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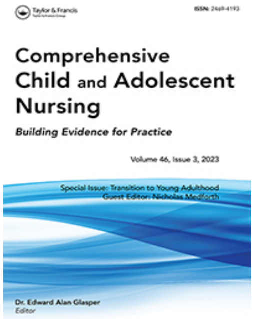

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Challenges, Complexity, and Developments in Transition Services for Young People with Disabilities, Mental Health, and Long-Term Conditions: An Integrative Review

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ABSTRACT

Transition to adulthood for young people is complex and multi-faceted, with additional hurdles for young people who have disabilities, long-term, or life-limiting conditions or mental health problems. The challenges in providing effective transition support are not new; researchers, policymakers, commissioners, and service providers have been grappling with the problem for several decades, with varying degrees of success. The aims of this integrative review were firstly to build on previous research to synthesize and evaluate recently published evidence. Secondly to provide an overview of the effectiveness of interventions (in one or a combination of health, social care, and education transitions) designed to support transition to adulthood in these groups of young people. A search of a range of databases retrieved published literature from January 2015 to January 2021 demonstrating global interest in the topic. Fifty-one articles were included following an appraisal of quality and eligibility. Qualitative, quantitative, mixed methods studies, and evidence synthesis were included. Some studies were clinically orientated whilst others examined the impact of the transition process, or utilized participatory approaches which give young service-users and families a voice. Transition between children's and adult health or care services as well as other life-course trajectories, such as life-skills development, education transitions, social inclusion and employability were evaluated. Thematic analysis and synthesis of articles retrieved in this review highlighted themes identified in previous reviews: timing of, and preparation for transition; perceptions and experience of transition; barriers and facilitators; transition outcomes. Additional themes included special considerations; dealing with complexity; advocacy, participation, autonomy, aspirations, and young people's rights; future work, research, and evaluation. Novel perspectives and diverse data sources contributed to holistic understanding of an ongoing priority for international policy, service development, and research: the complexity of providing effective transition support and achieving positive outcomes for young people with long-term and life-limiting health conditions, disabilities, and mental health difficulties.

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Supporting EvidenceSummary Tables are deposited in Figshare at 10.6084/m9.figshare.22347517

Background

Transition to adulthood for young people in general is complex and multi-faceted. It involves developmental progress across trajectories, such as education to employability; friendships and relationships; family and independence (Thompson et al., 2002). In young people who have disabilities, long-term or life-limiting conditions or mental health problems, there are additional hurdles (Caton & Kagan, 2007). This includes navigating their own transfer pathways between children's and adult health and social care services. Colver et al. (2019) highlight that in a typical United Kingdom (U.K.) National Health Service (N.H.S.) Trust serving a population of 270,000, approximately a hundred young people with long-term conditions requiring secondary care reach the age of 16 years each year. Transition extends over about 7 years so the number in transition at any time is approximately seven hundred.

The challenges for service users and providers are not new. Researchers, policymakers, commissioners, and service providers have been grappling with the problem of how best to plan for and support transition to adulthood in these groups of young people for several decades, with varying degrees of success (Care Quality Commission, 2014; Children and Young People's Health Outcomes Forum, 2012; Crowley et al., 2011; Joly, 2015; Medforth & Huntingdon, 2018; National Network of Parent Carer Forums, 2013; Royal College of Nursing/Royal College of Paediatrics and Child Health, 2013). This is despite a plethora of policy guidance documents published over the past two decades by organizations, such as The National Institute for Health and Care Excellence (2016) and the Social Care Institute for Excellence in the U.K. as well as professional bodies, third sector, and service user advocacy organizations.

Zhou et al. (2016) conducted an Integrative Review of international studies (mostly conducted in the USA, Canada, the U.K., and Europe) examining transitions of care processes for adolescents and young adults with chronic illness and disabilities. Despite inconsistencies in the evidence six main categories emerged from the data synthesis process: the timing of transition; perceptions of the transition experience; preparation for the transition; outcomes post-transition; barriers and facilitating factors. In the 5 years from 2010 to 2015, there had been improvement in health outcomes for some young adults post-transition, such as those who have diabetes or cystic fibrosis. However, overall outcomes (both physical and psychological) after transition to adult health care services, if recorded, have remained poor. This highlighted a need to establish consistent interagency collaboration and accurate tracking mechanisms to monitor outcomes post-transition.

Problem and research question formulation

The aim of this review was to build on the work of previous researchers to gather, synthesize, and evaluate the recently published evidence-based focussing on transition to adulthood in children and young people who have long-term or life-limiting health conditions, disabilities, or mental health problems. The purpose is to present a useful overview to practitioners, policy makers, and researchers so the reviewers limited the scope to research articles which evaluate specific transition interventions (tools, models, pathways, or integrated approaches), outcomes and service-user experiences. The research question was formulated using the PEO Framework (Khan et al., 2003): ***For young people with***

disabilities, long-term and life-limiting health conditions and/or mental health difficulties (Population) ***transitioning to adulthood which interventions*** (Exposure) ***are effective in achieving successful transitions*** (Outcomes)?

Approach

The complexity of developments in health and social care requires an approach allowing a combination of diverse methodologies (Broome, 1993; Cooper, 1998; Greenhalgh, 1997). Whittemore and Knafl (2005) established the acceptability of integrative review by improving the process of data collection and extraction, analysis, synthesis, and conclusion drawing. Integrative reviews have potential to present a comprehensive understanding of complex problems in health and care service delivery. Transition to adulthood for young people with disabilities, long-term or life-limiting conditions, or mental health difficulties is one such complex topic. The previous work of Zhou et al. (2016) was built upon to review articles that emerged between January 2015 and January 2021. The population of interest included young people with long-term or life-limiting conditions and disabilities and those who are facing mental health difficulties. It considered transitions along multiple life-course trajectories.

Literature search

Search strategy

The search utilized the following databases: BMJ Journals, CINAHL Plus with Full Text, Cochrane Library, Community Care Inform Children, Internurse, Kings Fund Library Database, MEDLINE, NHS Digital, and Paediatric Care Online. In addition, the National Institute for Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) data bases were searched. Combinations of terms used, including Boolean Operators and truncations: (young people or adolescent or young adult) AND/OR (disab* or long-term condition or life-limiting condition or mental health) AND/OR (Transition AND Young People AND health OR Disability OR Long-Term Condition) AND/OR (Transition Plan* OR Transition Tool*or Transition Path* Or Transition Coord* OR Transition Support OR Transition Passport).

Presentation: search outcomes, quality appraisal, and analysis of data

The search generated a total of 733 records. After duplicates were removed, the number was reduced to 165. Titles and abstracts were appraised to confirm those that matched the review question (12 were excluded). The remaining 108 records were reviewed against selection criteria. A further 57 records were excluded as they did not meet the specified eligibility criteria. A total of 51 studies were included

Articles meeting the inclusion criteria reported a wide range of qualitative and quantitative methods, from expert opinion pieces and realist evaluation to evidence synthesis. They indicated a global interest, reporting research conducted in countries including Argentina, Australia, Austria, Belgium, Canada, China, France, Germany, Hungary,

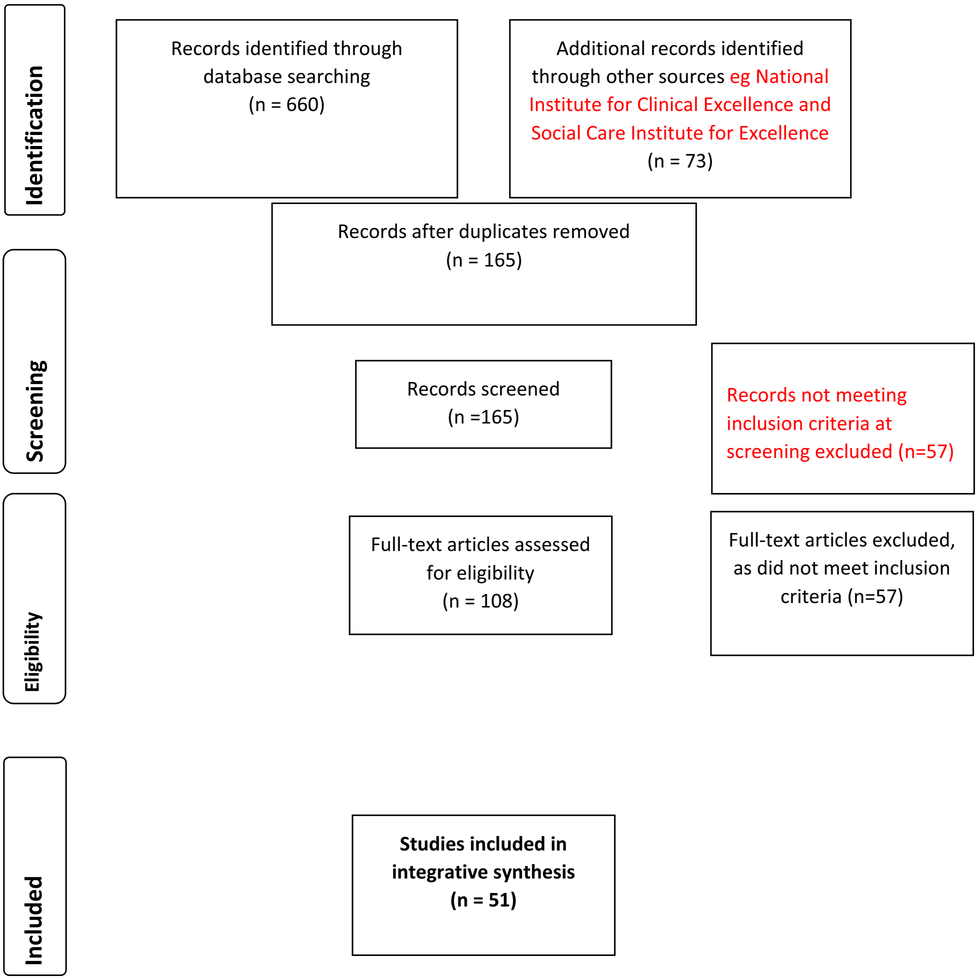

Figure 1. Flow chart summarising search process and outcomes adapted from the PRISMA group model (Moher et al., 2009).

Ireland, Italy, Malaysia, Spain, Sweden, Switzerland, United Kingdom, and United States of America.

Integrative review as a methodology is still evolving. A recognized weakness is rigor during the quality appraisal of retrieved articles (Hopia et al., 2016). The evaluation of individual studies requires methodologies consistent with the type of the research reviewed. The authors responded by applying a range of quality appraisal tools with criteria aligned to, or which best fit the methodological approach taken. Examples included Joanna Briggs Institute Critical Appraisal Checklists for Systematic Reviews and Research Synthesis, Qualitative Research, Analytical Cross-Sectional Studies, and Text and Opinion Papers (Joanna Briggs Institute, 2023); a Mixed Methods Appraisal Tool (Hong et al., 0000); National Institute for Clinical Excellence (2014) Methodology Checklist for Questionnaire Studies and SANRA Scale for the Quality Assessment of Narrative Review Articles (Baethge et al., 2019).

Where a directly applicable quality appraisal tool was unavailable the decision to include was based on confidence that conventional methods had been applied. Examples of reference points include guidance for the application of Delphi Methods (Nasa et al., 2021) and a Toolkit for Participatory Action Research (Hall et al., 2017). In the case of quality improvement initiatives, the decision to include was based on a judgment that established approaches were followed and that the findings had the potential to contribute to informing service developments.

Initial decisions regarding screening and inclusion were made by reviewer 1 (N.M.) on the basis that articles a) met the inclusion criteria and b) met 70% or more of the applied quality appraisal criteria. To mitigate the risk of bias in the evaluation process reviewer 2 (C.B.) randomly selected a 10% sample and independently appraised them. Only one article required discussion and resolution between reviewers. An Evidence Summary Table 1 illustrates the Quality Appraisal process is deposited to Figshare at 10.6084/m9.figshare.22347517.

Through a process of inductive content analysis common themes, topics, patterns of meaning, and sub-themes were identified (Braun & Clarke, 2021; Nowell et al., 2017). They included improvements, but uncertain outcomes; a period of potential vulnerability and risk; perceptions and interconnected experiences of transition; preparation and readiness for transition; barriers, facilitators, and emerging tools and models of best practice; outcomes post-transition; special considerations, dealing with complexity and recognizing that transition involves more than one trajectory; advocacy, participation, autonomy, aspirations, and the rights of young people.

The emergent themes and sub-themes provided the framework to organize the literature systematically. For example, the broad theme of special considerations enabled further illumination of challenges relating to specific conditions; dealing with complexity and recognizing that transition involves more than one trajectory. The synthesis process involved identification of barriers and facilitators, integration of best practice principles consistently cited as integral to a successful transition experience and illumination of examples of evaluated tools to assist practitioners. An Evidence Summary Table illustrating emerging themes is deposited in Figshare at 10.6084/m9.figshare.22347517.

Table 1. Inclusion and exclusion criteria.

Inclusion Criteria	Exclusion Criteria
Published research articles, clinical or professional papers highlighting or evaluating specific interventions designed to support transition to adulthood in young people who have disabilities, long-term or life-limiting conditions or mental health problems. Articles evaluating interventions, tools, models, pathways, or integrated approaches which focus on sector specific or multi-agency approaches to health, social care, and education transitions. (Evaluation may include outcomes and impact of transition including how transition was experienced by young service-users and their families.) Articles employing a range of quality appraised methodological approaches written through the lens of policy makers, practitioners, service-users and researchers. Articles accessible in full-text format, published in English language between January 2015 and January 2021.	Articles which do not meet a quality assurance threshold established through critical evaluation by the review authors. Expert reviews, policy and practice guidance, standards, frameworks, and gap analyses which do not provide a research-based evaluation of a specific intervention or transition experience.

Synthesis and discussion

Improvements, but uncertain outcomes; a period of potential vulnerability and risk

The transition period was characterized as one of the potential vulnerability for young people with long-term disabling health conditions (Allemang et al., 2019a). It was acknowledged as a period which could jeopardize disease stability (Jetha et al., 2019). Salomon and Trollor (2017) highlighted that young people with intellectual disability experience much poorer physical health and an increased risk to mental health during transition to adulthood. Vulnerability of the young person is exacerbated by inconsistency in service provision, particularly if they have complex medical conditions, such as liver disease (Toft et al., 2018) or congenital heart disease (Reekie, 2020). Similarly, a variable spectrum of experience along the dependence – independence continuum was reported in visually impaired young people leaving school (Williams, 2015).

Perceptions and interconnected experiences of transition

Inconsistent experiences highlight both positive and negative aspects of the process (Accardo et al., 2018; Allemang et al., 2019; Allende Richter et al., 2020; Bhawra et al., 2016; Camfield et al., 2019; Colver et al., 2019; Dunn, 2017; Gauthier-Boudreault et al., 2018; Hayward-Bell, 2016; Sivell et al., 2015; Smart et al., 2016). Transition is often perceived as a linear process, yet this is usually not the experience of stakeholders. Listening to young people and parents who are experts in their own experiences is crucial (Allemang et al., 2019; Boyce et al., 2020).

Gorter et al. (2015) reminded us of the interconnected experience of the young person, family, and service-providers. Rees (2016) found that parent's poor experiences of "pre-transitional" support hindered preparation for their young disabled child's future. It impacted on their ability to think positively and let go of the past. Surprisingly, young people were less concerned about the future. Waldboth et al. (2016) identified three emerging perspectives in families living with a chronic childhood disease:

(1) The young person's perspective on how to "live a normal life in an extraordinary way" and "manage a chronic and life-threatening disease."
(2) The parent's perspective on the "complexity of being a parent of a chronically ill child" and "concerns about the child's future."
(3) The sibling perspective regarding "concerns about the siblings future."

They argued for a stronger emphasis on the whole family concluding that all family members were at risk for psychosocial difficulties as they mutually influenced each other.

Hughes et al. (2018) examined learning disability service user experience finding that information relating to learning and social development was most important to inform transition planning. Health, communication, self-care, and independence were lower priorities. Participants valued continuity of care. Interviews conducted by Jiang et al. (2021) explored patient and parent perspectives on transition from pediatric to adult rheumatic disease services, suggesting similar themes may be transferable to other groups:

- avoiding repeat of past disruption (maintain disease stability, preserve adjusted personal goals, protect social inclusion).
- encountering a daunting adult environment (serious and somber mood, discredited and isolated identity, fear of a rigid system).
- establishing therapeutic alliances with adult rheumatology providers (relinquish a trusting relationship, seek person-focused care, redefine personal – professional boundaries, reassurance of alternative medical supports, transferred trust to adult doctor).
- negotiating patient autonomy (confidence in formerly gained independence, alleviate burden on patients, mediate parental anxiety).

Preparation and readiness for transition

Complex physical and mental health conditions bring varied and unique challenges, so transition planning is best started early (Boyce et al., 2020, Camfield et al., 2019; Peron et al., 2018). In Canada, transition planning is mandatory for young people with profound intellectual disabilities (Gauthier-Boudreault et al., 2017).

Transition was recognized to be a process rather than an event (Colver et al., 2019; Rees, 2016) yet there was still no consensus on the best time to begin. Variation from ages 12 to 18 was highlighted (Jensen et al., 2015; Klassen et al., 2015) with an acknowledgment that 16 may be too late (Hilderson et al., 2015). Whilst arbitrary ages and the concept of a transition threshold may still be in use, three key aspects emerged:

(1) Developmental readiness of individual young people (Peron et al., 2018; Toft et al., 2018).
(2) Parents’ readiness to let go (Allemang et al., 2019; Bratt et al., 2017).
(3) Characteristics of the long-term health challenges and disabilities experienced (Allemang et al., 2019; Bratt et al., 2017; Camfield et al.; Hilderson, 2015; Jensen et al., 2019; Schandrin et al., 2016; Reekie, 2019).

Zhou et al. (2016) concluded that readiness for transition should be assessed regularly and accurately by applying validated measurement tools. Health transition programmes tended to focus narrowly on readiness for transfer between children and young people’s and adult services. Klassen et al. (2014) developed and validated a generic scale (the TRANSITION-Q) to measure self-management skills in adolescents with chronic health conditions. It included items that represent the best indicators of skills needed for young people to be able to manage their own healthcare. Participants who agreed they were ready to transfer to adult healthcare reported higher TRANSITION-Q scores than younger participants who required assistance to complete the scale.

Transition between adolescent and adult mental health services was particularly inconsistent. Often plans started late at 17 or 18 years, partly due to the emergence of mental health concerns during the teenage years (Dunn, 2017). Delay is problematic for 50% of young people whose mental health problems emerge before 14 (Hendrickx et al., 2020). Young service users perceived services to be poorly planned and uncaring, prioritizing provider convenience over the interests of young people. To minimize serious risks for young service-users improved transition programmes should start at 14 with a clearly documented protocol and plan, supported, and evaluated by strategic level transition reviews across trusts (Dunn, 2017; Hayward-Bell, 2016; Hendrickx et al., 2020).

Santosh et al., (2020) reported the Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare in Europe (MILESTONE) study. In partnership with young service-users, the research team piloted, developed, and validated a Transition Readiness and Appropriateness Measure (TRAM). They found (TRAM) to be holistic and flexible to the neurodevelopmental readiness of individual young people. TRAM can be completed remotely using developmentally appropriate web-based interfaces to assist. The authors cautioned that Transition is not static and further evaluation of the TRAM is warranted to assess transition readiness longitudinally.

Different life-course trajectories should be considered at different ages. Rome et al. (2015) pointed out that in every step of the way, young people with disabilities have different experiences through transitions; processes start at primary school right through to applying for a job. For young people with hearing loss planning was usually found to start at the age of 13 but depends on the cognitive ability and psychological well-being of the young person (Spyridakou et al., 2019.) Transition to employment is a key aspect of transition to young adulthood, yet specific barriers to finding and sustaining productive employment was associated with disabling long-term health conditions (Jetha et al., 2019).

Barriers, facilitators, and emerging models of best practice

Bhawra et al. (2016) found significant gaps in primary care interventions to improve transition of young people with chronic health conditions from pediatric to adult healthcare. Examples of a range of interventions to support preparation for health, social care, and education transitions were described and evaluated in other literature items retrieved. Families valued holistic approaches. Barriers to successful transition and facilitating factors highlighted in the literature are summarized in Table 2.

King et al. (2021) involved parents in evaluating the benefits of residential immersive life skills (RILS) programmes for young people with disabilities. Programmes enhanced awareness of life possibilities and amplified existing capacities. Parents recognized accelerated growth in adaptability, motivation, and maturity, as well as community involvement. Smart et al. (2016) explored how engagement in goal pursuits in similar programs could be optimized. Using an engagement framework involving affective, cognitive, and behavioral components King et al. (2021) identified eight strategies young people considered effective:

(1) Building a relationship on familiarity and reciprocity.
(2) Guiding the program using young people's preferences and strengths.
(3) Assisting young people to envision meaningful change.
(4) Utilizing young people's learning styles.
(5) Promoting awareness of goal progress.
(6) Ensuring young people's access to a resource network.
(7) Providing multiple-decision opportunities.
(8) Enabling young people to show their capabilities.

Table 2. Themes and sub-themes highlighting barriers to transition and facilitating factors.

Gaps and Barriers	Facilitators
Understanding and Planning ● Attitude of adults and service providers – not recognizing the potential and life chances of the young person. ● Rigid "one size fits all" approaches. ● Failure to involve family as experts or give the young person a voice in decision-making. ● Lack of expertise in adult services. ● Lack of insurance cover where required. ● Poor self-management skills and self-efficacy in young person. ● Past negative experience of services and fear of losing current services. ● Uncertainty - no documented plan or dysconnectivity in the transition model or pathway. ● Disease or disability-related challenges ● Feeling well or perceiving condition to be cured rather than corrected.	**Understanding and Planning** ● Starting early with a developmentally appropriate approach (asset-based, young person-centred, recognizing future possibilities). ● Problem-solving, holistic, goal-orientated attitude. ● Recognizing family strengths, expertise, and involvement; supporting parents to let go at their pace. ● Advocacy training for care givers and the development of autonomy in young people. ● Responding to the engagement style and abilities of the young person and giving them a voice in decisions, thereby promoting autonomy and self-efficacy in the young person. ● Avoid repeat of past disruptions – preserve adjusted personal goals; protect social inclusion. ● Redefining personal/professional boundaries and establishing therapeutic alliances with adult providers. ● Attention to atmosphere and environment. ● Alleviate burden on young person and parental anxiety – reassurance of alternative medical supports. ● Education regarding the projected course of condition, its management and lifestyle implications.
Resource issues ● Limited resources or capacity (young person/family/service/community). ● Gaps in service provision. ● No identified coordinator/facilitator/navigator. ● Staff turnover.	**Resource issues** ● Identified Transition Co-ordinator/Facilitator/Navigator. ● 1:1 professional support/coaching. ● Peer Mentoring facilitation. ● Documented Plan/Health Passport/Transition Pathway/Booklet. ● Planning to ensure consistency despite staff turnover.
Strategic considerations ● Inadequate planning/strategy/commissioning. ● Informal institutional approaches ● Failure to collaborate across organizational boundaries, including primary, secondary health care, social care, education, employability services, and housing. ● Discontinuity. ● Inadequate investigation, monitoring, and evaluation of outcomes. ● Inadequate shared responsibility for care.	**Strategic considerations** ● Training Programmes/Education Support and individualized accommodations including employability support. ● Established partnerships between service users and providers. ● Ability to work strategically across organizational boundaries/sectors, including commissioning with enthusiasm. ● Post-transition follow-up/tracking and longer-term evaluation. ● Co-ordinated approaches locally, nationally, and internationally. ● Can research informed innovation lead to improved outcomes?

Comparable principles were applied to programmes targeting specific groups of young people, such as those who are neuro diverse. Examples involved a summer school where social group facilitation, peer mentoring, and self-advocacy training supported successful transition (Hotez et al., 2018). Involvement of the family to identify needs, special arrangements, and accommodations and to assist adult service providers to understand the young person's needs was key.

Campbell et al. (2016) examined a model of transition care for adolescents from pediatric services to adult health services supported through the implementation of a two-day nurse-led workshop. It involved 1:1 support followed up with SMS-based interventions supported through documentation in a Health Passport. González et al. (2017) found that patients with chronic health conditions and their parents in an Argentinian project recognized the need to have a medical summary, health care guidelines, and trust in the new provider.

Jensen et al. (2015) conducted a quantitative evaluation of a social worker facilitated pediatric rheumatology transition programme in the U.S.A. The social worker met with patients and their families, provided transition education materials, assisted patients in developing an individualized transition plan, assisted in making appointments with an adult rheumatologist at time of transfer of care, and followed up with patients to assess transition outcomes. Patients were contacted 6–8 months after initial appointment with the adult rheumatologist to assess whether they remained in the care of the adult provider. Less than half (42%) were considered to have transitioned successfully to adult care compared to 23% of all patients, however 81% of participants said that they were satisfied with the transition process.

The DON'T RETARD PROJECT is another brief transition intervention programme for young people with juvenile idiopathic arthritis with positive impact reported by Hilderson et al. (2015). The programme had five steps: two outpatient appointments with a Transition Coordinator; information day for young people and their parents; individualized transfer plan; and actual transfer.

In a Canadian study, Hartman et al. (2017) explored the possibility of applying the International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY) as a more holistic framework to inform transition programs from pediatric to adult healthcare for young people with complex disabilities, such as spina bifida. They found that the ICF-CY domains incorporating a holistic biopsychosocial model captured many key areas including categories that span health, education, social considerations, and the acquisition of skills and services, but may need supplementation regarding experience of transition, independence, and role of parents. Nevertheless, they concluded that the ICF-CY considers the presence or absence of the young person's skills and abilities and can help assess gains or losses of participation, ability, skill, and function over time.

Transition programmes for young adults with medically complex conditions and disabilities require an organization-wide approach as well as willingness to work between agencies and across organizational boundaries. Szalda et al. (2019) detailed essential elements of a hospital-wide transition programme for young adults with medical complexity. The Multidisciplinary Intervention Navigation Team (MINT) was designed to decrease inconsistency. MINT improved the availability, knowledge, and use of transition-related resources, saved considerable time among care team members, and increased provider comfort around transition-related conversations. System-level goals were to increase provider and leadership engagement; use of transition tools; use of electronic medical record-based clinical decision supports and improve transition practices through development of transition policies and clinical pathways. Increased transition education for patients and caregivers and increased adult provider referral network and implementation of an adult transition consult service for complex patients (MINT Consult) were also goals.

A Delphi Study conducted by Sivell et al. (2015) highlighted specific training needs of multidisciplinary adult specialist palliative care teams caring for young adults with life-limiting conditions. They advocated the development of a continuous rolling programme of tailored education, the content and delivery of which is agreed through collaboration between service providers and users. Topics broadly covered clinical, psychosocial, and practical issues, including data protection, and managing specific aspects of care.

Best practice principles and examples of supporting tools emerging from the review are synthesized below in table 3:

Table 3. Synthesis summarizing best practice principles and examples of supporting tools.

15 Emerging Principles for Best Practice	Tools to support the transition process.
(1) Implement a transition programme guided by young people's assets, aspirations, and preferences. (2) Commission to ensure strategic support and systematically monitor and evaluate outcomes, ideally longitudinally. (3) Provide transition training for young people, families, practitioners, and service-providers. (4) Identify a Transition Co-ordinator and possible successor in case of staff turnover. (5) Begin planning process as early as possible, ideally around 12 years, acknowledging that it may take up to 7 years (6) Ensure a documented Transition Plan is in place using established models, tools, passports, and technology where appropriate. (7) Incorporate evidence-based tools to assess transition readiness. (8) Take a holistic approach, incorporating multiple trajectories and where necessary working across organizational and sector boundaries. (9) Involve young person in decision-making at every step, taking account of individual capacity, development, engagement style, and advocacy needs. (10) Assess vulnerabilities and mitigate risks taking account of individual circumstances and conditions and associated management, care, and support requirements. (11) Include peer support, specialist clinics, and visits to adult service providers. (12) Take a whole-family approach building a trusting reciprocal relationship by acknowledging experience and assets; acknowledge and resolve family fears and concerns. (13) Develop professional relationships which ensure young people's access to a network of appropriate resources to open-up new life course opportunities, community participation and promote self-advocacy. (14) Review the developing global evidence base regularly; contribute to a shared a learning culture which enables consistent best practice and service development. (15) Co-produce and evaluate service developments in partnership with young service-users.	**Assessing Transition Readiness** TRANSITION-Q - a validated generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions. (Klassen et al., 2014) Transition Readiness and Appropriateness Measure (TRAM) developed, piloted, and validated in partnership with young people as part of the Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare in Europe (MILESTONE) study (Santosh et al., 2018). **Transition Preparation** Transition Preparation Programme which was asset-focussed and co-produced by young people, mental health practitioners and researchers to improve outcomes and experience (Dunn, 2017). Residential immersive life skills (RILS) programs for young people with disabilities. King et al. (2021). The STEPS Curriculum - involving peer mentors for college students with autism spectrum disorder (Accardo et al., 2018). Hotez et al. (2018) highlight a similar successful participatory summer programme. Spyridakou et al. (2019) - a replicable quality improvement project, engaging teenagers who have permanent hearing loss in transition preparation. **Multidisciplinary/Holistic Approaches** Multidisciplinary Intervention Navigation Team (MINT) a hospital-wide Transition Programme for young adults with medical complexity including (Szalda et al., 2019) International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY) as a holistic framework (Hartman et al., 2017). Transferable use of a sociocultural framework to support the transition experiences of visually impaired school leavers (Williams, 2015).

Outcomes post – transition

Poor outcomes post transition included loss to follow-up; worsening disease status and poor psychological and social outcomes (Allemang et al., 2019; Hendrickx et al., 2020; Jetha et al., 2019; Reekie, 2019; Salomon and Troller, 2017; Toft et al., 2018; Williams, 2015). Inadequate management and comorbidities led to young people and parents feeling powerless; a sense of having fallen "off a cliff;" being left "in the deep end or "tossed out on your own" (Gauthier-Boudreault et al., 2017; Gorter et al., 2015; Hayward-Bell, 2016). Success of transition programmes in mitigating these problems was variable with examples of some positive indicators.

Colver et al (2018, 2019) found exposures to recommended features of transitional healthcare were associated with better outcomes for young people with long-term conditions. Enthusiasts often led good practice, rarely generalized across specialties or to adults' services. The importance of adopting an institution-wide approach was emphasized. Camfield et al. (2019) agreed best practice depended on motivated professionals; transition to adult care for adolescents with epilepsy was best where key healthcare providers use novel approaches to complex care.

Campbell et al. (2016) found that comprehensive transition intervention programmes (including telephone support from a co-ordinator) led to little or no difference in well-being or quality of life measures and only slight reduction in the risk of disease-related hospital admissions at 12-month follow-up. Zhou et al. (2016) raised the need to establish accurate tracking mechanisms to monitor patients' outcomes post-transition.

One of the difficulties in identifying successful transition outcomes is that understandings are multi-faceted; influenced by aspirations of young people, experience of parents, perspectives of professionals, organizational cultures of stakeholders, and the focus of researchers. Implementation of different models nationally and internationally may contribute to challenges in assuring consistently best practice. For some, successful transition was measured in clinical outcomes (Camfield et al., 2019; Campbell et al., 2016; Peron et al., 2018; Toft et al., 2018).

Santosh et al., (2020) argued that for young people with mental health challenges knowledge of accessing services is more important than whether the young person can act independently or understands the degree of how the severity of their mental illness will impact. Participation and employability are also important (Harun et al., 2019; Jetha, 2019) whilst the autonomy and psychological well-being of the young person is the priority for others (Hotez et al., 2018; Jetha et al., 2019).

A more integrated perspective considering clinical outcomes, mental and physical health as well as functioning in social, educational, and economic life domains is advocated (Hendrickx et al., 2020; Hilderson et al., 2015; Reekie, 2019). Users of learning disability services prioritized continuity (in terms of the user record; team; response to changing individual needs; flexible accommodation of needs; therapeutic relationship and opportunities for ongoing personal development) as the concept which best defined positive transition outcomes (Hughes et al., 2018; King et al., 2021).

Schneider et al. (2016) found that alumni of a yearlong community college-based transition programme for young people with learning disabilities were doing well in terms of community participation, but less so when it came to employability and independent living. The focus of a study by Harun et al. (2019) examined employment experiences among young Malaysian adults with learning disabilities, suggesting that the implementation of a school to work transition programme relevant to the current job market is needed. Gender and the employability skills of young women with learning disabilities was an area for future development.

Special considerations, dealing with complexity and recognizing that transition involves more than one trajectory

Young people develop at different rates according to individual abilities, capacities, circumstances, and resources. They will be negotiating transitions in distinct aspects of their lives (identity; health; family; education; social relationships; friendships and intimacy; sexuality and sexual health; community participation; employability and potential future parenthood) at different points in their journey toward independence, autonomy, and economic independence.

Colver et al. (2018) reminded us that much of the evidence base drew on small studies of transition across single clinical specialties. Literature retrieved highlighted both shared and unique challenges of providing effective transition support in the general pediatric population even within a single service for young people with just one long-term health condition, such as congenital heart disease (Bratt et al., 2017; Reekie, 2019); hemoglobinopathies (Allemang et al., 2019); epilepsy (Camfield et al., 2020) and rheumatic disease (Hilderson, 2015; Jensen et al., 2015; Jiang et al., 2021).

Even in straightforward circumstances, long-term conditions bring added battles for young people. Hemoglobinopathies (sickle cell disease and thalassemia), for example, were associated with social isolation, poor self-esteem, low-self efficacy, and a lack of confidence in the future (Allemang et al., 2019). Long -term, life-limiting health conditions, disabilities, and mental health challenges add additional layers of complexity and inter-connectivity. Peron et al. (2018) highlight inter-generational considerations for genetic conditions.

Successfully navigating the transition to young adulthood becomes significantly more challenging for young people with physically disabling conditions such as spina bifida and cerebral palsy, which bring hurdles related to mobility, identity, and participation. Disability and poverty closely inter-connect, with disability often increasing health care and related costs whilst simultaneously limiting entry or stay in the labor market (Allcock, 2019). This in turn may lead to challenges relating to mental health, well-being, social inclusion, participation, and self-determination. Hartman et al. (2017) argued for a holistic, biopsychosocial model as a solution. Such approaches will need to span health, education, social care, and include multi-agency approaches. Attention to participation, the acquisition of skills and monitoring gains or losses, ability, and skill over time is essential. Colver et al. (2019) agreed the approach should be based on inclusive partnerships and respond to the young person's style of engagement, concerns, and confidence level.

Where clinically complex conditions, such as tuberous sclerosis complex are involved, the goal was defined by Peron et al. (2018) as providing the patients with medically appropriate, uninterrupted healthcare for as long as possible. Boyce et al. (2020) found parents perceived services as "not for our kids" because adult providers had extremely limited understanding of rare neurological conditions like Dravet syndrome. Salamon and Troller (2017) found that young people with intellectual disabilities are more likely to experience mental health challenges, physical health issues, such as obesity and sexual health-related concerns during transition. Neurodiversity brings its own challenges in terms of social inclusion and may also be associated with co-morbidities, such as anxiety and depression (Accardo et al., 2018; Hotez et al., 2018; Tunesi et al, 2019; Young -Southwold et al, 2016).

Young people with sensory disabilities face unique challenges. Spyridakou et al. (2019) implemented a quality improvement project, with the primary aim of significantly increasing the engagement of teenagers who have permanent hearing loss in transition preparation as well as to ensure good medical and audiological outcomes. A replicable multiphase intervention programme included staff updates; development of a clear transition protocol; allocated key worker; access and engagement. It increased the number of teenagers with a clearly documented transition protocol leading to sustained measurable improvement and better understanding of needs.

Williams (2015) used a sociocultural framework (rather than a service orientated model) to explore the transition experiences of visually impaired school leavers. The focus was on independence and identity; personal and study-based challenges; developing self-identity; self-advocacy and assertiveness; resilience; problem-solving; solution-focussed approaches and peer and friendship group influence. Orientation, mobility, and other independent living skills were key.

A particular group of young people who illustrate uniquely complex transition is young people living with a diagnosis of Human Immunodeficiency Virus (HIV). More young people are living and growing up with complex medical needs that exacerbate psychosocial challenges (Harris, 2015). As sexuality develops young people require self-confidence and maturity to negotiate relationships whilst avoiding the risk of onward transmission. They need accurate information, and a safe space to discuss and ask questions before they embark on any sexual experiences. Information needs include legal issues; available contraception options and awareness of post-exposure prophylaxis after sexual exposure to HIV (PEPSE). Persisting associated stigma and misunderstanding may amplify the difficulties.

Advocacy, participation, autonomy, aspirations, and the rights of young people

Participation, rights, and aspirations of the individual young person must be central to any transition support programme. Where young people are not able, or confident to speak for themselves, parents, transition co-ordinators or other practitioners must fulfill a role as the young person's advocate. They should ensure that the young person's wishes, concerns, goals, and feelings, developmental ability, and communication style are accommodated rather developing transition plans to fit existing models of service delivery (Camfield et al., 2019; Dunn, 2017). This may mean re-defining boundaries to negotiate service -user autonomy and alleviate the burden on young people and parents (Gorter et al., 2015; Hendrickx et al., 2020; Jiang et al., 2021; Reekie, 2019; Sullivan, 2016; Taylor et al., 2019). King et al. (2021) go further, raising the opportunity to open new life-course possibilities. Participating in the design, development, and delivery of transition programmes is essential if these goals are to be achieved.

Future research and evaluation

Suggested approaches were varied and reflected the interests of the authors. Some were clinically focussed seeking quantifiable evidence for improving outcomes, for example, randomized control design projects to evaluate transition outcomes for specific groups, particularly those who are currently under-researched (Camfield et al., 2019; Harris, 2015;

Hilderson et al., 2015; Peron et al., 2018, Toft, 2018). An example of a protocol published by Resseguier et al. (2018) highlights an on-going multi-centric French observational cross-sectional study of the determinants of adherence and consequences of the transition from adolescence to adulthood among young people with severe Hemophilia (TRANSHEMO).

Rees (2016) suggested three focus areas for future research; assessing pathway effectiveness; developing guidance for strategic managers and practitioners and evaluating the role of parents. Researchers should elicit stakeholder perspectives, including parental and family roles (Allemang et al., 2019; Taylor et al., 2019; Waldboth et al., 2016). Participatory approaches which give young service-users and families stronger voices, and the transformative potential of action research are needed (Hotez et al., 2018; Hughes et al., 2018).

Systematic longitudinal intervention studies and evaluations should extend beyond 12 months post-transition, including those involving health-related outcomes and preventative strategies for young people with complex disabilities and emergent mental health problems (Campbell et al., 2016; Colver et al., 2018; Gorter et al., 2015; Salomon & Trollor, 2017). A multi-dimensional perspective in the developing evidence base is essential; evaluating accessibility to under-represented groups or scope to develop additional scales to measure important transition-related bio-psychosocial constructs and psycho-social functioning (Klassen et al., 2014; Santosh, et al., 2018; Hartman et al., 2017).

System-level disintegration of the transition process across countries highlights the need for robust policy development and the use of powerful leavers to elevate the profile of transition support development (Hepburn et al., 2015).

Limitations

The rapidly evolving evidence base means it may not have been possible to include all relevant publications despite a carefully detailed search strategy; it is possible that new publications will have emerged. A notable example highlights the Ready Steady Go and Hello programme advocated by The Transition and Patient Empowerment Innovation, Education and Research Collaboration (2022).

Quality Appraisal in integrative reviews remains a recognized methodological dilemma. No single tool is applicable. Despite some similarities in tool criteria, it is impossible to use identical standards to compare like for like. There is no published consensus on satisfactory resolution. Decisions to include involved a pragmatic (imperfect) balance of deciding an acceptable threshold for quality assurance criteria across toolkits (70% of criteria met) or where not possible that established methodological had been applied. Nevertheless, this review provided opportunity to take stock of wide range of systematically retrieved and synthesized perspectives and approaches on transition support for young people in a range of complex circumstances; it illustrates an evolving picture of evaluated practice, policy, and research, illuminating directions for ongoing service development and future research.

Conclusions

The purpose of systematic and rigorous integrative reviews is to present a comprehensive understanding of problems relevant to health service development and policy. This review demonstrated a global interest in a topic that continues to present complex challenges for practitioners and policy makers who strive to improve transition support for young people growing up with long-term and life-limiting health conditions, disabilities, and mental health challenges. Central themes were unsurprising viewed in the context of previous research; the timing of transition; perceptions of transition; preparations for and outcomes post-transition; barriers and facilitating factors and the need to work together to develop formal channels to monitor outcomes post-transition. Additional themes included special considerations for specific groups of young people; suggestions for focussed continuing work, research and evaluation and the rights, participation, and aspirations of young people.

The review illuminated novel perspectives and research exploring the complexity of supporting young people who are developing in more than one life-course trajectory. The needs of under-represented groups were highlighted; participatory approaches giving voice families who are in the process of "letting go" and the drive toward independence, autonomy, and inclusion in young people who transition to young adulthood in complex circumstances.

The challenges are not new. Findings align with previous work demonstrating that collectively service providers are still not getting things right for all young people. Consequent risks (often serious) and variable outcomes for young people and their families persist, but encouraging developments in practice, strategic approaches, and applied research are also evident. For practitioners and policymakers finding solutions can seem overwhelming, however this review signposts practitioners and service developers to principles for practice improvement and evaluations of a range of emerging tools and models which are available to assist. Examples include frameworks and validated tools to assess transition readiness or experience and outcomes from a multi-dimensional perspective. Service providers need to ensure no young person is left to flounder and no family experiences unnecessary fears, burdens, or consequent stress. Follow-up, tracking evaluation, and assurance of positive transition outcomes and experiences of young people with long-term and life-limiting health conditions, disabilities, and mental health challenges remains a priority. It is only then that they can be confident that the aspiration shared by Waldboth et al. (2016) that all young people are enabled to "live a normal life in an extraordinary way" has been achieved.

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