, with these challenges frequently mentioned across multiple topics throughout their interviews.

To what extent are community members with lived experience included in the design or production of the research?

Three articles included community involvement in the design or production of the research. In one of the included articles (Tesfaye et al., 2023), the methods of the project were informed by the lived experiences of parents caring for an autistic child and autistic participants who assessed the suitability of the approaches and methods. Pillay et al. (2022) administered a survey to participants that was peer reviewed by a group of young autistic adults. This led to the inclusion of numerous items in the survey that would not have been identified otherwise. This study did, however, exclude participants with co-occurring ID. The second study utilised a participatory action research (PAR) design (Lam et al., 2020) distinguishing participants in their study from passive subjects often found in ‘conventional’ research. The authors intentionally shared the power of decision-making over the course of the study, ensuring participants were actively involved in discussing research questions, making decisions about methodological approaches, collecting and discussing their data (photos), and disseminating the findings.

Discussion

This scoping review highlighted that research investigating post-school transitions and mental health for young people with IDD generally explored post-school transition experiences for young people with autism and there was a dearth of research investigating post-school transitions spanning a broader array of IDD diagnoses. Furthermore, mental health emerged sporadically in the reviewed articles, often as an incidental finding rather than a primary focus of investigation. Most studies were from high-income countries and were qualitative in nature. Disability inclusive research practices were also uncommon. However, the methodological rigour of the included studies was generally strong, with a diverse range of approaches employed, including qualitative, quantitative, mixed methods, reviews, and randomised controlled trials (RCTs). Sample sizes were mostly appropriate, and researchers utilised a mix of validated and novel scales to measure outcomes. Additionally, research questions were typically well-defined, contributing to the robustness of the findings. Despite these strengths, the narrow focus on autism and the incidental nature of mental health findings point to significant gaps in the literature that warrant further exploration.

The most noteworthy finding of this scoping review is the limited research focusing on mental health during the post-school transition phase. Mental health was rarely defined as an a-priori aim, and this lack of attention could be attributed to several factors. The heterogeneous nature of IDD presents challenges in establishing standardised criteria for defining and assessing mental health outcomes (Pinals et al., 2022). Another potential barrier to defining and researching mental health outcomes for young people with IDD is a phenomenon known as diagnostic overshadowing. Diagnostic overshadowing, where symptoms of mental health issues might be misattributed to the individual’s IDD, can lead to underdiagnosis or inappropriate treatment (Dell’Armo & Tassé, 2024).

Additionally, mental health issues have been historically overlooked within disability research (Razza et al., 2014), which may have perpetuated a lack of focus on this critical aspect of post-school transitions for individuals with IDD. The consequences of this gap in research and definition are manifold. Without a clear understanding of what constitutes mental health and how to measure it effectively, school-based interventions and support services tailored to address the unique needs of young people with IDD during post-school transitions may be insufficient or inappropriate. This can lead to increased vulnerability to mental health challenges, decreased quality of life, and reduced social inclusion and participation in community life. Moreover, the absence of robust evidence on mental health outcomes may impede policymakers, educators, and service providers in making informed decisions regarding resource allocation and program development aimed at supporting this population during the crucial transition period from school to adulthood. Recent systematic reviews, such as those by Halvorsen et al. (2023, 2024), provided valuable insights into the suitability of various measures for assessing mental health difficulties in individuals with IDD. These reviews document the applicability and psychometric properties of general mental health assessment tools, specifically highlighting the challenges in adapting tools originally developed for the general population to individuals with intellectual disabilities and autism. For instance, Halvorsen et al. (2024) evaluated tools used for autistic individuals and underscored the need for a greater evidence-base for mental health assessment tools for autistic people. Similarly, Halvorsen et al. (2023) reviewed mental health measurement tools for children and adolescents with intellectual disabilities, emphasising that while some tools have adequate reliability and validity, standardised ID instruments are the most appropriate for this population. These findings point to a critical need for more tailored assessment tools alongside assessment of their appropriateness that accurately capture the unique mental health challenges faced by young people with IDD, particularly during the vulnerable post-school transition period. Without using such validated tools in research, it remains difficult to effectively measure and address mental health needs, further complicating efforts to develop targeted interventions and support systems (Flynn et al., 2017). Furthermore, addressing the dearth of a-priori definitions and rigorous research on mental health, using appropriate tools, in the context of post-school transitions for young people with IDD is crucial for promoting better health and well-being.

A noticeable trend observed within the reviewed literature is a disproportionate emphasis on young people with autism. Several articles excluded participants with co-occurring intellectual disability. The remaining articles focused on learning disorder, intellectual disability, or foetal alcohol spectrum disorder. However, no articles specifically used DD or IDD terminology suggesting this may not be a widely used term in the literature focusing on disability, post-school transitions, and mental health. There exists a notable gap in the representation of diverse IDD populations within the scholarly discourse which may be because IDD encompasses a broad range of conditions with varying characteristics and support needs. This heterogeneity can make it challenging to conduct research that adequately represents the diverse experiences within these populations. This imbalance may stem from factors such as the higher prevalence and visibility of autism and challenges in accommodating diverse populations in research methodologies. For example, conducting research involving individuals with other conditions under the IDD umbrella may require disability-inclusive and/or methodologies and considerations to accommodate diverse communication styles, support needs, and cognitive abilities which may be perceived as barriers to conducting the research. This may also be the reason for the limited number of articles that utilised disability inclusive research practises. Despite disability-inclusive research being recognised as best practice to ensure that the research addresses the needs and priorities of the community or stakeholders involved (Walmsley et al., 2018), only two articles described how community members with lived or living experience were included in the design and conduct of the research. To address this disparity, future research should be disability-inclusive and prioritise young people spanning a broader spectrum of IDD diagnoses, encompassing conditions such as Down syndrome, cerebral palsy, and intellectual disabilities. By shifting the focus towards a more inclusive representation of IDD populations, researchers can provide a comprehensive understanding of the unique challenges and needs encountered by individuals across the spectrum of intellectual and developmental disabilities. Furthermore, post-school transitions are likely to be more challenging for some young people with intellectual disability or developmental disability (Carter et al., 2012; Wei et al., 2014) and it can be inferred that their mental health outcomes are also likely to be adversely affected. However, a focus on mental health and post-school transition for young people spanning a broader spectrum of IDD diagnoses was lacking. Addressing these gaps is required to conduct inclusive research approaches that encompass the full spectrum of IDDs.

Some articles discussed barriers to successful post-school transition and there was some overlap between articles regarding the barriers addressed. For example, findings from this scoping review revealed that many young people with disability transitioning from high school may experience individual barriers (e.g., matters of disability and identity, lack of confidence and self-esteem), interpersonal barriers (e.g., lack of social support or community integration), and/or systemic barriers (e.g., issues with supports and services, lack of good jobs/post-school environments). While most of these articles were conducted with autistic youth, there were noticeable overlaps between articles that highlighted these barriers and provide insight into the kinds of action and supports that can be taken to assist young people with disability transitioning from high school.

Strengths and limitations of the review

This scoping review demonstrates several key strengths that enhance the comprehensiveness and reliability of the findings. The use of a systematic search strategy across multiple databases and sources ensured a thorough identification of relevant literature on post-school transitions and mental health among young people with IDD. Additionally, the broad inclusion criteria allowed for the exploration of a diverse range of articles encompassing various aspects of post-school transitions and mental health among young people with IDD. By incorporating articles focusing on different intellectual and developmental disabilities (including autism, learning disorders, and intellectual disabilities), the review provides a comprehensive overview of the existing research landscape in this field.

There are also limitations that should be acknowledged. Despite employing a systematic search strategy across multiple databases and sources, it is possible that some relevant articles were missed including articles that use different terminology to describe young people with IDD or the post-school transition period. Furthermore, the scope of this review was limited to English-language literature, which may have led to the exclusion of relevant articles published in other languages.

Conclusion

This review has identified several gaps in the literature surrounding mental health for young people with IDD in the context of the post-school transition period. This review highlights the limited understanding of mental health for young people with IDD transitioning out of high school. To fill these knowledge gaps a mixed-methods approach incorporating creative research methods is needed, utilising disability inclusive research designs. This inclusive strategy is essential for ensuring that the voices and experiences of groups who are marginalised, such as young people with intellectual disability or those who use alternative forms of communication, are heard. By employing techniques such as participatory action research, arts-based methods, or storytelling approaches, researchers can actively engage with these groups. Moreover, employing disability-inclusive research designs that prioritise accessibility and accommodate diverse communication styles can further enhance the inclusivity and validity of the research findings.

Funding statement

This study was supported by an NMHRC Postgraduate Scholarship (#GNT2022116).

Conflict of interest statement

The authors have no conflicts of interest to declare.

Ethical information

Ethics approval for this study was not sought through the University of Melbourne Human Research Ethics Committee as it was not required for a scoping review.

Acknowledgements

We express our gratitude to the co-researchers with lived experience of disability who provided insights into the design of this study and assisted with the interpretation of results. We also extend our thanks to the University of Melbourne librarians who supported this research.

Authorship statement

SD, GS, HD, and AK contributed to the conceptualisation of the study. Methodology was developed by SD and BW. Analysis was conducted by SD and MS. Data curation was managed by SD. The original draft was written by SD, with review and editing by MS, GS, HD, and AK. All authors read and agreed to the published version of the manuscript.

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Supplementary Item 1: Search strategy and key terms

Non-index terms were searched for via all fields. As this search was conducted before the introduction of the DSM-5 (2010) and subsequent rephrasing of mental retardation to intellectual disability, a sensitivity analysis was conducted to ensure our search terms adequately captured any articles using this terminology. No articles were identified as missing, so the below search terms were used in the final analyses.

PsycINFO (Ovid)

Date searched: 17 June 2024

#	Searches	Results
1	(“young adult” or teen* or adolescen* or young people or young person or youth).mp. or exp Emerging Adulthood/	701155
2	(adolescence 13 17 yrs or young adulthood 18 29 yrs).ag.	1026860
3	1 or 2	1276617
4	exp developmental disabilities/ or exp Intellectual Development Disorder/ or exp Intellectual Development Disorder/ or exp Intellectual Development Disorder/ or exp Cognitive Impairment/ or exp Learning Disabilities/ or exp Cerebral Palsy/ or exp Neurodevelopmental Disorders/ or exp mentally disabled persons/ or exp Autism Spectrum Disorders/	294979
5	(developmental disab* or developmental disorder* or intellectual disability or intellectual disab* or intellectual disorder*).mp. or developmental delay*.ti,ab,hw,id. or cognitive disability.ti,ab,hw,id. or learning disability.mp. or down* syndrome.ti,ab,hw,id. or learning disability.mp. or autis*.mp. or ASD.mp.	133507
6	4 or 5	322871
7	exp mental health/	99340
8	(mental illness or Mental Disorders or Well Being or well-being or psychosocial).ti,ab,hw,id.	414353
9	7 or 8	477812
10	exp Post-school Transition Planning/ or exp Transition Planning/ or exp Educational Programs/ or exp School to Work Transition/ or exp Higher Education/ or exp School to Work Transition/	139266
11	(post-school transition or postschool or transition to adulthood).mp.	3457
12	(transition-aged or transition aged or transition planning or post-secondary or post secondary).ti,ab,hw,id.	5110
13	10 or 11 or 12	145408
14	3 and 6 and 9 and 13	329
15	limit 14 to yr=“2000 -Current”	307
16	limit 15 to english language	296