Rapid Synthesis

Identifying Features of Approaches to Supporting Transitions from Child to Adult Care for Young People with Special Healthcare Needs

27 March 2020

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Rapid Synthesis:
Identifying Features of Approaches to Supporting Transitions from Child to Adult Care for Young People with Special Healthcare Needs

60-day response

27 March 2020

McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

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Timeline

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. This synthesis was prepared over a 60-business-day timeframe. An overview of what can be provided and what cannot be provided in each of the different timelines is provided on McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the rapid synthesis. The funder played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the rapid synthesis.

Merit review

The rapid synthesis was reviewed by a small number of policymakers, stakeholders and researchers in order to ensure its scientific rigour and system relevance.

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KEY MESSAGES

Question

- What are the features of novel approaches to supporting transitions from child to adult care for young people with special healthcare needs in Canada?

Why the issue is important

- In North America, up to 15% of youth experience a chronic condition and will eventually need to transfer from pediatric to adult care as they transition into adulthood.
- The process of transition from pediatric to adult care is often associated with a deterioration in health, as services fail to adequately meet adolescent and young adult patient needs.
- The needs of patients in transition extend beyond the medical transfer itself, as they require support in planning and preparation, building self-management skills, navigating new systems of care, fostering new relationships, applying for new programs, and dealing with significant changes in housing, vocation, education, and personal development.
- It is well recognized that there is little evidence on the specific features of interventions that are effective in supporting transitional care.

What we found

- We conducted a synthesis of research evidence, as well as a system analysis through a jurisdictional scan and interviews with key informants to identify examples of how transitions from child to adult care for people with special needs are supported in provincial and territorial health systems in Canada.
- For the synthesis of research evidence, we identified 25 relevant systematic reviews and extracted key findings in relation to four broad focus areas: 1) key features of service-user, provider- and organization-focused transition interventions; 2) stakeholder views and experiences with approaches for supporting transitional care; 3) barriers and facilitators for supporting transitional care; and 4) recommendations for improving transitional care.
- Regarding the reviews evaluating transition interventions at the level of the service-user, interventions focused on education, relationships and resources. At the level of providers, interventions were comprised of education, training, resource access, and staffing changes. At the organizational level, interventions included establishing dedicated transition clinics and formalized transition protocols and procedures.
- Regarding the reviews that identified transition experiences, patients dealt with fear and changing relationships, in and outside of the care setting. Parents were concerned about their child's preparedness, struggled to let go, and continued to struggle as advocates for care. Providers experienced a lack of coordination, limited resources and faced challenges with the patient-provider relationship (e.g., letting go of established connections or trying to foster new ones).
- Regarding the reviews that identified key barriers and facilitators to transition, the following key themes were extracted: timing and preparation needs; appropriate support and access to resources; and coordination and continuity in care.
- Key recommendations from the literature included: improving service integration; preparing for transition earlier; providing developmentally appropriate care; focusing on patient engagement; additional support to families and parents; facilitating peer support; developing transition programs and policies; increasing capacity to provide transition services; and enhancing provider education.
- Our jurisdictional scan identified 13 specific tools that assisted with transition. A number of programs and clinics were also identified, many of which implement these tools. The tools were implemented on a national, provincial, or hospital/community level, however, in many cases, the details about the tools and programs were limited.
- We spoke to 13 key informants who gave insights on their experience with transitions. Informants were from the Canadian provinces of Alberta, Ontario, Quebec and Nova Scotia as well as from Australia, the U.S, and the Netherlands. They approached the topic from the viewpoint of policymakers, managers, practitioners, researchers and/or patients. Informants discussed the features of the transitional care they experienced, the key challenges they faced with transition support, and successes and opportunities that should be considered for future strategies. Their insights gave useful context to the results of the literature review, and often clarified which features work or fail in practice.

QUESTION

- What are the features of novel approaches to supporting transitions from child to adult care for people with special needs in Canada?

WHY THE ISSUE IS IMPORTANT

Youth with special healthcare needs (i.e., those with one or more chronic conditions that cause some limitation in their lives) who transition into adulthood eventually need to transfer from pediatric to adult care. In North America, as many as 15% of youth have ongoing care needs which impact their health, their livelihoods, and their families.(1) These chronic conditions, which include a range of impairments and diseases, will require developmentally appropriate support as patients and families transition between services.(1) A recent high-quality Cochrane Review documented that the process of transition from pediatric to adult care is often associated with a deterioration in health, as services fail to adequately meet adolescent patient needs.(2) Child Health BC suggests that the transition process is more than just the medical transfer itself, and involves advanced planning and preparation, helping patients acquire independent self-management skills, education in navigating the new system, fostering the development of new care relationships, and applying for new programs.(3) This is in addition to supporting many other changes occurring in adolescents' lives outside of the care context such as education, vocation, housing, social relationships and increasing independence.

In 2018, the Canadian Paediatric Society updated a position statement on transitions to adult care for youth with special needs, and recognized the increasing awareness on the need for appropriate transition services.(4) In this statement they aimed to outline a framework and tools for pediatricians, family physicians, other healthcare professionals, parents and youth to foster more successful transitions. However, it has been recognized that there is low overall certainty about the evidence on the features of interventions that are effective in supporting transitional care.(2) In order to further understand the state of evidence as well as the features of existing transition programs and tools to support transitions from child to adult care, CanChild requested this rapid synthesis.

Box 1: Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences and the contexts in which they work.

Rapid syntheses can be requested in a 3-, 10-, 30-, 60- or 90-business-day timeframe. An overview of what can be provided and what cannot be provided in each of these timelines is provided on the McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

This rapid synthesis was prepared over a 60-business-day timeframe and involved five steps:
1) submission of a question from a policymaker or stakeholder (in this case, CanChild);
2) identifying, selecting, appraising and synthesizing relevant research evidence about the question;
3) conducting key informant interviews;
4) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence; and
5) finalizing the rapid synthesis based on the input of at least two merit reviewers.

WHAT WE FOUND

We conducted a synthesis of research evidence, as well as a system analysis through a jurisdictional scan and interviews with key informant to identify examples of how transitions from child to adult care for people with special needs are supported in provincial and territorial health systems in Canada. The findings from each of these components are provided in turn below.

Findings from a synthesis of research evidence

Our search in Health Systems Evidence yielded 307 results and our search of PubMed yielded 276 results. We identified 25 systematic reviews and 46 primary studies that included findings related to features of approaches to support transitions from child to adult care for people with special needs. We organized findings from the literature in relation to four broad focus areas:

- key features of service-user, provider- and organization-focused transition interventions;
- stakeholder views and experiences with approaches for supporting transitional care;
- barriers and facilitators for supporting transitional care; and
- recommendations for improving transitional care.

In summarizing the included literature, we focused on findings from systematic reviews and supplemented these with findings from single studies when they offered additional insights that were not included in the reviews. Most of the single studies focused on describing stakeholder experiences, while a minority assessed approaches to support transitions. We provide key findings for each of the focus areas in Tables 1-4 and in each of the sub-sections below. In addition, the detailed findings from each systematic review and single study are included in Appendices 1 and 2 respectively.

Examining the evidence on transition interventions

The focus of the synthesis was on documenting key features of transition interventions for people with special needs. In doing so, we also extracted key findings in relation to the effectiveness of transition interventions from the included systematic reviews. We found consensus in the systematic reviews that the evidence on the effectiveness of transition programs is limited. While there is broad support for programs that address the diverse needs of emerging adults,(5; 6) programs are often disease specific and it's often unclear which specific approaches that support transition are most effective. However, one medium-quality review found that successful programs commonly included patient education and joint pediatric-adult clinics or designated young-adult clinics.(7) In addition, a high-quality review suggested that programs with both a transition coordinator and dedicated transition clinics demonstrated better outcomes than those with a single component.(8) However, the evidence from both reviews focused on managing diabetes mellitus and concluded that further research on transition programs is needed. Finally, another review focused on identifying outcomes of structured-transition programs in reference to the triple aim framework and found the following beneficial results: 1) positive population-health outcomes were seen through improvements in adherence to care, patient-reported health and quality of life, self-care skills, and mortality reduction; 2) positive consumer experience outcomes were reported through increased satisfaction with transition, transfer, and life-course and health-related goals, helpfulness of a specific tool or online resource, autonomy and increased time alone with a healthcare provider; and 3) positive service utilization outcomes were found through increased visits to the new adult provider, reduced time lag

Box 2: Identification, selection and synthesis of research evidence

We identified research evidence (systematic reviews and primary studies) by searching Health Systems Evidence (www.healthsystemsevidence.org) and PubMed in December 2019. In Health Systems Evidence, we searched for overviews of systematic reviews, systematic reviews of effects and systematic reviews addressing other types of questions using the filters under System arrangements > Delivery arrangements for package of care/care pathways/disease management and continuity of care, and combined it with pediatric OR paediatric OR child OR youth in the open search. In PubMed, we used the Health Services Research queries topic-specific filter to search for process assessments and qualitative research (using a narrow search scope) using the following combination of terms: (pediatric OR paediatric OR child OR youth) AND (care transition) AND (special needs OR complex care).

The results from the searches were assessed by one reviewer for inclusion. A document was included if it fit within the scope of the question posed for the rapid synthesis.

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool (see the Appendix for more detail), and the proportion of the included studies that were conducted in Canada. For primary research (if included), we documented the focus of the study, methods used, a description of the sample, the jurisdiction(s) studied, key features of the intervention, and key findings. We then used this extracted information to develop a synthesis of the key findings from the included reviews and primary studies.

between the last pediatric visit and the first adult visit, reductions in hospital admissions and length of stay for readmissions, surgery rates, and radiation exposure.(9)

The systematic reviews provided some description on the features of different approaches supporting care transitions, which we summarize in Table 1. However, it should be noted that a reason for the difficulty in assessing effectiveness was, in part, attributed to the lack of specificity of these features and lack of universal transition outcomes. Given this, the details available about the features of some interventions that were identified is limited.

At the level of the service-user, interventions to support transition typically focused on; 1) education provision; 2) building relationships; and 3) resources to support information delivery and system navigation. Patient education generally consisted of one-on-one transition meetings with a provider, or group-transition workshops that incorporated practising strategies through role-playing and mentored learning.(2) The content for educational interventions was delivered through a variety of mediums and often were comprised of disease-specific education and/or generic-skills training focused on empowerment, autonomy and self-efficacy.(10) Parent education was also noted as a key component in transition interventions, although the details on this were limited.(7) However, in a medium-quality review focused on parental perspectives, parents identified that helpful educational interventions they experienced in practice included advocacy services, supportive mentoring to build skills, and preparation materials that incorporated timelines and key contact information.(11)

Building relationships in transition interventions was established through fostering patient-provider interactions and patient-peer connections. Two medium-quality reviews suggested that key approaches which helped build patient-provider familiarity included giving tours of adult care facilities, introducing patients to adult providers, organizing informal luncheons and scheduling introductory appointments with adult staff.(10; 12) Regarding peer connections, a high-quality review found that a key component of the transition programs it identified related to helping patients develop stronger social-support systems.(13) The programs focused on helping patients develop independent social skills and build new relationships, which was often supported by group-work sessions on issues such as dating, housing and roommates. In addition, group-peer sessions and peer mentors were often incorporated into interventions to not only deliver education and introduce patients to new services, but also to foster peer support.(10; 13)

Lastly, a number of approaches focused on providing patients and families with accessible and relevant resources to inform them about their care and to support system navigation. For example, phone and texting services complemented educational material and gave users a chance to provide feedback and ask questions about the care transition process.(2; 10; 14) These services could be provided over longer periods of time and allowed for support to be accessed 'out-of-hours' at more convenient times to a young-adult population. In addition, medical summaries, in the form of 'health passports', enabled patients to easily carry key health information with them at all times,(2; 7) while community-based referrals connected patients to resources outside of the care setting, including education, vocation and housing.(7; 13)

For providers, transition interventions similarly included; 1) education provision; and 2) linking resources to support transition and system navigation, but also included staffing changes and resource allocation to support care transitions. Regarding provider education, a low-quality review concluded that provider-training best practices have not been developed, and that providers gave limited examples of educational interventions beyond short-term pilot sessions for a select group of people.(15) However, the review did indicate that pediatric providers reported that transition-related content was often incorporated into their educational background. Another medium-quality review specifically noted that shared education and training between staff from different services was helpful in breaking down provider misperceptions and philosophical differences,(5) while a different high-quality review found that capacity building through training and instruction helped engage professionals in transfer services.(13)

Regarding the linkage of resources, one medium-quality review concluded that the primary focus of the care transition models included in its review was on approaches that supported providers to link care with other providers.(7) Multiple studies included in the review implemented transfer-of-care protocols, which aimed to support pediatric providers in making referrals to primary-care providers. Studies also reported on health providers making referrals to community-based service providers who dealt with employment, education and other types of training, although the details on how this was supported were not clear. Several studies in the review also noted the use of medical summaries to transfer key patient health information from pediatric providers to adult providers.

Regarding staffing changes and resource allocation, appointing a transition coordinator, assigning a cross-service worker (who would work in both pediatric and adult clinics) and organizing joint-provider appointment attendance were repeatedly identified as important approaches to support continuity of care across transition.(2; 7; 8; 10; 12-14; 16) The profession of the transition coordinators varied and they took on a diverse set of tasks, including booking first appointments, attending transition appointments, providing administrative support, linking patients with useful resources, regularly following up with patients over the course of the transition, and providing emotional support. A high-quality review suggested that, similar to a transition coordinator, a cross-service worker who worked in both pediatric and adult clinics, could help ensure referrals were made and help improve communication, collaboration and preventive work.(13) However, a low-quality review noted that that there was often a reliance on a single transition worker to help support the implementation of transitional-care programs, and that this may not be a sustainable approach.(16) Instead of a single coordinator, some interventions included jointly attended appointments by pediatric and adult providers to facilitate a gradual transition and improve information sharing.(10; 14)

Lastly, a small number of interventions were described at the organization level which included; 1) creating separate transition clinics; and 2) establishing transition protocols and procedures for organizations. Developing a separate multidisciplinary young-adult transition clinic was included as an organizational change to facilitate better care transitions in several systematic reviews.(8; 10; 14) For example, one medium-quality review described a youth morning clinic occurring bi-monthly during the care transition period.(14) A high-quality review suggested that the timing of such clinics is important, noting that offering clinics at more convenient times for young people such as evenings and weekends would be necessary to ensure uptake.(8)

While formalized transition protocols and programs were generally seen as important, their details were often limited, with one review noting that most 'programs' were actually pilots or single services with little evaluation of key elements.(16) One medium-quality review found that the transition protocols it identified were focused exclusively on referrals from pediatric care to primary-care providers.(7) A high-quality review which identified two mental health transition programs concluded that program success was attributed to the incorporation of social, educational, occupational, and behavioural interventions that focused on a lifespan approach to build self-sufficiency.(13) The two programs included in this review implemented a range of interventions such as treatment plans, peer support, a transition coordinator, community service recognition and a focus on relationship building, but again, details were limited.

Table 1: Interventions to support transitional care identified in systematic reviews

Focus of Intervention	Type of Intervention	Key features
Service-user	Education provision	• One high-quality review that examined interventions aimed to support youth in transition found that educational interventions consisted of one-on-one meetings to discuss transition issues, or group transition workshops focused on planning and practising strategies for obtaining resources through role playing and mentored learning.(2) • A medium-quality review that examined the effectiveness of transitional care programs found that the content of patient interventions often focused on disease-specific education, which aimed to improve transition understanding and self-management, and/or generic skills training, which aimed to increase autonomy in systems navigation.(10) • This same review noted that these interventions were delivered through a variety of mediums including in-person teaching, printed materials, or internet activities.(10) • Another medium-quality review found that half of transition service models it reviewed included services and support for parents, even going as far as including them in the service model.(7) However, the review noted that these parental supports lacked detail. • Another medium-quality review specifically examining parents' roles in care transitions found that only one of the 47 studies in their review used an experimental design to examine a parent-focused intervention.(11) However, this review noted parents often identified helpful interventions they received in practice, which included advocacy services, supportive mentoring to build skills, and preparation materials that describe timelines and key contact information were helpful.(11)
	Building relationships	• Two medium-quality reviews identified that key interventions for service users often aimed to build the patient-provider familiarity prior to transfer.(12; 14) These strategies included giving tours of the new facility, introducing patients to adult providers, organizing luncheons, and actually scheduling in first appointments with adult staff. • In a medium-quality review, parents described that positive interventions incorporated a family-centred approach, where joint meetings with pediatric and adult providers or meetings with the adult provider prior to transfer were helpful in preparing for future interaction.(11) • In addition to the patient/patient-provider relationship, facilitating the patient-peer relationship was also noted as an important interventional approach. One medium-quality review noted that group-peer sessions, which were often used as a way to deliver education, also allowed for peer support.(10) • A high-quality review on programs implemented to support transition described that both the interventions included in their review focused on helping patients develop stronger social-support systems, focusing on fostering independence, social skills and relationships, with supplementary group work on dating, housing, family, and roommates.(13) One study in the review also used a mobile peer-support worker to introduce new patients to the program.
	Resources to support information delivery and system navigation	• One high-quality review (2) and two medium-quality reviews (10; 14) described that phone, texting or chatbot services were an important mechanism to link patients to important information, as well as allowing patients to ask questions in an interactive format. These services could be delivered over a longer time period, often over a year, and facilitated maintained contact with flexible timing, where support could be provided

Focus of Intervention	Type of Intervention	Key features
		‘out-of-hours’ at more convenient times to a younger population. In addition, enhanced follow-up could be initiated if there was a known increase in failed attendance.(10) o One primary study described a co-designed chatbot text messaging platform with scripted interactions to increase engagement and deliver educational content on self-care skills such as understanding one's chronic condition and medical history, ordering prescription refills, contacting a doctor's office, and preparing for doctor appointments. Based on the responses, the chatbot replied with encouragement, tips and links to online resources.(17) • One high-quality review (2) and one medium-quality review (7) described interventions that provided a medical summary, often in the form of a ‘health passport’ that patients could carry with them at all times, which insured that key information about their condition, previous interventions, medication purposes, and other specialized needs were accessible. • Finally, one medium-quality review (7) and one high-quality review (13) described that referrals to community-based supports outside of the healthcare setting that address broader issues such as employment, post-secondary education, housing or other relevant training were key to addressing the holistic life-course needs of the patient.
Provider	Education and training	• A low-quality review focused on providers’ roles in care transition concluded that templates of best practice for training have not been developed.(15) Limited training examples were cited by providers other than piloted short-term training for selected groups of people. However, the review also indicated that significantly more pediatric specialists reported the inclusion of transition-related content in their educational background and highlighted one study that saw a significant improvement in the post-test scores of medical students after the delivery of an online program regarding transitional-care information. • One medium-quality review that focused on assessing the effectiveness of different transition models concluded that shared education and training, standardized approaches to record-information transfer, and evaluating outcomes achievement were helpful in breaking down provider misperceptions and philosophical differences.(5)
	Linking resources	• A medium-quality review which assessed health transition models concluded that the most prominent component of implemented transition models related to the transfer of care between providers.(7) The review outlined that multiple studies included transfer-of-care protocols which specifically aimed to support referrals to primary-care providers. Several studies also reported implementing medical summaries to be transferred from the pediatric provider to adult provider through the mail or with the patient. Finally, a smaller group of studies also reported that providers would make community-based referrals to other service providers that dealt with employment, post-secondary education, or other types of training.(7)
	Staffing changes	• Eight different reviews, ranging in quality, all described interventions that incorporated staffing changes to better support care transitions.(2; 7; 8; 10; 12-14; 16) These changes usually included appointing a transition coordinator, assigning a cross-service worker (who works in both pediatric and adult clinics) or organizing joint provider attendance to increase continuity of care. • Appointing a transition coordinator, a role that varied in terms of prior discipline, was reported across the reviews as a key approach to improve continuity of care. A high-quality review described the transition coordinator as someone who would help make first appointments, ensure a formal referral letter was obtained, provide the patient with key contact

Focus of Intervention	Type of Intervention	Key features
		details, connect patients with resources that addressed a range of issues (such as transportation options, useful websites, information about their condition), and provide the patient with ongoing follow up (to discuss well-being, other life events and care-transition difficulties).(2) Another high-quality review added that the coordinator's support often was outside of the healthcare setting and often included accompanying patients to school or job sites.(13) Two medium-quality reviews suggested that transition coordinators specifically aided continuity by providing a single point of contact, often attending each appointment to ensure consistency, and referring patients to drop-in groups or education events based on their individual needs.(10; 14) Although the length of time the coordinator would work with each patient was not consistently described, appointment scheduling, follow up check-ins, and phone calls would often occur over the course of a year. • Similar to a transition coordinator, a high-quality review noted that the addition of a cross-service worker helped to specifically shape the process of communication and referrals across services, improving preventive work, collaboration and discussion.(13) • Finally, another staff change that was commonly suggested was organizing pediatric and adult providers to attend appointments jointly during transition. Two medium-quality reviews described that joint attendance, especially during the first and last appointments in each care setting, helped facilitate a more gradual transition and allowed for information sharing among providers and patients.(10; 14) • However, one medium-quality review noted that there was often a reliance on single transition champions to take forward the implementation of transitional care, and that although this provided a single point of contact, it often risked sustainability.(16)
Organizational	Developing separate transition clinics	• Three reviews mentioned the development of separate multidisciplinary young-adult transition clinics as a strategy to better support the needs of this population.(8; 10; 14) • One medium-quality review noted that establishing a separate young-adult clinic helped young people feel less out of place as they were surrounded by other young people with similar experiences.(10) These clinics were held on different days from general clinics to allow providers to focus on the young adults. A second medium-quality review added that the option of attending a young person's clinic occurred bi-monthly.(14) • A high-quality review noted that these transition clinics were jointly staffed by pediatric and adult providers, and incorporated multidisciplinary teams, which included physicians, registered nurses, certified educators, mental health providers, and registered dietitians.(8) These clinics were offered during evenings or weekends to be more convenient to the schedules of young adults. Even further, the review identified that two studies implemented dual transition clinics, where youth transitioned from pediatric care to a transition clinic to a young-adult clinic to adult care.(8)
	Establishing a transition program/plan/ protocol	• Evidence on structured transition programs was limited, where 'programs' often were comprised of a pilot service or a new singular approach. If described, these programs often lacked detailed description. However, one low-quality review concluded that although there was minimal evidence for specific approaches or tools to employ in transitional care, formalized transition programs generally appeared to demonstrate decreased incidence of acute events and improved satisfaction of patients with their transfer. One medium-quality review found that the transfer-of-care protocols it identified majorly addressed referrals to primary-care providers.(7) A high-

Focus of Intervention	Type of Intervention	Key features
		quality review which identified two mental health transition programs found that studies attributed program success to the incorporation of social, educational, occupational and behavioural interventions that focused on a lifespan approach to build self-sufficiency.(13) These two programs included a range of interventions such as treatment plans, peer support, a transition coordinator, community service recognition and a focus on relationship building.

Synthesizing stakeholder views and experiences

In addition to the reviews that examined transition interventions, several reviews also assessed the perspectives and experiences of patients, caregivers and providers during care transitions, with most being focused on patient perspectives (see Table 2). Although the reviews focused on a range of conditions, a meta-synthesis on transition experiences concluded that transition concerns seem to be comparable across diagnoses.(18) Moreover, patients, parents and providers were all found to feel consistently unprepared for care transition, expressed concerns about the lack of coordination, and faced significant changes in relationships established before transition.

For patients, experiences during care transitions generally related to: 1) dealing with their own fears and concerns about transitioning; 2) managing experiences with care provision and the patient-provider relationship; and 3) handling changes in relationships and life events outside of the care setting. In regards to how patients dealt with transition concerns, patients often expressed feeling lost and abandoned in the process, where being ‘pushed out’ of old services and unprepared for new services were key contributors.(19) Some patients expressed that the lack of information, support and coordination they experienced caused them to fear the unknown and worry that their health records would not be appropriately transferred.(20; 21) Despite this, patients desired to explore their autonomy and build self-management capabilities.(20; 22) Regarding how patients managed their care provision and provider relationships, patients often became attached to their pediatric providers and were apprehensive about the different treatment philosophies in adult care.(18; 20; 23-25) Patients recalled that they had to face more chronically unwell patients in adult care and that their specific needs as a young adult were not seen.(5; 18; 25) However, patients also had an explicit desire to build relationships with their providers and be respected as a part of their care team.(19; 22) Finally, in regards to handling changes in relationships and issues outside of the care setting, patients noted that they often faced a social stigma with being treated, where approval and disapproval from peers was a prominent concern.(5; 18) They handled balancing changes in parental involvement with new-found independence (18; 19) and required support for an evolving range of needs, which included education, vocation and housing.(5; 21)

Parent experiences during care transitions related to three categories: 1) worrying about their child’s preparedness for life; 2) handling their own inability to ‘let go’; and 3) ongoing efforts to advocate for appropriate care provision. First, parents often felt that the transition from pediatric to adult care was abrupt, and that transition planning started too late.(5) In addition, it was found that parents felt inadequately prepared for their child assuming responsibility for their own care and were worried about their child’s ability to engage in a social life, have an education and/or a career, and to handle finances.(21) One medium-quality review noted that parents of children with both mental and physical disabilities were equally fearful that their children’s futures would be unfulfilled or diminished.(11) Second, parents shared that the process of ‘letting go’ was particularly challenging, which involved stepping back from responsibilities in their child’s care as well as from their relationships built with pediatric providers.(11) Families felt a sense of loss and were concerned about building an entirely new network of support.(21) Regarding parents fighting as advocates for appropriate care, a medium-quality review focused on young people with intellectual disabilities and found that uncoordinated transitions often forced parents to continue to struggle to find appropriate care in adult services.(21) Parents faced a maze of absent, incorrect or conflicting information, and were also met with restrictive eligibility criteria in applying for new services.(11; 21) A medium-quality review noted that although parents desired to demand the best care, they often felt devalued and wanted to be respected as part of a team.(19)

Finally, provider experiences during transition were less commonly documented in the reviews, with only two reviews addressing their concerns.(5; 15) Their experiences primarily related to: 1) a lack of service coordination; 2) challenges with the patient-provider relationship; and 3) limited resources. Firstly, a low-quality review concluded that providers generally experience a system that lacks comprehensive and seamless transitional care, and although providers are aware of the importance of transitions, there remain significant gaps in actual service provision.(15) There was often confusion about role responsibilities during transition, combined with a lack of understanding between pediatric and adult services. The second medium-quality review added that there was no consistent use of formal transfer arrangements, pediatric and adult care often had differing referral criteria, and shared client planning was limited.(5) Regarding providers' experiences with patient relationships, pediatric providers noted that it was challenging to identify patients who needed a referral and it was difficult to end established patient-provider relationships.(5; 19) In contrast, adult providers often struggled to understand the holistic needs of their young-adult patients and found it difficult to engage with them because patients often faced stigma, health limitations and/or underdeveloped self-management skills.(15) Regarding limited resources, although a lack of fiscal resources often prevented investments in transition services, providers stated that the inherent separation of systems and a lack of leadership to prioritize young-adult care were fundamental problems preventing successful transition.(5) Furthermore, a lack of knowledge and access to information about relevant community-based agencies or what constitutes appropriate holistic transition planning was identified as a challenge.(19)

Table 2: Experiences of transitional care identified in systematic reviews

Focus of Experience	Type of Experience	Key features
Service-user: Patient	Dealing with their own fears and concerns about transitioning	• A common theme across most reviews which examined patient experiences was that patients often felt abandoned and unprepared during transition. A medium-quality review specifically described this phenomenon as 'falling off a cliff' where patients experienced being pushed out into an unfamiliar system with little knowledge about how their needs would be met.(19) • One medium-quality review (21) and one low-quality review (20) found that transition was often experienced as an abrupt event with a lack of planning and support. There was little assurance about information being appropriately transferred and subsequent gaps in care were a concern. Patients noted that having to retell their story was a particularly negative experience. • However, a medium-quality review also notes that although many studies reported patients feeling lost and unprepared, there were some studies in which patients experienced the transition as 'transformative', embracing the opportunity for increased self-management and autonomy.(26) • Achieving increased independence was often viewed positively, as one medium-quality review (22) and one low-quality review (9) noted that developing an adult identity, establishing one's own likes and wants, and taking ownership of their care were important milestones. Being able to gain a sense of control and acquire relevant skills was a desire.
	Managing experiences with care provision and the patient-provider relationship	• Significantly, all reviews which assessed patient experiences highlighted that patients had often established a familiarity and comfort with the pediatric environment, especially in their attachment to their pediatric providers, and were fearful of the different treatment philosophies they would experience in adult care. • Three medium-quality reviews specifically noted that patients faced more chronically unwell patients in adult care and often felt their specific needs as a young adult would not be appropriately seen.(5; 18; 25) Patients perceived adult-care doctors and nurses as being impersonal, disease-focused, and less competent in managing their care.

		• Two medium-quality reviews also described that young people desired to feel respected as a part of their care team and wanted to establish strong relationships with their providers.(19; 22)
	Handling changes in formative relationships and life events outside of the care setting	• In addition to relationships established with providers, young-adult patients were also increasingly concerned about their relationships with their peers. One medium-quality review noted that patients expressed that peers with a similar disease or experience often offered crucial support in helping them manage their own lives.(18) In addition, a medium-quality review found that the social stigma patients experienced with receiving healthcare treatment often prevented subsequent engagement.(5) • Regarding the parent-patient relationship, two medium-quality reviews highlighted that transition was often a time of conflict for patients, as they struggled to balance their increasing independence with their parents' reluctance to let go.(18; 19) However another recent low-quality review described that balancing self-management with parental involvement in the context of intellectual disability was often found to be unnatural.(21) • One medium-quality review and one low-quality review noted that patients often experienced a lack of a holistic approach in adult services, where links to age-appropriate services outside of the immediate care setting such as accommodation, employment and housing were not provided.(5; 21)
Service-user: Parent	Worrying about their child's preparedness for life	• One medium-quality review noted that parents often felt as if the transition to adult care was too abrupt, and that transition planning needed to start earlier.(5) Parents specifically noted that they wanted their children to be better integrated into their local community, and an increased focus on helping them gain a sense of accomplishment and establish healthy peer relationships though flexible wrap-around services. There was evidence that there was a lack of community resources to deal with a variety of needs including socially stigmatizing attitudes, social anxiety and social isolation. • Another two medium-quality reviews also concluded that parents themselves felt inadequately prepared for their child assuming responsibility for their own care, as well as feeling worried about their child's ability to have an education and/or a career, and to handle finances.(21; 25) An additional medium-quality review added that parents of children with both mental and physical disabilities were equally fearful that their children's futures would be unfulfilled or diminished.(11)
	Handling their own inability to 'let go'	• A medium-quality review focused specifically on the experiences of parents during transition noted that the process of 'letting go' was also particularly challenging for them, which involved stepping back from their care responsibility as well as from relationships built with pediatric providers.(11) An additional low-quality review added that families often faced a sense of loss and feared having to build a new network of support for their child.(21) • Several single studies further emphasized that parents may also experience a compromise in their own health during transition, as they struggled with balancing rejection with wanting to ensure the best care was provided for their child.(27; 28)
	Fighting as advocates for appropriate care provision	• A low-quality review focused on young people with intellectual disabilities found that uncoordinated transitions often forced parents to have to fight as advocates for their children in order to ensure appropriate care was provided in adult services.(21) This review also noted that transition was a time of emotional turmoil for parents, and that navigating a maze of absent, incorrect or often conflicting information was particularly challenging. Another medium-quality review added that parents often experienced these difficulties because of restrictive eligibility criteria and the loss of services when a young person 'aged out' of access.(11)

		• A medium-quality review also noted that parents often experienced feeling devalued and wanted to be respected as part of a team.(19) Feeling a part of a partnership in navigating the healthcare system was desired. A single study added that implementing a family facilitator-led transition peer-support group connected parents with other families who had been through the process and strengthened their network of support.(6)
Provider	Lack of service coordination	• Although service-user experiences were more commonly examined, two reviews focused on provider perspectives.(5; 15) In the first medium-quality review, providers emphasized that communication between services was extremely variable with no consistent use of formal transfer arrangements.(5) A lack of care continuity was often attributed to separate child and adult mental health systems with differing referral criteria, procedures to access services and a lack of shared client planning. • The second review, which focused solely on provider perspectives, also found that providers experience a lack of a comprehensive, coordinated, and seamless system of care. The review noted that although providers were often aware of the importance of coordinated care transitions, significant gaps remained in the actual provision of transition services.(15) Providers often faced confusion about role responsibilities during transition, especially in understanding which roles would be provided in pediatric or adult care.
	Challenges with the patient-provider relationship	• Providers also experienced challenges with the patient-provider relationship, which was also touched on in both reviews.(5; 15) • Both reviews highlighted that pediatric providers experienced difficulty in terminating their relationships with patients and their families because of the attachment that they had developed.(5; 19) Although pediatric providers often developed strong relationships with their patients, adult providers commonly struggle to actually understand the needs of adolescents and their parents.(24) These providers also found that young people would also not engage with them, or provided services because of the stigma associated with being treated.(5) Deficits in the patient's self-management skills or health limitations often impeded adequate communication.(19) • In addition to the direct patient-provider relationship, adult providers noted that excessive parental involvement was a barrier in care transitions.(24) They also noted that pediatric providers often had a lack of confidence in the adult providers' ability to provide comparable levels of care which was often a problem as well.(19)
	Limited resources	• The medium-quality review noted that although limited fiscal resources were a definite concern in preventing the development of services for young adults, the main resource barrier was a lack of leadership to increase continuity of care and prioritize this age group.(5) • The medium-quality review emphasized that inadequate training often resulted in significant provider knowledge gaps, and that a limited access to transition-related resources in a centralized and standardized format was problematic.(19) Providers' limited availability to dedicate extra time to these issues was a concern.

Key barriers and facilitators to transition

A final set of systematic reviews also aimed to identify key barriers and facilitators to care transitions with details provided in Table 3. These barriers and facilitators related to: 1) timing and preparation needs; 2) appropriate support and access to resources; and 3) coordination and continuity in care. These factors were consistent across the systematic reviews, regardless of whether they were coming from the perspective of a patient, provider or organization. Barriers and facilitators were often provided in the reviews in addition to an assessment of a transition program, as a part of the collection of stakeholder experiences, or as a synthesis of their own.

Regarding timing and preparation, it was consistently recognized across the reviews that inadequate planning prior to transition was a significant barrier, and that early and gradual preparation for transition was ideal. One medium-quality review suggested that a key facilitating factor was the patient's development of independent self-management skills prior to transition. This was in contrast to excessive parental involvement and the inability of parents and pediatric providers to let go.(29) However, this review also suggested that the time and age to start and complete transitional care was contested within the literature, with some studies suggesting that chronological age was appropriate, and others advising that a measure of developmental maturity be used. Another medium-quality review similarly suggested that patient independence in attending appointments prior to transition, a higher level of established patient self-efficacy, and patients possessing a formal written referral to a specific adult-care provider were all protectors against care gaps experienced during transition.(30) This was in contrast to having a history of missed appointments, having a lower family income, experiencing greater travel distance to a clinic, and being of the male gender. A medium-quality review additionally highlighted that a lack of transfer itself was most commonly due to the service user refusing to accept a referral to adult services or the child providers not making a referral in the first place.(5) In terms of enabling a positive transition experience, transition planning meetings between providers, youth and parents, periods of parallel care with both pediatric and adult providers, and the provision of preparation materials, transfer timelines, key contact information and a portfolio of healthcare information were all facilitators to adequately preparing.(5; 11; 13)

In addition to preparatory considerations, providing the appropriate types of support and accessible resources during transition was also identified as fundamental across the literature. One medium-quality review suggested that identifying the most appropriate care for the young adult was facilitated by joint working and information sharing between providers, youth and parents.(13) This type of communication was also found to help develop therapeutic patient-provider relationships, something identified as important by service users.(5; 13) Although adult-centred providers who failed to recognize the needs of young adults beyond their diagnosis were seen as barriers to providing appropriate support, providers who acknowledged holistic needs pertaining to education, vocation, housing, independence, social interactions, body image, sexual health, alcohol and drugs, and anxiety were facilitators.(31) However, from the perspective of providers, a key barrier preventing the provision of appropriate transitional care was that they faced limited access to relevant resources that helped them identify and address patient transition needs.(15) Patients also faced significant barriers to accessing support services, which was the result of limited resources to help identify and complement services, limited availability of provider's time to actually deliver or link services, limited health-insurance coverage for new services, long waiting lists to access recommended services, and a lack of tracking mechanisms that could help providers follow up with patients regarding their service use.(29)

Finally, in addition to concerns about timely preparation and appropriate accessible support, issues surrounding coordinated and continuous care delivery often shaped positive transitional care. Barriers to coordinated care usually resulted from the gaps that existed between pediatric and adult systems, where no information was provided to patients and families about the changes they would face.(26) Often, these gaps existed:

- logistically, in terms of inter-system communication methods;
- clinically, in terms of how clinical responsibility was assigned;
- organizationally, in terms of separate funding and governance structures; and
- culturally, in terms of differing norms and attitudes.(13)

Although excessive parental involvement was identified as a barrier preventing patients from preparing for transition, their role as a dependable facilitator and care advocate during transition was often a central component of continuity.(11; 29) Similarly, assigning a consistent cross-service coordinator during transition and/or establishing jointly staffed transition clinics helped close the systematic gaps between care services.(21; 31) Beyond coordinating care between pediatric and adult-care services, several reviews noted that coordination was also needed between care providers and patients as well as between care providers and other service providers outside of the care setting. For example, a low-quality review suggested that recognizing care transition as a multi-dimensional and multi-agency process is essential, where the perspectives patients need to be accounted for and collaborative efforts need to be made between multiple sectors.(21) Incorporating feedback from a range of stakeholders, identifying what services are required and who will provide them, and subsequently monitoring and evaluating these processes were noted to help guide delivery best practices.(31)

Table 3: Barriers and facilitators of transitional care identified in systematic reviews

Focus of the barriers and facilitators	Key findings
Transition timing and preparation needs	The majority of studies which highlighted key barriers and facilitators to transition suggested that the time taken to adequately prepare, the development of key preparatory skills, and the identification of predetermining factors that facilitate or inhibit transition success were crucial considerations. For example: • A medium-quality review suggested that a key facilitating factor was the patient's development of independent self-management skills prior to transition. This was in contrast to excessive parental involvement and the inability of parents and pediatric providers to let go.(29) Other preparation barriers related to patients not being referred to a specific adult provider, patients not being offered a visit to adult care prior to transition. and the patient's health condition complexity. • This review also suggested that the timing to prepare patients, the preferred time of transition and the age at which the transition occurs were key issues explored in a variety of studies.(29) Overall, there was little consensus about appropriate timing of preparation and the transition itself, with some studies suggesting that chronological age was appropriate, where others suggested that a measure of maturity be implemented. • Another medium-quality review similarly suggested that patient independence in attending appointments prior to transition, a higher level of established patient self-efficacy, and patients possessing a formal written referral to a specific adult-care provider were all factors protecting against care gaps experienced during transition.(30) However, this review also highlighted that factors such as a history of at least one missed appointment, having lower family income, experiencing greater travel distance to a clinic, and being of the male gender were predetermined characteristic barriers that may suggest a more targeted approach.(30) • A high-quality review which identified key barriers and facilitators to transition suggested that transition planning meetings between providers, youth and parents prior to transition was a key factor in promoting subsequent care continuity.(13) This review also suggested that in regards to provider preparation needs, capacity building through training and education was crucial to promote subsequent engagement in transfer-related activities. Similarly, two low-quality reviews identified that providers having limited time to dedicate toward transition preparation. and providers facing gaps in knowledge, training and experience in transitional care were significant issues.(15; 31) • A medium-quality review additionally highlighted that a lack of transfer itself was most commonly due to either the service user refusing to accept a referral to adult services or the youth providers not making a referral in the first place.(5) In terms of facilitating a positive transition experience, the review noted that gradual preparation with transition planning meetings and periods of parallel care prior to transition were preferred. • Similarly, another medium quality review suggested that joint meetings with both pediatric and adult providers prior to transfer, in addition to the provision of preparation materials, transfer timelines, provider contact information and portfolio of healthcare information, were crucial in adequately preparing for a successful transfer.(11) • Finally, a low-quality review highlighted that in addition to having a significant time period before transition where young adults can build basic skills, flexibility in the actual timing of transfer was crucial and should be decided between the provider and the family, depending on the youth's cognitive development, physical abilities, environment and family support.(31)

Focus of the barriers and facilitators	Key findings
Appropriate support and access to relevant resources	In addition to preparatory considerations, providing the most appropriate support during transition and giving better access to relevant resources was a commonly discussed factor. For example: • One medium-quality review suggested that identifying the most appropriate care for the young adult was facilitated by joint working and information sharing between providers, youth and parents.(13) This type of communication was also found to help develop therapeutic patient-provider relationships, something identified as important by service users.(13; 29) • A low-quality review emphasized that interested adult-centred healthcare providers who focus not only on the patient's health condition, but also on more holistic issues regarding independence, social interactions, body image, sexual health, alcohol and drugs, and anxiety, was a key facilitator.(31) In addition, addressing financial planning, continuing education, and vocational training was identified as especially appropriate for this age group and should also begin before the transition. • From the perspective of providers, a key barrier preventing the provision of appropriate transitional care was that there was limited access to relevant resources.(15) Providers didn't know where to access resources and noted that a lack of a centralized repository for such information was a significant concern. • Another medium-quality review concluded that the accessibility of services to service users, even if they were provided, was a significant barrier in transitional care. This lack of access often resulted from limited resources which helped identify and support services, limited availability of the provider's time to actually provide or link services, limited health-insurance coverage to a diverse range of services that were often provided in child care, long waiting lists to access new services, and a lack of a tracking mechanism that providers could use to follow up to make sure service access was sustained.(29) • A low-quality review focused on intellectual disabilities similarly found that a key factor in 'making transitions happen' related to ensuring that policies and procedures were in place to account for patients' complex service needs.(21) In the case of intellectual disabilities, acknowledging parental expertise was essential in enabling successful transition. Providing parents with access to transparent information about medical records, resources to better navigate the health system, and supports to foster networking and advocacy skills were crucial in facilitating comprehensive support.
Coordination and continuity in care	Even if preparatory considerations were addressed and appropriate services were made accessible, often gaps in the coordination and continuity of care inhibited success in transitional care. For example: • One medium-quality review highlighted that the obstacles faced by service users in transition majorly pertained to service gaps, which often reflected the significant differences between child and adult-care systems.(26) The support services offered in adult care often substantially differed from those in child care, and the information available about these changes was limited. The review also added that limited transferring of key clinical information regarding a patient's condition and their management was a significant barrier. • A different medium-quality review suggested that the factors which led to gaps in care often existed at several levels.(13) First, from a logistical perspective, cost considerations and limited inter-system communications often inhibited continuity in care. Providers often had limited experience with or understanding of care transitions, and there was little financial capacity to dedicate to improving this. Second, at the organizational level, there were often different and unaligned incentives in providing care, and opposing governance structures in decision-making. Third, at a clinical level, clinical governance issues, which usually pertained to clinical responsibility in providing care, caused providers to be uncertain about if/how their roles incorporated transitional care. Finally, from a cultural perspective, differences in the beliefs, approaches, attitudes and language toward care were notable between child and adult systems. Child services were described as proactive, family-oriented, inclusive and holistic, whereas adult services usually neglected to focus on broader social determinants of health, intervening with medication or crisis management.

Focus of the barriers and facilitators	Key findings
	• This same review noted that regarding facilitators to transition, adding a cross-service worker in child and adult care would help prioritize the needs of youth within adult services, promote a standardized process for making referrals, improve the scope for a holistic focus on social determinants of health, and increase more consistent communication.(13) They specifically noted that a peer support worker who could engage with youth and providers might also be supportive. • A medium-quality review noted that although excessive parental involvement was highlighted as a barrier which inhibited successful transitions, parents acting as key facilitators to provide consistency in care was also noted as an important facilitator.(12) In a medium-quality review, parents identified that in addition to specific care services, receiving familial, personal and networking supports were facilitators in their transition and helped them advocate for comprehensive coordinated care.(11) • A low-quality review identified that the major facilitator to helping 'make transitions happen' related to recognizing care transition as a multi-dimensional and multi-agency process where the holistic needs of patients need to be accounted for through the collaborative efforts of multiple sectors.(21) Clear roles and responsibilities for providers, education and resources for young adults and their families, and the identification of a key worker to coordinate care were all described. • This same review also suggested that assigning a transition coordinator helped facilitate the assurance that individual care needs were met, essential information was communicated, and coordinated handovers were completed. Specifically, a commitment to follow up after transition and the establishment of transition outcomes were helpful in identifying what a patient's transition needs were and whether these needs were actually met.(21) • A low-quality review specifically highlighted that any type of transition planning should use a coordinated approach, specifically incorporating feedback from the patients, their family, the pediatrician, the primary-care physician, and the adult providers.(31) The review describes that pediatrics providing a medical summary including the details of current treatments and recommendations to adult providers would facilitate a more seamless transition. The subsequent identification of what services will be required and who will provide them during and after transition is equally as supportive. Monitoring and evaluating these processes can help guide organizational best practice. • This same review also highlights that transition clinics might be especially helpful in facilitating care transitions as young adults can consult with both pediatric and adult providers, can connect with other peers and can practise becoming more independent in their own decision-making.(31)

Recommendations for improving transitional care

In addition to the main results, several reviews compiled recommendations for improving transitional care, which were either a result of suggestions from stakeholders or a synthesis of their main findings. We organized these recommendations into nine thematic groupings, which are presented below and expanded on in Table 4.

1) Improving service integration
2) Preparing for transition earlier
3) Providing developmentally appropriate care
4) Focusing on patient engagement
5) Supporting families and parents
6) Facilitating peer support
7) Developing transition programs/procedures/policy
8) Increasing capacity to provide transition services
9) Enhancing provider education

Table 4: Recommendations for improving transitional care identified in systematic reviews

Recommendations	Key features
1. Improving service integration	• One medium-quality review concluded that the results of their systematic review suggest that greater integration between pediatric and adult services is needed.(13) Although financial costs may be prohibitive, collaborative working, individual case management and structured wraparound services are approaches that would help serve as a bridge between disjointed systems. A different medium-quality review also suggested that regular meetings, shared protocols, joint clinics, transfer summary templates and designated transition coordinators are approaches to better increase collaboration between services.(24) • Another medium-quality review recommended that regular transition consultations with a multidisciplinary team be scheduled well in advance of planned transfers.(22) Key medical information should be seamlessly transferred between providers and patients, often in the form of a 'health passport', and patients should also experience an overlap in care where they have access to both pediatric and adult providers during transition.(22; 31)
2. Preparing for transition earlier	• One low-quality review assessed recommendations for transitional care from the perspective of patients and it was suggested that they would like to start preparation early to gain a sense of control and acquire skills necessary to take more responsibility.(20) This review further recommends that transition should be presented as a normative event throughout pediatric care and that it not be presented as an abrupt shock. • A medium-quality review also suggests that discussions about transition should occur in early adolescence to promote the development of self-care skills.(17) This review further suggests that young adults should also have the opportunity to meet adult providers prior to transition. Another low-quality review suggests that clinicians themselves have a responsibility to foster the autonomy in young adults through clinician-patient communication.(31) • A medium-quality review concluded that patients wanted more information on the transition to care, transition and adult resources, and community referrals, emphasizing that transfers should only happen after adequate preparation has been given and during a time of condition stability.(26) A different review further added that early strategies to promote independence should consider using the internet and other technology-based initiatives.(22)
3. Providing developmentally appropriate, confidential care	• In a low-quality review which synthesized patient recommendations, patients suggested that services providing developmentally appropriate and confidential care, balancing formality and nurturing, would be beneficial.(20) A different medium-quality review further added that services which are responsive, accessible and holistic regarding the needs of young adults are essential.(5) • A medium-quality review which also synthesized patient recommendations concluded that patients wanted care to be more individualized, desiring providers who were empathetic, communicative and had an established knowledge about their health needs. They also wanted their care to include access to services from other systems such as education and employment.(26)
4. Focusing on patient engagement	• A medium-quality review concluded that patients not only wanted to have their care individualized, but also wanted to be involved as full participants in the development of their care planning.(26) Clarifying and discussing the patient's own expectations about the transition process should help set benchmarks for subsequent care.(20) • A low-quality review further recommended that the specific needs of young people must be acknowledged, and that subsequent services should focus on embedding a coordinated approach to planning, where clear roles and responsibilities are set out.(21) Transition should always be a stepped process that continuously incorporates the priorities and concerns of patients.(22)
5. Supporting families and parents	• A medium-quality review recommended that care be family-centred, and that patients and their families would both benefit from continuous support to address their needs over time.(25) A different medium-quality review concluded that providers must also find ways to include parents in the care of young adults in a way that still ensures the patient's autonomy and privacy.(24)

Recommendations	Key features
	• However, a different medium-quality review focused on the perspectives of parents concluded that although transition recommendations often incorporate support services for parents, the literature available to inform and guide practice is limited.(11)
6. Facilitating peer support	• A medium-quality review suggested that providing opportunities for young adults to receive peer support from others with shared experiences is recommended.(22) • This same review further suggested that first appointments in adult care could be arranged at times where other young adults are also there in order to help minimize feelings of displacement and loss.(22)
7. Developing transition programs/ procedures/policy	• A medium-quality review concluded that structured transition programs should be universal and incorporate a developmental approach, recognize broader lifestyle implications, help patients build self-advocacy, and focus on allowing patients to better navigate the care system.(24) • A different low-quality review further suggests acknowledging patient-transition needs at a strategic level through collaborative inter-agency policy development is imperative.(21) Policy should be informed by existing quality standards and models focusing on coordination through clear roles and responsibilities.
8. Increasing capacity to provide transition services	• A medium-quality review specifically recommended that in order for any holistic transitional care to be implemented, there is a need to expand capacity to provide these transition services.(5) A different low-quality review further emphasized that adequate funding and resources must be allocated for young-adult patients with complex needs, which included government funding for specialized programs.(31)
9. Enhancing provider education	• In the clinical implications of a low-quality review, it was recommended that key concepts regarding care transitions must also be translated into the curricula of nursing, rehabilitation and medical schools.(31) A different medium-quality review focused on recommendations for nurses further suggested that there be an increased focus on capacity building through education, program development and continuous evaluation.(19) • In a low-quality review focused on provider perspectives, providers recommended that in addition to education, the development of accessible resources, the development of new services, and making improvements to already established programs be a focus to better enable successful care transitions in practice.(15)

Findings from a system analysis of transitional care programs and tools

Our system analysis of transitional care programs and tools included a jurisdictional scan and interviews with key informants to identify examples of how transitions from child to adult care for people with special needs are supported in provincial and territorial health systems in Canada. We provide the findings from each below.

Key findings from a jurisdictional scan of programs and tools for supporting care transitions

Our jurisdictional scan identified 13 specific tools that assisted with the transition from pediatric to adult care (see Table 5). These programs and tools are implemented on a national, provincial or hospital/community level. To conduct the scan, we identified tools from a preliminary scan that had been conducted by the requestor of this rapid synthesis (CanChild) and from members of a network focused on supporting transitions from pediatric to adult care. We then identified details about each example through reviewing websites and other documentation. However, in many cases the details about the programs and tools identified were limited. We provide a summary of details for each example in Table 5. Additionally, a number of programs and clinics were identified, many of which implement these tools. Additional details extracted about each tool, clinic or program (where possible) are presented in Appendix 3.

A number of tools were identified that have been implemented to aid with transition on a national level. The Good 2 Go Transition Program at SickKids Hospital in Toronto developed tools that have been implemented by various jurisdictions across Canada. The MyHealth 3-Sentence Summary allows youth to create a list of statements relating to: 1) their age, name, condition, and medical history; 2) treatment plan; and 3) questions for their next medical visit. The MyHealth Passport was created by researchers at SickKids, and allows youth to create a wallet-sized card that includes information such as medical history, medications and other health information. The former Good 2 Go Program has now been integrated with hospital services at SickKids.(32)

The MyTransition App was developed by researchers at McMaster University in Hamilton to assist with transitions in healthcare. This app includes a number of components, including the MyHealth 3-Sentence Summary and MyHealth Passport. Additionally, this app includes the TRANSITION-Q scale, which measures a person's transition readiness and ability to self-manage with a variety of quantifiable questions. The MyTransition App has been adopted by a number of healthcare organizations nationally, and tools of the application have been implemented across many jurisdictions as well.(33)

Further on a national level, the KIT: Keeping it Together for Youth tool is a transition tool developed by the CanChild Centre for Childhood Disability Research and the Hamilton Family Network. This tool includes a user guide, transition workbook, and educational videos that are accessible online. A physical copy of the organizational workbook, which allows youth to record information about their health, school and work, can also be ordered and/or downloaded.(34)

A number of tools and programs were identified that function at a provincial or territorial level. In British Columbia, ON TRAC is an online toolkit including resources such as transition timelines, family checklist and quizzes for youth.(35) The British Columbia Pediatric Society has developed the Youth Mental Health Transition Protocol Agreement, which is available to youth transitioning to adult mental health and substance-use services. This agreement targets youth aged 17 to 21, and outlines guidelines for supporting youth. These guidelines include expectations for transition plans and assessment of youth fit for Health Authority Adult Mental Health and Substance Use services.(36) The Doctors of BC have developed a number of Transition Care Management Plans, which are online tools accessible to healthcare providers managing patients in transition. These management plans were developed with the goal of ensuring a smooth transition process for youth with specific neurological and cardiac conditions, and include components such as referral flowsheets and care frameworks for patients at different levels of risk.(37)

In Alberta, the Launch™ program by the Sinneave Family Foundation supports emerging adults with Autism Spectrum Disorder with a range of services available online and in-person. Planning supports such as video modules, group workshops and individual coaching are designed to support people with autism as they transition from youth and school to the community.(38) Alberta Health Services have also developed Well on Your Way, transition tools available online and to patients at the Alberta Children's Hospital. These resources include transition guidelines for youth, readiness checklists for youth and parents, and planning tools for families. Cerebral Palsy Alberta also supports youth with Cerebral Palsy transitioning to adult health services by providing individual counselling, group support and transition workshops.(39)

A number of tools and resources were identified that are available on a local, hospital or community-based level across Canada. A number of hospitals have implemented online and/or in-person resources designed to support youth in their transition to adult healthcare. Tools vary between jurisdictions, and include group workshops, life skills coaching, fact sheets and transition handbooks. Many hospitals have implemented popular transition tools such as preparation checklists, MyHealth Passport, MyHealth 3-Sentence Summary, and transfer-readiness checklists.

Table 5 provides details on the mechanisms of these various transition tools. Additionally, each tool emphasizes various recommendations from the Canadian Association of Pediatric Health Centres (CAPHC) National Transitions Community of Practice guideline. The ways in which tools emphasize particular recommendations was determined by stakeholders, and may be dynamic in many cases. Further consultation and monitoring of the effectiveness of these tools is indicated.

Table 5: Overview of tools designed to support transitions from child to adult care for young people with special healthcare needs in Canada

Organization	Programs/tools	Jurisdiction	Focus	Transition age	Method of intervention
BC Children's Hospital (35)	ON TRAC	British Columbia	• Chronic disease/disability	• Youth ages 12-24	• Accessible online without a referral • Integrated toolkit including resources for healthcare providers, families and youth
British Columbia Pediatric Society (40)	Transition Tools and Resources	British Columbia	• Mental health disorders	• Youth ages 17-21	• Accessible to youth transitioning to adult mental health and substance-use services • Health authorities and physicians assist in transitioning services in collaboration with youth and families • Toolkit includes transition timeline, medical transfer summaries, physician location, support for physicians, community resources
Doctors of BC (37)	Transition Care Management Plans	British Columbia	• Neurological and cardiac conditions	• Youth ages 18-25	• Accessible online to healthcare providers managing patients in transition • Templates for collaborative care in transition, developed for a range of specific conditions
University of British Columbia (41)	UBC Continuing Professional Development e-learning module	British Columbia	• Youth with chronic health conditions and disabilities	• Youth transitioning to adult care	• Accessible online and free to all • Four 15-minute modules focusing on transitioning youth with chronic health conditions and disabilities
Sinneave Family Foundation (38)	Launch™	Alberta	• Autism Spectrum Disorder (ASD)	• Emerging adults transitioning from school to community (13-14 years and up)	• Accessible online; mix of free and fee-for-service interventions • Planning support for caregivers and individuals (e.g., video module, group workshops, coaching)
Alberta Health Services (42)	Well on Your Way: Helping Youth Transition to Adult Healthcare	Alberta	• Chronic disease	• Youth transitioning to adulthood (ages 12-17 years and up)	• Accessible online and available to patients at outpatient clinics at AB Children's Hospital • Supports healthcare providers, patients and families • Resources include transition workshops, community partnerships, planning tools
Cerebral Palsy Alberta (39)	Youth Transitions	Alberta	• Cerebral Palsy	• Youth ages 16 to 25	• Individuals can become Cerebral Palsy Association in Alberta members through a client intake form found online • Customized supports for youth with cerebral palsy transitioning to adult health services
	MyTransition App	National	• Chronic disease	• Youth ages 12-18	• Accessible online

McMaster Children's Hospital (33)					• App designed to support transition and measure skills using the TRANSITION-Q transition readiness scale
	The KIT: Keeping It Together for Youth (34)	National	• Youth with disabilities	• Youth from birth to age 21	• Organizational tool for youth with disabilities transitioning to adulthood • Accessible online; workbook encourages youth to record information related to school, budget, work, social life, personal care and life skills, and health condition/disability information
Children's Hospital of Eastern Ontario (43)	Transition to Adult Care Tools	Hospital	• Chronic disease	• Youth before and during transition at age 18	• Accessible online • General toolkit and complex special needs toolkit • Access to the MyTransitionApp (developed at McMaster University)
Holland Bloorview Kids Rehabilitation Hospital (44)	Transitions to Adulthood services	Hospital and community	• Youth with disabilities	• Youth 15 years and older	• In-person services • Services include life skills coaching, occupational therapy consults, youth engagement
SickKids (32)	SickKids' Resource Navigation Service	Hospital, community, national	• Chronic disease, special needs	• Youth before and during transition at age 18	• Online and in-person services available • Services include MyHealth 3 sentence summary, information booklets, MyHealth Passport, developmental guidelines, articles on specific diseases
Surrey Place (45)	Health Care Transitions Toolkit	Community	• Youth with intellectual and developmental disabilities	• Youth ages 14-25	• Accessible online • Tools include a life-transitions guideline, capacity for decision-making guideline, decision-making checklist, guidance for healthcare providers
Children's Hospital at London Health Sciences Centre (46)	Patient transitions	Hospital	• Chronic disease	• Youth before and during transition at age 18	• Three main system-wide models: o Transition introduction in early teenage years o Clinics run by both pediatric and adult healthcare providers • Pediatric providers engaging with patients to prepare for transition
Montreal Children's Hospital (47)	Transitioning to adult-care tools	Hospital	• Chronic disease	• Youth before and during transition at age 18	• Online and in-person services available • Tools include transition preparation checklists for adolescents and parents, medical passport, transfer-readiness checklists
IWK Health Centre (48)	Transition to Adult Health Care resources	Hospital and community	• Chronic disease, mental health and addictions	• Youth before and during transition at age 18	• Online and in-person services available • Services include general transition fact sheets, transition handbooks, mental health and addictions guidelines, and community contacts

Findings from key informant interviews about how transitions for young people with special healthcare needs are supported

We spoke to 13 key informants who gave insights on their experience with transition support for young people with special healthcare needs. Key informants were identified through a national working group focused on enhancing transitions in care and based on the suggestions of those who we interviewed. Key informants were asked to describe the transition program they were involved with, who was included in the care team, how the program was structured across organizations, how the program was resourced, whether the program was evaluated, what components contributed to or hindered success, and whether they knew of any other innovated programs, services or initiatives to support transition. Informants from the Canadian provinces of Alberta, Ontario, Quebec and Nova Scotia were included, as well as representatives from Australia, the U,S. and the Netherlands. Informants also represented a variety of perspectives, approaching the topic from the viewpoint of a policymaker, manager, practitioner, researcher or a patient. Informants discussed the features of the transitions they had experienced and discussed key challenges, successes and opportunities from their own perspectives. The key features discussed among informants have been summarized below in Table 6.

Table 6: Insights from key informants about transition support for care transitions for young people with special healthcare needs

Type of insight	Features of insights	Description of insights
Key features of approaches to support transition	Not reinventing the wheel; using generic tools and guidelines	• Several key informants emphasized the importance of developing generic tools and guidelines that can be centrally accessed and further adapted and applied for specific conditions. • They emphasized that many different models exist, but that a lot are not actually taken up or sustained in practice because there is a lack of broad support. • Focusing on developing a comprehensive approach that can be used by clinics, parents and/or patients was identified as a priority.
	There is no silver bullet solution; focus on the approach, processes and navigation	• A shared insight among informants was that transitions were complex and that no silver bullet solution would be universally applicable. • Instead of continuing to search for the 'perfect' mix of tools, focusing on supporting comprehensive service navigation, improving processes of care transitions and widely communicating shared approaches to follow were seen as essential. • Some jurisdictions focused on supporting process mapping in clinics to help identify who was in charge and how transfer worked. • Others focused on establishing concrete knowledge of the services and supports within and outside of care that they could connect people to. One informant mentioned that it doesn't necessarily matter who it is done by or how it is done.
	Better recognizing what patients want, need and have access to	• Informants acknowledged that although their services were ultimately employed to support patients, there was often a gap in recognizing what patients wanted, needed and had access to. • Peer-facilitated workshops and patient partnering were theorized to allow like-peers to connect, but in practice, several informants found that these approaches were not suitable. Patients often didn't want another visit on top of everything else and if they did attend, quality engagement was difficult to achieve. In addition, some patients were in remote locations or had circumstances that made it hard for them to navigate their care options.

Type of insight	Features of insights	Description of insights
		- One practitioner informant suggested that youth were reluctant to carry around a piece of paper such as a 'Health Passport', and often were more concerned about other social considerations outside of their healthcare. - One parent informant suggested that even though schools are where youth spend most of their time, schools are often not equipped to handle special care needs. In order to get access to further support services outside of immediate care, patients have to emphasize what they can't do rather than what they can.
	The role of a 'transition coordinator' differs considerably	- Another common theme across key informant interviews was that the responsibilities of a 'transition coordinator' varied significantly. - Not only were transition coordinators employed at different hours and for different durations, but some were focused exclusively on supporting systems navigation and making resources available, while some were more directly involved with patients and provided a 'familiar face' during times of transition. - In the literature it was often not clear what the distinguishing features of transition coordinators were.
	Joint transition clinics are often impractical	- Several informants, which included a number of physicians, suggested that joint clinics attended by both pediatric and adult staff were logistically challenging to operate and not feasible as a long-term solution. Pediatric and adult systems are discrete in their functioning, and other methods to support transition may be more applicable. - One informant suggested that a developmental clinic run by two interested physicians once a week was a positive initiative, but concluded that it was generally not well known and might not have the capacity to upscale.
	Evaluation of transition success has not been a priority	- Nearly all key informants suggested that employing methods to measure the success of transition was not a priority and often not feasible. A 'successful' transition was seen as difficult to define and there were limitations with almost every measurement approach. - Several informants described that qualitative feedback pre- and post-transfer was sometimes used to gain an understanding of whether patients were satisfied with their experience, but that linking data to health outcomes or other long-term considerations was not done. - One practitioner informant suggested that linking data such as emergency visits and loss to follow-up might be more feasible and useful if online patient documentation was further developed. - Another informant suggested that their transition program lost funding from administration because measures were focused on the number of tools provided, patient's readiness for transition and patient satisfaction, rather than on economic cost-benefit analyses and health-outcome measures. - Getting patients to attend their first adult appointment was seen as a 'success' in the short term, but measuring whether a young person was better able to reach their long-term potential was challenging. - A final informant suggested that adolescence is a difficult time to sustain adherence across many health-related interventions.
	Advocacy, leadership and framing to	- A number of key informants, especially those who felt they had made progress in supporting transition, suggested that strong advocacy for transition support, putting dedicated leaders in place, and framing

Type of insight	Features of insights	Description of insights
	communicate the need for transition support	transition as a necessary component of care, were essential to prompting a wider interest in the need for transition support. • Several informants were worried about the sustainability of transition-coordinator positions and expressed concern that not enough clinicians worried about transition-related issues in the first place. • One informant cited that their transition service was initiated by one individual who approached the hospital foundation to back putting transition support into practice. • Other informants cited that awareness of transitions was the first step in making progress; people won't use any tools or frameworks if they don't care about the issue in the first place.
Features of challenges in supporting transition	Patient burnout; developmentally sensitive time	• Key informants expressed that patients experiencing 'burnout' during transition made discussing the tough issues difficult. • Framing transition as a component of care more explicitly from the beginning of a youth's journey might mitigate some of the added stress. • One informant suggested that working on small building blocks spread out over a longer duration would be an approach to better ensure patient needs are met. • Adolescence is a developmentally challenging time to be transferring care and removing the immediacy of a transfer experience was cited as beneficial.
	Distance to supports and travel required	• Most key informants revealed that helping patients in remote locations was a definite challenge. • Travel distance often prevented transitional care from being provisioned, and prevented patients and caregivers from getting to better know their care teams and be active partners.
	The differing needs of parents and siblings	• In addition to recognizing the diversity of patients who require unique needs, parents, siblings and other close relatives have their own needs which often manifest in different ways and require separate supports. • A number of informants suggested that social groups meant for patients were often more relevant for parents. • One informant advocated that although parents and patients are often accounted for in transitional support, siblings often struggle with their role during this challenging time.
	Sustained resources are limited (staff, time and money)	• Many informants suggested that a lack of resources was often the fundamental limiting factor in adequately supporting transition. • These resources included the availability of dedicated staff, the time necessary to properly engage, and the money required to implement services and resources. • The sustainability of transition services over time was also a major concern. Many programs were funded for a limited duration and were often reliant on the initiative of one individual. These issues limited capacity and made it difficult to implement broad advertising. • From a user perspective, sourcing out other services often took time, and if they were accessed, the waitlist to receive support was long.
	Little provider interest, combined with differences in care philosophies	• Concern about the lack of widespread interest, especially among physician providers, was evident in most key informant interviews. • If there is a lack of incentive to support transition, the development of even the best tools would not be relevant.

Type of insight	Features of insights	Description of insights
		• Most informants pointed to the distinct systems, policies and philosophies of the adult and pediatric systems and that there were often limited relationships to build upon.
	Shifts in leadership in service provision and policymaking	• In addition to the shift of personnel within transition support services, which were often reliant on the knowledge and initiative of that one person, shifts in administrative and political leadership were huge barriers to overcome for practitioners and patients.
	Inadequate information-sharing systems	• Although specific details were not provided, informants cited that inadequate systems to share and store information inhibited ongoing care management, long-term patient follow-up and a lack of general knowledge about outcomes.
Features of successes and opportunities to support transition	Focus on building relationships first, both with patients and across stakeholder groups	• The importance of 'building relationships first' was a key facilitator mentioned by several informants. • One informant who described a successful transition service attributed their success to concentrating on building partnerships with adult-care teams and community groups, building a profile as a service through responding to patient and family feedback, and building a reputation among clinicians in their own hospital. • Transition coordinators attributed success on an individual patient level to meeting face-to-face with patients and caregivers, establishing familiarity before transition commenced. • Finally, a coordinator who focused on service navigation attributed success to getting as familiar as possible with local agencies in order to efficiently connect patients to the right resources.
	Individual leadership, advocacy and education to spread awareness and spur motivation	• One informant who described a successful transition service suggested that putting in place leaders to spearhead initiatives and spread awareness was a key component of their service gaining recognition and subsequent support. • Many of the informants had found success in 'getting others on board' and making sure the issue of transition support was known widely.
	Moving away from finding the silver bullet of a method, and focus on supporting system navigation	• As mentioned above, a number of key informants suggested moving away from searching for the 'perfect' mix of tools, and focusing on supporting comprehensive service navigation, improving processes of care transitions, and widely communicating shared approaches. • Many of the issues that patients and caregivers face occur at the system level (i.e., different eligibility criteria for youth and adults), which can be difficult for any one individual to overcome.
	Using telehealth, virtual care, apps and social media	• Finally, although most informants didn't know how this would manifest in practice, many mentioned that capitalizing on telehealth, virtual care and social media to connect with patients and partners would be key in providing transition support.

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APPENDICES

The following tables provide detailed information about the systematic reviews and primary studies identified in the rapid synthesis. The ensuing information was extracted from the following sources:

- systematic reviews - the focus of the review, key findings, last year the literature was searched, and the proportion of studies conducted in Canada;
- primary studies - the focus of the study, methods used, study sample, jurisdiction studied, key features of the intervention and the study findings (based on the outcomes reported in the study); and
- websites: details of programs and tools were extracted from websites.

For the appendix table providing details about the systematic reviews, the fourth column presents a rating of the overall quality of each review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered "high scores." A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8).

All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Appendix 1: Summary of findings from systematic reviews about features of approaches to supporting transitions from child to adult care for young people with special healthcare needs in Canada

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
Evaluating the effectiveness of interventions that aim to support young people with chronic conditions as they transition to adult care (2)	• This review included four studies that covered spina bifida, heart disease, Type 1 diabetes and a range of chronic conditions. • The following transitional care programs were described: o A one-on-one meeting with a nurse and a 'health passport' ▪ The session included discussion about the transition importance, confidentiality, their cardiac condition, complications, medication, contact names, and relevant websites. Case studies were used to address health behaviour and written materials were supplied. The 'health passport' included the name of their cardiac condition, previous cardiac interventions, medication names and purposes, and if there was a need for endocarditis prophylaxis. o A web- and SMS-based educational intervention ▪ Involved an eight-month program that targeted self-management of monitoring disease symptoms, appropriate treatments, and working with healthcare providers to manage care. Participants received themed online materials and tailored text messages to ensure the content was understood and to reinforce concepts. Participants could also report health concerns. It was not clear who delivered the intervention. o A structured transition program with a transition coordinator ▪ The transition coordinator was used to make the first adult diabetes service appointment and provide their contact details. The intervention participants received adult diabetic services, directions and transport, useful websites, information about personal diabetic healthcare, and a formal referral letter. This was followed by four phone calls (in the first week, and at three, six and 12 months) to provide support and discuss well-being, life events, transition difficulties, and contact with adult diabetic services. o A two-day workshop in transition preparation training ▪ Three modules assessed goals (related to health, school, community living, housing, recreation and leisure), facilitated the creation of a comprehensive transition plan (identifying service needs, service referrals, and contact information) and practised strategies for obtaining services (role-playing, one on-one sessions, coaching, audio-visual aids, internet and mentored learning). It was not clear who delivered the intervention. • The one-on-one nurse-led intervention and the web/SMS intervention suggest that these interventions may lead to slight improvements in transitional readiness and chronic disease self-management.	2015	9/10 (AMSTAR rating from McMaster Health Forum)	1/4
Identifying determinants of care gaps in	• This review included 10 studies that covered sickle cell disease, congenital heart disease, congenital adrenal hyperplasia and juvenile idiopathic arthritis. • Risk factors and protective factors of care gaps were identified and categorized:	2014	5/9 (AMSTAR rating from	4/10

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
young people with chronic conditions as they transition to adulthood (30)	o Demographics: ▪ Risks: Living independently from parents, male gender, lower family income, and greater travel distance to adult specialized clinic. ▪ Protectors: Older age of the patient at the last pediatric visit was reported to be either a risk factor or a protective factor. o Disease-related characteristics: ▪ Risks: Milder disease activity, severity and complexity. ▪ Protectors: Having at least one comorbid condition. o Use of healthcare services: ▪ Risks: Fewer outpatient visits in pediatric care over the three-year period before transfer, the last visit taking place outside a university hospital, childhood hospitalizations, and a history of at least one missed appointment. ▪ Protectors: Having a written referral to a specific professional who would provide adult follow-up care and attending the first or second outpatient visit in an adult clinic. o Patient behaviour: ▪ Protectors: Greater independence in attending appointments, belief that follow-up should be continued in specialized adult care, higher levels of self-efficacy, abstaining from substance use, and full compliance with antibiotic prophylaxis regimens.		McMaster Health Forum)	
Reviewing the evidence of the effectiveness of transitional care programs in young people with chronic conditions (10)	• This review included 10 studies which examined diabetes mellitus, cystic fibrosis and organ transplant recipients. • Programs were reviewed and categorized by type. Their features are described: o Patient-focused: ▪ Disease-specific education that aimed to improve transition understanding and self-management skills. Strategies included one-on-one teaching, printed materials, websites, and group-peer sessions. ▪ Generic skills training to increase overall autonomy and ability to navigate the health system. Strategies included one-on-one teaching and internet-skills training. o Staffing-focused: ▪ Named transition coordinators were assigned to improve the continuity of care in the transition process and help the patient plan and prepare. Strategies included providing a single point of contact, attending each appointment, emotional and psychological aid, and administrative support. ▪ Joint clinics run by pediatric and adult physicians to facilitate a gradual transition, improve continuity and improve information sharing. Attendance of staff from different services or clinics was a defining feature. o Service delivery-focused: ▪ Separate young-adult clinics helped young people feel less out of place. The young-adult clinics were held on different days from general clinics.	2010	5/10 (AMSTAR rating from McMaster Health Forum)	2/10

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	▪ Out-of-hours phone support was designed to provide support to young people at times convenient to them. Advice on management of complications and self-management was a focus. ▪ Enhanced follow-up was initiated if there was a known increase in failed attendance during adolescence. Phone calls were made to encourage patients. • The studies tended to focus on health outcomes, not on outcomes reflecting a holistic transition process.			
Reviewing the impact of transition interventions for young people with chronic conditions (14)	• The review included five studies which encompassed patients with Type 1 diabetes and sickle cell disease. • The transition intervention varied greatly in their activities, frequency of contact, and types of healthcare providers. Their features were described: o A systems navigator aids transitioned patients by maintaining phone and email contact, providing support and identifying barriers to accessing services. The navigator provides resources such as websites, drop-in groups and education events. o A pediatric-nurse care manager provides a tour of the adult clinics, organizes a luncheon with pediatric staff, and makes appointments with adult providers. o A transition coordinator makes the first appointment with adult care, provides patients with their contact details, the adult-care contact details, website resources, personal health information and a formal referral. The coordinator also provides regular telephone support over the first year. o The pediatric physician identifies patients ready for transition and offers them the option to continue attending a young person's morning clinic occurring bi-monthly. o The pediatric physician sends a letter informing the adolescent and family about the transition process, while a transition coordinator follows the patient throughout their last year in pediatric care. Both pediatric and adult providers jointly conduct the last visit in pediatric services and the first visit in the adult clinic. • Three of the five studies (the systems navigator, the pediatric-nurse care manager and the physician joint visits) found that the transition intervention was associated with increased rates of transfer while the other two showed no statistically significant effects.	2015	4/9 (AMSTAR rating from McMaster Health Forum)	1/5
Identifying differences in care philosophies as youth transition to adult mental health services (23)	• The review included 11 studies and suggested that there are consistent differences in care philosophies between youth versus adult mental health services as described below: o Developmental versus Diagnostic Approaches ▪ Youth services tended to consider youth and their current developmental difficulties as being shaped by biological, psychological and social factors. Services were provided to address this wide range of considerations. ▪ Adult mental health services tended to focus on mental illness management, paying less attention to developmental concerns. Psychopharmacology was described as the central approach. o Family/Social versus Individualistic Approaches	2013	6/9 (AMSTAR rating from McMaster Health Forum)	0/11

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	▪ Youth services tended to approach problems within a social context of family, school and other social factors. A networked approach was considered for service delivery. ▪ Adult services considered patients to be autonomous adults with less focus on family or social contexts. o Protective versus Responsibility Approach ▪ Youth providers tended to focus on being protective and nurturing. ▪ Adult providers aimed to respect adult autonomy and expected patients to be responsible and self-motivated. • Better understanding of philosophical differences, planning and service delivery may foster shared approaches between child, adolescent and adult mental health services to better meet the needs of transitioning youth.			
Assessing healthcare-transition (HCT) service models to enable the transition of children with special care needs into (7)	• This review included 18 studies which covered Type 1 diabetes, sickle cell disease, organ transplants, juvenile idiopathic arthritis, cystic fibrosis, noncategorical developmental disabilities, inflammatory bowel disease, and perinatally acquired human immunodeficiency virus. • The features of the HCT service models were described relatively generally. o Five studies' transfer-of-care protocols addressed referrals to primary-care providers. o Eight studies indicated that a medical summary was a component of care transfer. o Six intervention models included separate services and supports for parents or involved the parents in the service model. o Nine of the studies reported the use of a service coordinator within the HCT service model. The disciplines of this service coordinator varied. o Four of the studies reported community-based referrals to transition and adult services for employment, post-secondary education and training purposes. • The study reported that the studies they included generally failed to describe the details of the intervention, including its description, frequency and intensity.	2013	4/11 (AMSTAR rating from McMaster Health Forum)	3/18
Assessing the evidence on programs/services aimed to address youth-to-adult transition in mental health services (13)	• This review included six studies, two of which had mental health care transition programs. Features were described generally. o One transition program included treatments for mental illness and substance abuse and included a mobile peer-support specialist to introduce transitioning youth to the intervention. Personalized support included having transition staff accompany youth to a college or job site. o A young-adult service (YAS) program emphasized the need to create and maintain stable, strong bonding relationships for each of their various supports, and to not reject or eject any youth from treatment. o In both programs, personal independence was promoted with therapeutic groups on relationships, dating, housing, family and roommates. Educational and vocational services assisted youth in finding higher education and employment.	2013	7/10 (AMSTAR rating from McMaster Health Forum)	0/6

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	o The studies attributed success to the incorporation of social, educational, occupational, behavioural and cognitive interventions aimed at long-term recovery and maximization of self-sufficiency. • Four studies evaluated existing mental health services in transitioning youth to adult care. o Barriers to effective transitions were categorized as: ▪ logistical (ineffective system communication between youth and adult services; ▪ organizational (differing incentives resulting from adult and youth systems having separate funding and governance structures); ▪ clinical governance (responsibility of clinical care for the youth while they transition); and ▪ cultural (differences in the beliefs, approaches, attitudes and language toward treating youth versus adults with mental illnesses). o Facilitators to transition were identified and recommend: ▪ transition-related meetings (transfer planning meetings, joint working, information transfer) between caseworkers, youth, and parents; ▪ capacity building (through training and education to engage professionals in transfer activities); and ▪ creation/addition of a cross-service worker (to shape the process of referrals across services, improve the scope for preventive work, increase possibilities of collaboration, and provide the availability of a forum for formal and informal discussions).			
Reviewing evidence on transitional care for adolescents with chronic conditions moving to adult care (6)	• This review included 15 studies which covered general chronic illnesses, including spina bifida. • This review gave little detail about the features of the studies included, but noted: o that formal transition programs generally demonstrated decreased incidence of acute events and improved satisfaction of patients; o that the current state of transitional care in patients with chronic illness is deficient in providing consistent and sufficient transfer; o there is minimal evidence indicating the optimum method or tool to employ for transitional care in patients with chronic illness; and o development and interjection of effective transition models will require meticulous consideration and collaboration of the entire health care team.	2014	3/9 (AMSTAR rating from McMaster Health Forum)	1/15
Examining patients' perspectives on factors that affect transition from child to adult care (20)	• This review included 46 studies which covered a wide range of physical chronic illnesses (studies involving patients with mental illness, learning disabilities, or cognitive impairments were excluded). • Patients' perspectives on the factors affecting their transition from child to adult healthcare were categorized by: o patients' feelings and concerns: ▪ attachment and feelings of trust toward child health care provider. ▪ negative experiences or hearing about negative experiences with adult care, ▪ having to retell their story, and	2009	3/9 (AMSTAR rating from McMaster Health Forum)	6/46

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	▪ ensuring medical records are appropriately transferred; o patients' recommendations about transition: ▪ patients favour services that provide developmentally appropriate care and a balance between formality and "babying", ▪ patients would generally like to be responsible for their healthcare by gaining a sense of control and acquiring skills. and ▪ patients often experience transition as an abrupt event and widely report joint visits with providers, as well as visits to adult care before transfer; o outcomes after transfer: ▪ positive comments include efficient adult staff, feeling like adults, having more control over decision-making and feeling more responsible about the management of their condition, ▪ negative experiences include being confronted by older and sicker patients, the loss of relationships developed in child care and that adult care was not carried out in a way that encompassed all the needs of the patients, and ▪ a large number of studies have reported that attendance to medical follow-ups suffers a decline after transfer to adult care, with patients' developmental maturity, older age, and consent to the transfer being associated with higher satisfaction with the adult-care environment; and o mode of transfer: ▪ it was found that patients most satisfied with their transition were those who had been transferred to a young-adult clinic within the same hospital and had met the providers before the transfer, while higher dissatisfaction and a decline in clinic attendance were found in patients directly transferred to an adult clinic. • Using a transitional framework proposed by Schumacher and Meleis, the review made recommendations for successful transition under the following categories: o meaning given to transition by patients; o expectations about transition; o level of patient knowledge and skill; o transition planning; and o environment and resources.			
Evaluating outcome evidence of structured interventions to	• This review included 43 studies which evaluated transition interventions for youths with a single condition, most often Type 1 diabetes, followed by kidney or liver transplants and juvenile idiopathic arthritis. No included study examined transition outcomes for youths with mental/behavioural health conditions or common chronic conditions, such as asthma.	2016	6/10 (AMSTAR rating from McMaster	5/43

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada

transition youth with chronic conditions to adult healthcare (9)	- This study focused specifically on outcome measures in reference to the triple aim framework and did not attempt to describe features of interventions.
	- The study concluded that structured transition interventions for youths with chronic conditions generally resulted in beneficial outcomes in reference to the triple aim framework; 28 of the 43 included studies found statistically significant positive outcomes within the triple aim framework.
	  o Population health outcomes (20 studies): improvements in adherence to care, patient-reported health and quality of life, self-care skills, and mortality reduction.
	  o Consumer experience outcomes (eight studies): satisfaction with transition, transfer, and life-course and health-related goals, helpfulness of a specific tool or online resource, and autonomy and increased time alone with a healthcare provider.
	  o Service utilization outcomes (nine studies): increased visits to the new adult provider, reduced time lag between the last pediatric visit and the first adult visit, reductions in hospital admissions and length of stay for readmissions, surgery rates, and radiation exposure.
			Health Forum)	

Reviewing the transitions of care process for youth with chronic illness to adult-care services (29)	- This review included 61 studies that examined chronic conditions in general, and diabetes.
	- Six main categories of the transition of care process were documented in the review.
	  o The timing of transition. Key considerations included:
	    ▪ timing to educate patients about transition process;
	    ▪ the preferred timing to transition; and
	    ▪ the age of transition.
	  o Perceptions towards the transition process. Key considerations included:
	    ▪ positive and negative feelings towards transitioning;
	    ▪ differences in care services, environment and delivery;
	    ▪ parental concerns and worries; and
	    ▪ provider perspectives.
	  o Preparation for the transition. Key considerations included:
	    ▪ readiness assessment tools; and
	    ▪ characteristics impacting the quality of the transition process.
	  o Patients' outcomes post-transition: Key considerations included:
	    ▪ evaluating the effectiveness of transition programs.
	  o Barriers to transition. Key factors were:
	    ▪ inadequate preparation prior to transition;
	    ▪ ability to access and use adult-care services;
	    ▪ complex health conditions;
	    ▪ excessive parental involvement in the care of patients; and
		2014	6/9 (AMSTAR rating from McMaster Health Forum)	7/61

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	▪ inability of some pediatric healthcare providers to relinquish care of the patient. o Facilitating factors transition. Key factors were: ▪ preparation prior to transition; ▪ structured written plan/program to guide; ▪ key healthcare provider from pediatric-care services to coordinate the transition; ▪ the quality of healthcare providers and relationship built up with the patients; ▪ parents acting as a facilitator; and ▪ patients' self-management skills.			
Reviewing evidence on the effectiveness of different models of transitional mental health care, service-user and staff perspectives, and facilitators/barriers to effective transition (5)	• This review included 19 studies which examined mental health services exclusively. Studies on the transitions of young people with learning difficulties, physical disorders and psycho-social transitions use were excluded. • Although a part of this review assessed effectiveness with little description of the intervention features, service-user perspectives, staff perspectives and facilitators and barriers to transition were discussed. o Service user perspectives: ▪ The stigma of mental health care prevented engagement in services. ▪ Adult mental health care generally serves older, chronically unwell patients. ▪ Adult mental health care generally lacked age appropriate services and did not address accommodation needs, employment needs, provide information on available services, or sufficiently include parents. ▪ Parents wanted their children to be better integrated into their local community and worried about lack of preparedness for adult life. ▪ Transition planning started too late in the care journey to adult services. ▪ Restrictive eligibility criteria and the loss of services in transition. ▪ There is a need to provide adult mental health services that young people would choose to use, that are responsive, accessible and holistic in their approach. o Staff perspectives: ▪ Poor communication between youth and adult services. ▪ A lack of understanding of each other's services. ▪ Role confusion between teams. ▪ Problems in identifying and referring young people needing care. ▪ Young people not engaging with services because of stigma. ▪ Different treatment philosophies between youth and adult services. o Barriers and Facilitators ▪ Although lack of fiscal resources often impeded services for young adults, the main impediments were described as: • separation of child and adult mental health systems; and	2012	6/10 (AMSTAR rating from McMaster Health Forum)	0/19

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	• a lack of leadership and prioritization of this age group ▪ Other key factors included: • user refusal to accept referral to adult care; • care professionals not making a referral to adult care; • importance of gradual preparation, including transition planning, parallel care and consistency of key workers; and • importance of addressing other life transitions including housing, reproduction, and physical illness. • Overall, the review concluded that high-quality evidence of transitional care models is lacking.			
Analyzing the needs of parents of youth with special healthcare needs transitioning to adult services (11)	• The review included 47 studies which covered a range of chronic conditions including non-categorical, cancer, cystic fibrosis, juvenile rheumatoid arthritis, transplants, sickle cell disease, spina bifida, mental illness and intellectual and developmental disabilities • A number of common concerns were identified. o Changing expectations pertaining to future planning ▪ A common fear was their children's futures would be unfulfilled or diminished. ▪ The concerns about the future of their children were consistent, whether children had mental or physical disabilities. o Changes in the parental role ▪ Parents shared that the "letting go" process was challenging. o Changes in the children's role ▪ Parents commonly expressed concerns about their children's ability to assume responsibility for their care. o Exploration of parental perspectives of the transition experience ▪ Positive and negative experiences, gaps in services, and suggestions for improvement were consistently expressed by parents. ▪ Positive experiences emphasized advanced planning and joint meetings between pediatric and adult-care providers. ▪ Concerns included transition occurring during an acute episode and parents being excluded from adult-care services. o Parental stressors related to healthcare transition ▪ Foremost was the termination of relationships with pediatric providers and the uncertainty associated with adult care. o Perspectives about helpful support/services provided ▪ Family support. ▪ Advocacy services.	2013	4/9 (AMSTAR rating from McMaster Health Forum)	7/47

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	▪ A joint meeting with both pediatric and adult–pediatric specialists or meeting the adult provider prior to transfer. ▪ Preparation materials that provided transfer timelines and adult provider contact information. ▪ A portfolio of healthcare information provided to the adult providers. o Parent's perceptions of the child's HCT experience. ▪ In several studies in this review, the parents served as their children's voice. ▪ It is evident that parents provided important information, insights and perceptions about the transition experience. • The study concluded that parents have a myriad of needs that are not yet fully understood, and that healthcare-transition research is in the early stages of development.			
Identifying components of interventions that support youth with Type 1 diabetes transitioning to adult care (8)	• This review included 18 studies which examined participants with Type 1 diabetes. • The majority of transition programs lasted a year or less in duration but ranged from three months to seven years in duration. Transition intervention components varied among studies and are described. o Seven studies included a transition coordinator ▪ Coordinators were either physicians, diabetes educators, or nonmedical staff. ▪ Duties included appointment scheduling, follow-up of youth who missed appointments, and monthly check-in phone calls. o Eleven studies included a transition clinic ▪ Approximately half were jointly staffed by pediatric and adult providers. ▪ Multidisciplinary teams included physicians, nurse practitioners, certified diabetes educators, mental health providers, and registered dietitians. ▪ Clinics were designed to be offered at more convenient times for young people such as evenings and weekends. ▪ Two studies implemented dual transition clinics where youth transitioned from pediatric care to a transition clinic to a young-adult clinic and finally to adult care. o Five transition interventions offered group education ▪ These sessions included socialization and skill building. ▪ Websites, books, newsletters and private social networking were used. o Other features included a discharge summary of the patient's history and joint visits with both a pediatric and adult provider. • This review suggests that transition interventions may be effective in maintaining glycemic control and/or prevent its worsening during transition for patients with Type 1 diabetes.	2016	8/10 (AMSTAR rating from McMaster Health Forum)	2/18

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	• There was a trend that programs that included both a transition coordinator and a transition clinic demonstrated better outcomes than those with a single component, but it remains unclear which specific elements of the transition programs were most effective. • Only four studies showed improvements in clinic attendance, and all of these made use of a coordinator.			
Reviewing the outcomes and experiences of transition for young people with cystic fibrosis (24)	• This review included 21 studies, all with participants with cystic fibrosis. • The review found that structured transition programs were associated with increased satisfaction, discussions about transition, self-care and self-advocacy skills, more independence, lower anxiety, and increased self-management and parent management of physiotherapy and nutritional supplementation. • Regarding young people's experiences with transition, four themes emerged. o Concerns about transition ▪ Leaving behind familiar staff in the pediatric centres and not knowing the adult staff was a common concern across all studies. ▪ Concerns generally included having to leave their pediatric doctor, meeting a new healthcare team, the adult team not being as caring, differences in care provision, decline in care quality, exposure to infection, difficulty accessing a specialist centre, lack of information on adult care, and finance and insurance issues. o Transition readiness ▪ Patients who underwent a transition program perceived these programs as being helpful. ▪ Helpful elements included meeting the adult team in a pediatric setting (familiar face in adult setting), orientation tours of adult services, social worker involvement, written and verbal information, and talking to other patients. ▪ Across studies, the two most useful elements were meeting the adult-care providers and visiting the adult centre. o Psychosocial needs ▪ Psychological support varied between pediatric and adult services, and between staff in both services, with psychological support more easily available in pediatric services. o Variations in care ▪ The need for a standardized transition program was a key recommendation across all studies. • The study concluded that guidelines and policy tend to be based on expert clinical experience and a best-practice approach rather than strong evidence from empirical studies. Furthermore, the contribution of the different transition program components to desired outcomes is unclear.	2015	6/9 (AMSTAR rating from McMaster Health Forum)	2/21
Synthesizing how young adults with chronic diseases	• This study included 18 studies which covered a range of chronic conditions including non-categorical, HIV, congenital heart disease, transplantation, diabetes, sickle cell disease, cystic fibrosis, haemodialysis and juvenile idiopathic arthritis.	2008	5/9 (AMSTAR rating from McMaster	2/18

Focus of systematic review	**Key findings**	**Year of last search/ publication date**	**AMSTAR (quality) rating**	**Proportion of studies that were conducted in Canada**
experience the transition from pediatric to adult hospital care (18)	• This meta-synthesis of experiences revealed that during transition patients felt themselves to be in a kind of limbo between different cultures. Young adults' transition experiences seem to be comparable across diagnoses. Experiences were categorized into four themes. o Facing changes in significant relationships ▪ Relationships in youth versus adult hospital care were quite different. In adult care doctors and nurses were described as being impersonal and disease-focused. ▪ Peers with a similar chronic disease offered crucial support in managing life. ▪ Meeting older people with the same disease was challenging, because the young people were confronted with their future prognosis. o Moving from a familiar to an unknown ward culture ▪ Adapting to the cultural differences between the pediatric and adult healthcare environments was a challenge. ▪ Pediatric professionals had treated their health problems in collaboration with their parents, whereas in adult care patients themselves had to deal with questions. o Being prepared for transfer ▪ The timing of transfer based on biological age was an issue in most of the studies. ▪ A sudden transfer was experienced as the most unsatisfactory. ▪ Lack of preparedness made the adolescents and young adults feel redundant and unwanted. ▪ Patients appreciated collaboration between the two hospital settings, although, in their experience, continuity of care was not always present. o Achieving responsibility ▪ Transfers force movement towards independence. ▪ Meeting the expectations and challenges of becoming a grown-up had an impact on the accountability. ▪ The young people sought knowledge about their disease and its treatment. ▪ Transition could be a time of discord because of parental reluctance to let go of their responsibility and allow the young adult to take over.		Health Forum)	
Examining the experiences of young people with intellectual disabilities and their carers during transition to adult care (21)	• This review included 12 studies which exclusively covered intellectual disabilities. • The emergent themes were identified across all the studies. o Becoming an adult ▪ Self-management and balancing autonomy with parental involvement in the context of intellectual disability ▪ An unnatural change in expectations, especially for young people with complex intellectual disability who never develop beyond a child's developmental age o Fragmented transition process and care	2019	6/10 (AMSTAR rating from McMaster Health Forum)	1/12

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	▪ A lack of preparation, planning, information, support and coordination are frequently reported. ▪ Unplanned transfer often results in a loss of information and gaps in follow-up. ▪ No holistic overview in adult services can leave patients falling between the gaps of services. o Parents as advocates in emotional turmoil ▪ Uncoordinated transitions often forced parents to be advocates, with a deep sense of having to 'fight' for appropriate care in adult services. ▪ Parents were forced to navigate a maze of absent, incorrect or conflicting information. ▪ Families faced a sense of loss and rejection as they had to let go of established relationships. ▪ A fear of the unknown, while building a new network of support was a concern. o Making transitions happen ▪ Early preparation for transition and identifying a lead agency were imperative. ▪ Clear definitions of responsibilities improved provision of information. ▪ A transition coordinator was seen as beneficial in ensuring that care needs were met. ▪ Joint transition clinics may facilitate better working relationships between child and adult health services. ▪ Adequate follow-up and ongoing involvement of pediatricians are needed after transition. ▪ Family and patient-centred approach, with strong parent-provider relationships are important. ▪ Nurses have the potential to help implement a holistic, life-course perspective that includes family and wider psychosocial needs.			
Identifying barriers associated with the transition to adult-care for cerebral palsy and spina bifida patients (31)	• This review included 149 studies which included patients with cerebral palsy (CP), spina bifida (SB) and other conditions if they provided key information related to clinical transition that was considered relevant. Other conditions included diabetes, respiratory disease, renal impairment, juvenile idiopathic arthritis, inflammatory bowel disease, cystic fibrosis, congenital heart disease, celiac disease, cancer, organ transplant, and epilepsy. • Many barriers to transition for people with CP and SB were identified; most were similar to those experienced by adults with other complex chronic illnesses. They were described as follows: o inability to "let go" of long-standing relationships between the patient and the child care provider; o reluctance of young adults to leave the safety and familiarity of family-centered care; o adult services rarely engage with families in the same way as do child-centred services, and parents may feel excluded from the decision-making process; and o adult-centred physicians may have limited training and experience with childhood chronic illnesses, and therefore have limited knowledge or interest in caring for these young adults. • This review identified key elements from the literature that were described to support a positive transition to adult-centred healthcare. There was, however, limited empirical evidence to support the impact of these elements. o Preparation: There should be a significant period of preparation before transition.	2007	2/9 (AMSTAR rating from McMaster Health Forum)	Not available

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	o Flexible timing: The provider and family should establish the timing of transfer and it should be flexible, depending on the youth's cognitive development, physical abilities, environment, and family support. o Care coordination: Transition planning should be coordinated, and include stakeholder feedback, up-to-date medical information and a transition plan (which includes planning for issues related to finance, education and vocational training). o Transition clinic visits: Visiting a transition clinic and consulting with both the child and adult-entered healthcare providers can aid in transfer. o Interested adult-centred healthcare providers: Adult-centred providers should care for the chronic condition and also address issues such as independence, social interactions, body image, sexual health, alcohol and drugs, and anxiety.			
Investigating the experiences of families of youth transitioning into adulthood with a chronic condition (25)	• This review included 33 studies with a focus on progressive genetic childhood conditions including neuromuscular diseases, cystic fibrosis, hemophilia and sickle cell disease. • Three perspectives emerged from the findings, focusing on the transition into adulthood. o The young person's perspective on how to live a normal life and manage a chronic disease ▪ Young people did not feel prepared for the transfer and reported a lack of information. ▪ They were afraid of losing health professionals whom they trusted, and envisioned adult carers as less competent in managing their disease. o The parents' perspective on complexity of being a parent of a chronically ill child and their concerns about the child's future ▪ Parents felt it was difficult to give their children more responsibility to make their own decisions regarding life and health. ▪ Parents also worried about their child's ability to engage in a social life, have an education and career, and to handle finances. o The sibling's perspective on their concerns about the sibling's future ▪ The information about siblings' experiences is limited, but also revealed concern for their siblings' ability to take care of themselves in future. • The study concluded that more detailed investigation of the family experience, belief systems, family relationships and interaction pattern, and a description of major challenges and coping strategies at a family level is needed.	2013	6/9 (AMSTAR rating from McMaster Health Forum)	6/33
Reviewing providers' roles, understandings and views on transitioning	• This review included 55 studies which covered a wide range of disability and special-care needs. • The review generated four general themes about providers involved in healthcare transitions. o Adult provider competency: Studies indicated that adult providers had limited clinical training and experience associated with young adults in transition.	2013	3/9 (AMSTAR rating from McMaster	6/55

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
youth with special healthcare needs to adult care (15)	o Provider perspectives: Studies reveal a general lack of a comprehensive, coordinated and seamless system of care for youth who transition to adulthood and transfer to adult health care. o Provider attitudes: The studies indicated that providers are aware of the importance of healthcare transition, however, there remain significant gaps in actual provision of transition services. ▪ Provider barriers identified: • Difficulty terminating relationships • Provider knowledge gaps in understanding the healthcare transition needs of patients and where to access resources • Providers' limited time • Confusion about role responsibilities during transition • Paediatric providers believing that adult providers do not provide comparable care ▪ Provider supports identified: • Centralized repository for transition resources with institutional access • Transition guidelines to facilitate transfer • Organization transition champions • Provider training • Provider accountability o Healthcare-transition service models: Widespread gaps exist in implementation, including a general lack of transition policy, lack of access to adult providers, negative attitudes toward implementation, lack of knowledge about community-based agencies, and lack of consensus of what constitutes appropriate transition planning.		Health Forum)	
Synthesizing the literature on youth transitioning to adulthood with complex medical conditions (19)	• This review included 11 studies which covered a wide range of disability or special care needs. • Three themes emerged. o It's like falling off a cliff: Transition was associated with feelings of being pushed out and abandoned, facing an unfamiliar system and uncertainty with how their needs will be met. o Paradox of independence: Views on independence varied, but often young people's goals for independence did not align with their parents' goals, creating conflict. o It takes a village: Young people and their parents often experienced feeling devalued and wanted to be respected as part of a team. Coordinated support throughout the process was important.	2014	4/9 (AMSTAR rating from McMaster Health Forum)	6/11
Examining the perspectives of young people with special	• This review included 35 studies which covered a range of disability and special-care needs including Type 1 diabetes/endocrine problems, congenital heart defects, juvenile rheumatoid arthritis, sickle cell disease, HIV, irritable bowel disease, cystic fibrosis, solid organ transplant, brain tumours, epilepsy, hemophilia, and spina bifida.	2012	4/9 (AMSTAR rating from McMaster	7/35

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
healthcare needs on their transition to adult care (26)	• Five thematic areas of focus were extrapolated from the literature. o Patient reflections of their experience with transition services ▪ Many studies reported patients feeling lost, unprepared and nervous about transition. Others reported the transition process as transformative, where learning self-management skills and improved knowledge of condition was life affirming. o Recommendations for the development of transition services ▪ Informational needs: Wanting more information, earlier ▪ Service models: Wanting care to be individualized, with involvement as a member of the team ▪ Provider characteristics: Wanting empathy, communication and knowledge about their condition ▪ Access to care: Wanting service coordination, including care in other systems (education and employment) ▪ Philosophy of care: Adult environments were often found to be uninviting, not caring for developmental needs o Obstacles identified with the transition process to adult care ▪ Obstacles majorly pertained to gaps in services, where services provided in child care settings were no longer available in adult care. A lack of information and communication about these changes during transition was noted. o Expectations related to the eventual transfer to adult care ▪ Varying expectations were noted. Uncertainty and concern was dominant about entering an unfamiliar territory and not knowing what to expect. Fear about deteriorating health status was noted. Others noted changes impacting relationships with parents, peers and providers. o Issues pertaining to becoming self-reliant with self-management of their special healthcare needs ▪ The extent to which the transfer of care was successful often related to how independent youth were at managing their needs. All of the thematic areas cited integrated self-management as a goal, concern, and an essential component of service design.		Health Forum)	
Reviewing successes in transitioning youth with special healthcare needs to adult care and identifying evidence for	• This review included 15 studies which covered a range of disability and special-care needs including cystic fibrosis, developmental disability, diabetes, and congenital heart defects. • This systematic review addressed two questions. o The success with which youth make the transition to young adulthood ▪ The review indicates that those with more complex conditions or with conditions affecting the nervous system appear to have less good transitions. ▪ In addition to education, employment, relationships, and establishing independent living, those with special healthcare needs have the added challenge of managing transitions, understanding health histories, and assuming responsibility for their own healthcare. o The evidence for what interventions may enhance transition, especially to adult healthcare	2010	4/9 (AMSTAR rating from McMaster Health Forum)	1/15

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
enhancing transitions (12)	▪ Evidence is generally limited, but there is some support introducing youth to adult providers before leaving the pediatric system; one study supports using care coordinators to improve outcomes.			
Identifying models of transitional care for young people with special healthcare needs (16)	• This scoping review included 19 studies and it aimed to identify models of transition services for young people with disability and special healthcare needs including four models for CP, 14 models for diabetes, and no models for ASD. • The review noted that most studies were descriptions of new service provisions or pilots with little service evaluation of key elements of effective implementation. • The models included emphasized that young people have different individual experiences of transitional care and that there is a need for flexibility in supporting transition. • The review noted that there was often a reliance on single transition champions to take forward the implementation of transitional care, which may risk sustainability.	2011 (publication date)	3/9 (AMSTAR rating from McMaster Health Forum)	Not available
Examining the views of young people with diabetes and nephrology on their transition to adult care (22)	• This review included 14 studies which focused on young people diagnosed with diabetes or CKD. • Five major themes were identified. o Preparedness ▪ Timing of transfer: feeling pushed out ▪ Access to providers: more discussion and communication ▪ Parental involvement: getting prepared with parents o Overwhelmed by an impersonal environment in adult service ▪ Sterile and unwelcoming: feeling lost in a new setting ▪ Navigating new processes: not knowing what to expect ▪ Feeling displaced: surrounded by old people o Independence ▪ Developing self-esteem and an adult identity: establishing own likes and wants ▪ Taking responsibility and ownership: self-management of care o Valuing familiarity ▪ Building trust: relationship building ▪ Peer support: connecting with those in a similar situation o Service and information needs ▪ Leniency and lack of access: no one following up ▪ Efficiency: getting lost in the system because of new structures ▪ Information needs: needing more communication	2009	6/9 (AMSTAR rating from McMaster Health Forum)	4/14

Appendix 2: Summary of findings from primary studies about features of approaches to supporting transitions from child to adult care for young people with special healthcare needs in Canada

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Approaches to support transition				
Developing a patient education program based on the experiences and needs of adolescents with chronic conditions in transition	Publication date: 2017 Jurisdiction studied: Germany and Switzerland Methods used: Group and individual interviews	Adolescents aged 15 and above with Type 1 diabetes, cystic fibrosis or chronic inflammatory bowel disease who were either still being treated in pediatric care or had already transferred to adult care	- After analysing interviews, a curriculum and manual were developed for an educational program in a 'workshop' format. - The workshop was a two-day patient-education program in a group setting prior to transfer. - The guiding principle was empowerment; supporting the adolescents through various interactive methods to develop adequate knowledge, skills, understanding and motivation regarding their chronic conditions.	- The effectiveness of this newly developed patient-education program was evaluated in a subsequent study, indicating significantly positive intermediate to long-term effects. - The study concluded that patient-education programs promoting adolescent self-management and empowerment increase the preparedness for transition.
Identifying the educational needs of young people with chronic conditions in transition	Publication date: 2018 Jurisdiction studied: France Methods used: Semi-structured interviews	17 young people (15 to 25 years of age) who live with a chronic condition and are involved in, or close to, transferring	- This study explored the educational needs of young people with chronic conditions during transition.	Five education needs emerged: - learning how to have a new role; - learning how to adopt a new lifestyle; - learning how to use a new healthcare service; - maintaining a dual relationship with pediatric and adult care; and - having experience sharing with peers. Educational measures should focus on the acquisition of broad skills, while also being person-centred.
Identifying the roles of a patient navigator during transition	Publication date: 2019 Jurisdiction studied: Canada Methods used:	A purposive sample of healthcare providers with a variety of backgrounds within pediatric and adult systems in Alberta, Canada, With 34 key stakeholders included in the final sample	- Patient navigators (PNs) are designed to facilitate the transfer from pediatric to adult care. - Consistent definitions, key tasks, roles and responsibilities are lacking in guiding scope of practice and implementation.	The study concluded that a patient navigator service encompasses four key stages: - identification of young people with special healthcare needs and families requiring support; - preparation for transfer; - health-system navigation; and - post-transfer support.

	Semi-structured interviews and focus groups			
Examining a pilot healthcare transition education intervention for adolescents with special care needs	Publication date: 2011 Jurisdiction studied: U.S. Methods used: Pilot program and focus group interviews	137 students from 13 high school special education classes in five geographically and demographically diverse high schools .	• The 40-hour curriculum was implemented 1/1.5 hours per day, five days per week. It included the following topics. • Moving toward adulthood; the importance of self-advocacy • I'm an adult. So now what? • Which doctor is for me? • Do I need insurance? (understanding health insurance) • What do I need to know about medications? • What is sexual health and why is it important? • How can I avoid getting hurt or injured? • Wrap it up! Constructing a Health Journal and Medical Summary	• The curriculum was perceived by both students and educators as highly relevant and valuable. • The data indicate many are not receiving critical information or learning healthcare management skills in their homes or community. • Recommendations from participants included allowing more time to implement the module and creating another version for students at lower reading levels. • Many parents did not understand how to fill various forms, and had difficulty assisting their child in completing Health Journal activities.
Examining the role of parents as transition experts in a peer-led support group	Publication date: 2011 Jurisdiction studied: Canada Methods used: Focus groups, narrative summaries, and qualitative surveys	Parents of transition-age youth with physical or developmental disabilities (12 to 18 years) receiving augmentative communication support were eligible to participate	• Two-hour Family Facilitator-led Transition Peer Support Group sessions were conducted monthly for one year. • Parents of youth with disabilities who had transitioned or were in the process of transitioning were hired as Family Facilitators. • Sessions were small and included open dialogue, social support, sharing of health, social and economic resources and expert guests. • The goals of the groups were to build on a client- and family-centred service, enhance professional understanding of	• Parents reported gaining new knowledge and became more active and future-oriented in their planning. • Parents strongly valued the facilitator role and benefited from the social support provided by the group. • Experiential knowledge was deemed as a valuable resource for parents. • The study concluded that Youth Facilitators should be considered in the future.

			transition needs, and offer ways of supporting parents.	
Assessing the role parents have in medical-record management during the transition to adult care among patients with spina bifida	Publication date: 2005 Jurisdiction studied: U.S. Methods used: Focus groups and structured interview	A convenience sample of six patients (aged 18–21 years receiving comprehensive care at a centre for spina bifida and spinal cord injury), six family members and one private-duty home nurse committed to participate	Results were clustered around four questions: • Who is involved in record keeping? • How is the information stored? • What information is kept and shared among the different constituencies? • When do patients and parents need the information?	• The study suggests that parents play a central role in the medical information and record management. • These records tended to be organized as time-lines, to capture the temporal continuity of care. • Medical records tended to be distributed among a large number of healthcare providers and institutions, with no central record or healthcare person in charge of coordinating. • The study concluded more research is needed into how electronic personal-health records can take into account parents' and patients' central role as medical-information managers.
Designing a chatbot service to guide adolescents with special-care needs through transition(17)	Publication date: 2019 Jurisdiction studied: U.S. Methods used: Co-design workshops, pilot study and qualitative feedback	The pilot study included 13 patients between the ages of 14 and 17 who are seen in a Pediatric Inflammatory Bowel Disease, Cardiology, and Type I Diabetes specialty clinics	• The co-designing process incorporated a multidisciplinary team of stakeholders, including patients, caregivers, clinicians, quality-improvement facilitators and designers. • The chatbot was a text-messaging platform with scripted interactions to increase engagement - measured by the response rate to text messages - and deliver educational content on self-care skills. • The chatbot was designed to send weekly text messages to patients to begin to prepare them for the transition-of-care journey. Topics included understanding one's chronic condition and medical history, ordering prescription medication refills, contacting a doctor's office, and preparing for doctors' appointments. Based on the responses, the chatbot replied with appropriate encouragement, tips, and links to online resources.	• A scripted text messaging platform was deemed feasible and appears to be well received by patients and caregivers. • The platform was associated with a high engagement rate for educational topics and suggested skill attainment was seen in three areas: tracking medications, completing medication refills, and contacting a provider's office with questions. • However, study participants did not feel more confident with the "softer" skill of self-advocacy. • The co-design workshop was equally important for fostering engagement, and participants indicated a strong interest in more peer-peer opportunities in transition. • The text-messaging platform had little financial cost, however, there was a significant time commitment.

Addressing transition gaps through an educational intervention among family nurse practice students	Publication date: 2018 Jurisdiction studied: U.S. Methods used: A mixed-methods randomized controlled trial pilot study	14 nurse practitioner students (randomly assigned to either a waitlist control group or an intervention group)	• The educational curriculum focused on the medical needs of transition-age youth with autism for family nurse practitioner students. • The intervention consisted of three major components including didactic (a single three-hour class), online educational modules (a series of three one-hour online modules) and experiential learning (designed to support health professionals in building confidence, interest, and sensitivity in their work with individuals with ASD and their families) completed over an eight-week period. • The aim was to address self-efficacy, specific knowledge gaps and prejudicial attitudes.	• Quantitative and qualitative data provided support that participation in the intervention may improve and enhance knowledge and level of self-efficacy in working with transition-age youth with autism. • However, it appeared the intervention group had a trend towards slightly more prejudicial attitudes.
Examining an initiative to improve transition outcomes among youth with emotional and behaviour disabilities	Publication date: 2016 Jurisdiction studied: U.S. Methods used: Mixed methods evaluation	Focus groups of 25 participating transition-age youth with emotional and behavioural disabilities, caregivers, staff, and supervisors	• The Healthy Transitions Initiative (HTI) sought to improve outcomes for transition age youth in the areas of education, employment, housing, mental health, and co-occurring disorders, as well as decreasing contacts with the juvenile and criminal justice systems. • The average length of stay in the program was 12 months. • Following referral, a transition facilitator (TF) contacted the youth and/or their family. Youth meet regularly (weekly to bimonthly) with their TF. TFs connected participants with a range of services including Supported Employment (an empirically supported intervention),	• Focus groups identified beneficent aspects of the program: comprehensive case management, community-based services, individualized services, and flexibility of the transition facilitators. • Youth reported TFs helped them with personal challenges such as stigma, self-esteem and anger management. • Overall, focus group data suggested that participants were satisfied with the HTI program and its services. • Suggestions for improvement included more group and social activities for youth, supports and information for caregivers, and a need for additional resources, particularly in regard to staffing, housing, and transportation.

			educational support, housing support, case management, coaching regarding social skills, independent living skills, and problem solving. • Youth were also able to participate in group therapy with the program's peer-support partner, and parents are given the option to participate in parent information sessions.	
Examining a pilot developmental assessment tool which assesses transition tardiness for youth with special-care needs	Publication date: 2019 Jurisdiction studied: US. Methods used: Mixed methods	Twenty-eight pediatric healthcare providers completed a total of 108 tools. Providers included 15 physicians, six nurses, registered nurses and nurse practitioners, and seven Masters of Social Work (MSW)-level social workers. The distribution of providers was relatively equal across the three chronic illnesses: endocrinology, gastroenterology and hematology.	• Developed by pediatric hospital social workers, the tool was comprised of a series of developmentally sensitive assessment instruments for providers to use with patients from birth to 21 years of age (two- to three-year spans). • The assessments intended to be generalizable to all chronic illnesses to help determine the proficiency of youth in domains of knowledge acquisition and skill mastery required for medical independence. • Each measure assesses developmentally appropriate skills in five domains: health assessment, communication with medical providers, use of medication/medical equipment, access to insurance/medical records, and management of lifestyle choices.	A total of six themes emerged from the interviews about the tool: • Themes related to positive practice behaviour changes were: 1) thinking developmentally,; 2) focusing on the patient, and 3) structuring the approach. • Themes related to barriers using the tool consisted of clinic visit time constraints, tool length, and discipline-specific challenges related to the psychosocial assessment component.
Developing a hospital transition program for adolescents with medical complexity	Publication date: 2019 Jurisdiction studied:	The Children's Hospital of Philadelphia (CHOP)	• A Multidisciplinary Intervention Navigation Team (MINT) was developed to decrease variations in pediatric-to-adult medical transitions.	• Key results were: identifying 11 transition champions, increasing the number of divisions with transition policies from 0 to 7, increasing utilization of electronic medical record-based transition support tools from 0

	U.S. Methods used: Pilot program		- System-level goals were to: 1) increase provider and leadership engagement; 2) increase transition tools; 3) increase use of electronic medical record-based clinical decision supports; 4) improve transition practices through development of transition policies and clinical pathways; 5) increase transition education for patients and caregivers; 6) increase the adult-provider referral network; and 7) implement an adult transition consult service for complex patients (MINT Consult).	to 7 divisions, seven psycho-educational events, and developing an official clinical pathway. - 25 referring pediatric providers reported that MINT helped: - identify adult providers; - coordinate care with other Children's Hospital of Philadelphia specialists; and - saved greater than 2 hours of time.
Examining participation in a transition education program among young adults with congenital heart disease	Publication date: 2019 Jurisdiction studied: France Methods used: Pilot program	123 patients were included in the study. CHD patients aged 13-25 were offered to participate in the transition program.	- This transition education program aimed to facilitate transfer to adult cardiology and bring more autonomy to teenagers. - This study analysed the factors influencing the participation in a transition education program. - Program consisted of one educational outpatient visit, one group session (structured into four parts: medical aspects, living with CHD, administrative workshop, individual interview) and one transfer preparation visit.	- Both groups showed similar socio-demographic and quality of life characteristics, low level of physical activity and high exposure to risk behaviours. - Patients with complex CHD, poor disease knowledge, risk behaviours, alcohol, and aged <20 year were more likely to join the program. - There was a trend for a lower education level in the group who did not participate.
Assessing the effectiveness of recommendation implementation which covered the quality of care and care coordination during health care transition	Publication date: 2018 Jurisdiction studied: U.S. Methods used: Randomized intervention	Adolescents and young adults with special healthcare needs were enrolled in a randomized intervention	- Expert consensus by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians recommends the use of healthcare transition (HCT) care coordination. These recommendations have never undergone rigorous assessment. - This study assessed the effectiveness of recommendation	Key results were: - Intervention participants had a Patient Assessment of Chronic Illness Care score at 12 months of 3.6 versus 3.3 compared with participants in the control group (P = .01). - Intervention participants had higher average scores for patient activation, problem solving, and coordination/follow-up. - The Client Perceptions of Coordination Questionnaire revealed that intervention participants had 2.5 times increased odds to receive the services they thought

			implementation on quality of chronic-illness care and care coordination during HCT for adolescents and young adults. • The intervention group received all aspects of enhanced usual care but was also assigned a HCT nurse who coordinated the delivery of specific intervention services. • These services included a face-to-face review of the readiness assessment with the participant and/or caregiver, a status assessment of ongoing HCT planning and preparation, and monthly phone calls with the participant and/or caregiver to update and fill gaps in the HCT action plan. • The HCT nurse care coordinator also provided participants with a transition checklist, a portable medical summary, and assisted with the process of selecting an adult primary-care treatment.	they needed, and had 2.4 times increased odds to have talked to their provider about future care.
Assessing the impact of an educational transition intervention on transition readiness among youth with congenital health disease	Publication date: 2014 Jurisdiction studied: Canada Methods used: Clinical trial	15–17-year-olds with moderate or complex congenital heart disease (CHD) or cardiomyopathy	• This study sought to determine the impact of a transition intervention on improving knowledge and self-management skills among this population. • Participants were systematically allocated to either usual care (controls) or a one-hour nurse-led one-on-one teaching session about their heart. • The primary outcome was change in Transition Readiness Assessment Questionnaire (TRAQ) score at 6 months, possible scores ranging from 1	When comparing the intervention group with the usual-care group at six months post-intervention: • the mean self-management TRAQ score significantly increased: 3.59 (±0.83) versus 3.16 (±1.05), respectively (p=0.048); • the mean self-advocacy TRAQ score insignificantly increases: 4.38 (±0.56) versus 4.01 (±0.95) (p=0.18); and • the mean MyHeart score significantly increased: 75% (±15) versus 61% (±25) (p=0.019).

			(low) to 5 (optimal), as well as Cardiac knowledge (MyHeart score, range 0–100).	
Examining the use of text messages in a transition intervention focused on using MyHealth Passports	Publication date: 2014 Jurisdiction studied: Canada Methods used: Pilot	Inclusion criteria were age 15-17 years, diagnosed with moderate or complex heart disease, and currently being followed by the Division of Cardiology at Stollery Children's Hospital	• The intervention included creation of a MyHealth Passport and subsequently SMS (text messages between the intervention nurse and study participant). • The MyHealth Passport guides teens to enter their healthcare information which is printed onto a wallet-sized card. • All text interactions began with the nurse addressing any questions the teen had. “Do you have any questions?” The next questions were “Where is your MyHealth Passport now?” and “Have you used your MyHealth Passport or shown it to anyone else?” The interaction was to be predominantly guided by the teen after the nurse gathered the above data. • The study aims were to determine the preference of text messaging, assess the effectiveness of texting to collect data regarding the use of MyHealth Passport, examine the nature of the texting interaction, and understand the risks and benefits of texting.	The study concluded that texting was effective in collecting information regarding the MyHealth Passport. All but one teen had their MyHealth Passport on them. All teens reported showing their MyHealth Passport to at least one person. Benefits of texting were identified as: • flexibility; • ability to respond over time; • information presented in byte-sized amounts; and • information directly related to patient questions. Risks of texting were identified as: • interactions may not be in-depth; • distraction of teen and researcher; and • invasiveness.
Experiences and perspectives of transition				
Assessing the role of health advocacy during the transition of patients with special health needs to adult care	Publication date: 2015 Jurisdiction studied: U.S.	13 young adults, 9 parents, 12 healthcare providers from various fields and seven community service providers	The study aimed to: • explore barriers and facilitators to the transition; and • generate a theoretical understanding of how families and supportive professionals can decrease barriers to transition.	Three major categories describing important social processes within transition were predominant in the interviews: • fighting for healthcare; • obtaining resources; and • getting ready to transition.

	Methods used: Semi-structured interviews	A range of conditions were represented: cystic fibrosis, congenital heart disease, diabetes, spina bifida, intellectual disability, cerebral palsy, inflammatory bowel disease, and myasthenia gravis		The studies summarized these themes as "Transition Advocacy" where the "Advocate" role was performed by family members, healthcare or agency professionals, or sometimes the youth.
Examining the experiences, barriers and enablers during complex transitions	Publication date: 2015 Jurisdiction studied: Canada Methods used: in-depth, semi-structured, qualitative interviews	10 clinicians, 11 community partners, and three young adults (21-23 years old) with complex care needs from Ontario, Canada (transitioning from a pediatric hospital to an adult community residence)	The study's objective was to understand the experiences, barriers and enablers entailed in transitioning.	Enablers and barriers included: • structural factors: leadership, advocacy, timing/funding ; • availability of care: inter-agency partnerships and appropriate housing; • organization of care: model of care consistency, interprofessional teamwork, extension of roles and clarity of roles; • relational factors: communication, development of trust and rapport, family involvement; and • personal factors: transition readiness.
Assessing the transition experience of youth with autism spectrum disorder and their caregivers	Publication date: 2015 Jurisdiction studied: U.S. Methods used: Focus groups	13 youth (15-22 years of age) with Autism Spectrum Disorder and their caregivers	The aim of this study was to examine the healthcare transition experiences of youth with Autism Spectrum Disorder and their caregivers.	Parents' discussions emphasized: • loss of relationship with provider and lack of support transitioning; • providers' lack of knowledge about Autism Spectrum Disorder; and • concerns about losing guardianship. Youth emphasized their confusion and anxiety around: • medical providers' role; and • managing their medical lives independently.
Exploring the transition needs and experiences of youth and adults with cerebral palsy, spina bifida and acquired brain injuries	Publication date: 2009 Jurisdiction studied: Canada Methods used	15 youth and 15 adults with cerebral palsy, spina bifida, and acquired brain injuries of childhood, and their parents	This study sought to explore the specific issue of transition to adult-oriented healthcare in a Canadian context. Participants discussed their healthcare services, their experience with clinical transition, and contributing factors.	All participants identified challenges in transition, including: • lack of access to healthcare; • lack of professionals' knowledge; and • lack of information and uncertainty regarding the transition process. Two solutions were identified in the study: • early provision of detailed information; and

	semi-structured individual interviews			• more extensive support throughout the clinical transition process.
Exploring the views of professionals in transition care	Publication date: 2016 Jurisdiction studied: U.K. Methods used: Focus groups	36 health professionals across child and adult services who had expertise in working with young people with various health conditions and disabilities	This study aimed to explore the views of professionals involved in transitional care, the process of transition in their services, and the barriers and facilitators to transition.	Eight key factors that have an impact on transition emerged from the data: • young person's age; • length of the relationship between young person and professional; • transfer of responsibility; • service provision; • complex needs; • using a multidisciplinary team; • the health conditions; and • clear pathways/guidelines.
Assessing parents' perceptions of the transition experiences of their children with neurological disorders (28)	Publication date: 2011 Jurisdiction studied: Canada Methods used: In-depth semi-structured Interviews	Purposive sampling to elicit 17 parents of 11 young adults with complex chronic neurological conditions and intellectual impairments	The study aimed to gain an understanding of parents' perceptions of their young adults' transition experiences.	Findings suggest that parents perceived: • a sense of abandonment from the heathcare team; and • a sense of fear and uncertainty in navigating the transition. Parents believed that what hindered the transition process was: • lack of sufficient coordination; • vulnerability of the young adult; • lack of appropriate resources to meet multifaceted needs; and • compromised parental health. The transition process was felt to be facilitated by: • parent's resourcefulness; • family support; and • establishing relationships within the adult healthcare setting.
Describing the experiences of mental health service users, parents and professionals during transition	Publication date: 2012 Jurisdiction studied: U.K. Methods used: Interviews	11 service users, six parents and three responsible clinicians in mental health services	The aim of this study was to describe the experiences of child and adolescent mental health service users, parents and professionals in relation to transition to adult mental health services.	Positive experiences were described as: • informal and gradual preparation; • transfer planning meetings; • periods of parallel care; and • consistency in key workers. Negative experiences were: • transfers to adult services; • changes of key worker; and

				• waiting lists. Other life transitions such as changes in housing, pregnancy, physical illness, and the involvement of parents were noted as powerful extraneous influences.
Exploring the past transition experiences of adults living with cerebral palsy	Publication date: 2018 Jurisdiction studied: Canada Methods used: Semi-structured in-depth interviews	Nine adults living with cerebral palsy (between the ages of 20 and 40), were purposively recruited in Ontario, Canada	Participants completed a one-hour interview that explored their experiences seeking and receiving information.	Three themes described patient experiences: • the importance of support systems to assist young people in receiving and seeking information throughout the transition; • overcoming environmental barriers (wait lists, employment, housing) to seek timely information; often their needs were not future-based, but rather immediate, which meant turning to informal supports like friends or family; and • the need for real-life opportunities to experience the responsibilities of adult life, such as directing their own care.
Examining the transition experiences of families of young adults with intellectual disabilities (27)	Publication date: 2019 Jurisdiction studied: Scotland Methods used: Semi-structured interviews	10 family carers of young adults with intellectual disabilities in Scotland	To explore the experiences of the families of young adults with intellectual disabilities at the point of transition.	Transition emerged as a highly emotional and challenging period for family carers. Their experiences were captured in five main themes: • a deep sense of loss, safety, and vulnerability, plus a fear of the unknown; • an overwhelming process to re-establish care relationships during uncoordinated planning; • parents having to act as transition coordinators to make transitions happen; • adult services were unprepared to meet multifaceted needs; and • parental health was a concern, as they felt alone in a new environment.
Describing provider perspectives on the challenges of caring for youth with mental health problems in transition	Publication date: 2019 Jurisdiction studied: Canada Methods used: In-depth interviews	10 child mental health providers	This qualitative study focused on describing provider perspectives on the challenges of caring for youth with ongoing and recurring mental health problems.	Three main themes emerged from the data on child mental health provider perspectives: • providers believed in the chronic course of common child mental health problems; • providers perceived challenges of caring for youth with ongoing mental health concerns in community mental health settings; short-term treatment models were insufficient and child providers would have to bend the rules to be responsive to client ongoing needs; and

				• providers were reluctant to discuss transitions to adult care, citing a tendency to focus on the short term. Reluctance stemmed from uncertainty about who needs adult mental health services, when this discussion was appropriate and what adult services would be available.
Assessing how adults with spinal muscular atrophy experienced their healthcare transition	Publication date: 2019 Jurisdiction studied: Australia Methods used: Interviews	17 patients with spinal muscular atrophy who had transitioned to adult care	The purpose of this study was to explore the lived experiences of healthcare and well-being of adults with spinal muscular atrophy.	Sixteen of the 17 participants described their experience as "challenging and scary". Difficulties were associated with: • learning to navigate a new and complex healthcare system; • engaging with unfamiliar specialists whose approach was often impersonal and compartmentalizing; • differences in information provision and expectations, with a stronger emphasis on self-management and care co-ordination; and • identifying and accessing specialists and multidisciplinary clinics for adults. Positive experiences occurred in the context of: • structured, well-supported environments, often having a consistent healthcare provider throughout the process – a clinician who was well-acquainted with them and their needs. Many participants voiced a desire for: • tailored, disease-specific, adult multidisciplinary clinics with a strong focus on holistic, patient-centred care co-ordination.
Exploring the views of mental health professionals on the services supporting transition	Publication date: 2018 Jurisdiction studied: Germany Methods used: Focus groups	Four group discussions with 24 mental health professionals with various backgrounds	This study aimed to explore the views of mental health professionals on services for young people during transition.	The overarching theme identified was that patients were lost in transition with a failure to adequately capture and address the complex situation of a young patient. Sub-themes included: • uncoordinated institutional transfer; • lack of networking and collaborative planning; • a lack of health literacy inhibiting the diffusion of responsibility between patient and provider; • addressing emerging adulthood as a vulnerable phase; • increased pressure of a diagnosis; and • importance of the patient-provider relationship.

Describing the transition experiences of youth with complex care needs, their parents and professionals.	Publication date: 2018 Jurisdiction studied: U.K. Methods used: Case studies and interviews	Six young people (with long-term disabilities and complex needs), their parents, and relevant professionals	This study aimed to describe the experiences of young people, parents and professionals.	Recurrent shortcomings revolved around failing to recognize the level of anxiety raised because young people may not be ready to operate as adults in their new settings. • Young people's worries included having to get to know new people, fears around safety and competence, and still needing parents there to explain. Participants in the project shared their priorities for getting transition planning and support right. • The young person should be involved throughout to ensure services that are effective in meeting diverse needs. • A key worker should manage the transition process and ensure integrated services, taking the pressure off parents and carers. • Having a young people's group and special clinics may help to make them feel less alone, unsure, anxious, unsafe, or disempowered. • Advocacy services may be helpful, particularly for young people with severe learning disabilities. • The support of experienced transition practitioners may help families to overcome some of the barriers and navigate hurdles • Transition planning should start earlier (before 18) and is best staggered at a manageable pace.
Assessing the changing social networks during transition of young people with intellectual disability	Publication date: 2013 Jurisdiction studied: U.K. Methods used: Semi-structured interviews and pictorial 'Talking Mats'	43 young people with intellectual disabilities, in Bradford, England, who were approaching transition	The study examined changing social networks and had a particular emphasis on ethnicity.	Four themes emerged. • Family: Family was a feature of all the social networks, although young people often expressed a desire for greater independence. • School, friendships and leisure: The majority of young people had limited social networks and were able to socialize with friends independently. • Young people's aspirations: The most common wishes were to be involved in activities that non-disabled peers accessed more easily and regularly. • Social network stability: Social networks tended to be stable unless the young person made the transition from school or college.

Exploring the experiences of young people with ADHD during transition	Publication date: 2013 Jurisdiction studied: U.K. Methods used: Semi-structured interviews	Ten ADHD patients accessing mental health services clinics in Nottinghamshire and their carers/parents	The aim of the study was to explore the experiences of young people with ADHD during transition.	Four key themes emerged. • Clinician qualities and relationship: Clinicians being 'nice', 'understanding', 'supportive and 'informative'. • Responsibility of care: Support from parents was often practical and pertained to providing help with attendance and taking medication. • Nature and severity of problems: The severity of participants' problems seemed important in relation to whether they would be accepted by adult services. • Expectations of adult mental health services: Parents expressed the desire for their child to receive a consistent service and for them to be included in consultations.
Examining experiences of parents in transitioning their adolescent with epilepsy and cognitive impairment to adult care	Publication date: 2013 Jurisdiction studied: U.S. Methods used: Interviews	Seven parents or guardians of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments who had transitioned to an adult provider more than one year ago but less than five years ago	This study aimed to explore the processes that parents of adolescents with epilepsy and cognitive impairments undergo as they help their adolescents' transition to adult health care.	The following themes emerged: • crisis sparks transition: transition was most commonly sparked by a crisis; • parents in turmoil: they expressed feelings of fear, rejection, and uncertainty; • parents as advocates: They assumed the roles of protector and information gatherer; • web of information: as they served as advocates, parents expressed difficulty locating and understanding information; and • captive waiting: because of the discontinuity between agencies, the parents wait for answers before they can move forward. Several factors that enabled transition were discussed: • establishing an interpersonal parent-provider relationship; • parental advocacy; and • networking.
Assessing the transition needs of patients with spina bifida	Publication date: 2011 Jurisdiction studied: U.S. Methods used:	10 participants with spina bifida ranging in age from 18 to 25 years	The purpose of this study was to examine the transition to adulthood in young adults with spina bifida and to explore condition-related needs and life skills required.	Three themes emerged. • Struggling for independence: A wish to rely less on others for care at an earlier age. Recommendations included early role negotiation and opportunities to explore independence. • Limited social interactions and experiences with stigma: Feelings such as 'freak', 'kids making fun' and 'the looks' were persistent. Recommendations included

	Interviews			education against labelling and fostering peer interaction. • Building inner strength: Connectedness with family and a spiritual power were sources of strength, as well as engagement in activities. Recommendations included fostering connectedness.
Assessing the role of pediatric nurses in transition planning of complex cases	Publication date: 2019 Jurisdiction studied: U.S. Methods used: survey questionnaire	A volunteer sample of 1,814 survey respondents of registered nurses, with over 64% of respondents having performed HCTP activities related to complex chronic illness management	The purpose of this study was to address a gap in current knowledge specific to pediatric nursing professionals' roles and responsibilities in healthcare transition planning (HCTP).	• Items regarded as most important were supporting disease self-management and speaking with families about complex needs. • Predictors of perceived importance were role, inclusion of transition planning in a job description, percentage of time in direct care, caring for those aged 14 years and older, and level of knowledge about HCTP.
Assessing the transition process of youth living with HIV	Publication date: 2018 Jurisdiction studied: U.S. Methods used: Interview data and electronic medical records (baseline and follow-up)	135 youth living with HIV at baseline and nine-month follow-up, who were preparing to transition to adult HIV care within six months	This study aimed to assess the transition process of youth living with HIV.	At the nine-month follow-up only 37% of youth had successfully transitioned to adult care. Adolescent and adult clinic staff offered these recommendations: • staff training around adolescent development; • creating formal transition protocols • strengthening communication and data sharing between the adolescent and adult clinics; and • offering more comprehensive transition-specific services to support youth. Youth specific recommendations were: • providing support and skill development for youth to manage their own healthcare; and • allowing youth to guide their own individualized transition plan.
Assessing two case studies of patients who recently experienced transition to adult services	Publication date: 2018 Jurisdiction studied: U.K. Methods used: Case Studies	Two young people who had recently experienced transition to adult services, their parents, and professionals	These case studies aimed to understand and evaluate the real-world transition experiences of young people, their families, and the professionals involved.	Key themes identified were: • working towards better outcomes; • making sure that no young person "falls through the gap"; • focusing on the young person as an individual; and • sharing experience through training. Keys to success were identified as:

				• specialist transition practitioners and teams who are skilled in focusing on the unique needs of each young person they work with: o practitioners need to be able to support young people as an individual, coordinate a timely transition process, collaborate with others, navigate challenges, and be willing to share their expertise through the provision of training.
Exploring current practices and experiences from specialist centres in transitioning young people with home parenteral nutrition to adult services	Publication date: 2016 Jurisdiction studied: U.K. Methods used: questionnaire	Consultant gastroenterologists who were members of the British Association of Parenteral and Enteral Nutrition (BAPEN) and members of the Nutrition and IF working group of the British Society of Paediatric Gastroenterology and Nutrition (BSPGHAN)	This study aimed to understand current practices and experiences from specialist centres in transitioning young people to adult services.	The practices and processes of transition reported were highly variable: • time taken to achieve transition ranged from under six months up to two years; and • the most frequent concerns to be identified were confusion around care routines and psychological problems at the time of transition. The study concluded that: • a transition pathway and service standards for adolescents on home pediatric nutrition should be developed; • consideration should be given to creating checklists for practical concerns; and • key worker and psychology input to enhance emotional resilience of the young people and carers is important.
Identifying current transitional care practices and beliefs among physician providers in cerebral palsy clinics	Publication date: 2017 Jurisdiction studied: U.S. Methods used: Descriptive survey	11 physician leaders in the aforementioned cerebral palsy clinics	This study aimed to identify and describe current transition-of-care practices and beliefs among physician providers.	Key findings were: • over half of the clinics had a structured transition program, but only one transitioned their patients to adult providers by 22 years of age; • no respondent was "completely satisfied" with their transition process, and only one respondent was "moderately satisfied"; • the majority of respondents felt the ideal care setting for adults with CP was a comprehensive, multidisciplinary adult-focused clinic in an adult clinic; • the top 3 perceived barriers to successful transitions were: o limited adult providers willing to accept CP patients. o concern about the level of care in the adult system, and o a lack of financial resources.

Examining the current practices, knowledge and attitudes of high school staff in health transition planning	Publication date: 2014 Jurisdiction studied: U.S. Methods used: Survey	Representatives of Illinois high schools surveyed on their current practices, knowledge, and attitudes about healthcare transition planning	The aim of this study was to survey Illinois public high schools to identify transition-planning efforts and staff-training needs, and use those results to develop and implement training.	Key results were: • transition programs most frequently included young people with intellectual disabilities and autism spectrum disorders; • when respondents identified barriers to their transition planning, a lack of inclusion of health-related issues in the transition plans was noted; • this was said to be due to lack of necessary guidance from healthcare professionals, with other reasons including a lack of resources, lack of knowledge about healthcare transition on the IEP team, and lack of funding; and • in terms of what would be helpful in transition planning, the following was noted: o information and training, o sample transition plans incorporating health goals and services, and o handout for families about healthcare transition.
Assessing the current transition practices, policy awareness, and transition barriers among pediatric rheumatology providers in the United States and Canada	Publication date: 2014 Jurisdiction studied: U.S. and Canada Methods used: Survey	158 Childhood Arthritis and Rheumatology Research Alliance (CARRA) members	This study aimed to assess current transition practices, transition policy awareness, and transitional-care barriers and needs.	Key practice findings included: • fewer than 10% were very familiar with current AAP guidelines about transition care for youth with special-care needs; • eight percent have a formal written transition policy, but 42% use an informal approach; and • patient request (75%) most frequently initiates transfer to adult care. Two major barriers to transition were identified: • fragmented adult medical care; and • lack of sufficient time to provide services.
Exploring the perspectives of caregivers, team facilitators and youth on the family environment and wraparound care during transition	Publication date: 2012 Jurisdiction studied: U.S. Methods used: Questionnaires	The research involves two studies: Study 1: Participants for this study were primary caregivers in families (218) Study 2: Participants in this study were caregivers, wraparound team facilitators, and youth	Study 1 aimed to explore caregiver perceptions of role-related strain and family environment quality. Study 2 aimed to explore facilitator, caregiver, and youth perceptions of wraparound processes.	In Study 1, older age was associated with higher levels of caregiver strain. • These results indicate that caregivers of older youth experience higher levels of strain, and suggest the possibility that the family environments of older youth may also be poorer (e.g., show less cohesion, poorer communication and fewer shared activities). In Study 2, older age was associated with differences between youth and other team members' perceptions of wraparound processes.

		from the same teams (256 teams) In both studies, age was treated as an ordinal variable, in which 10- to 12-year-old youth were placed in a category, 16- to 17-year-olds were placed in a second category, and each of the remaining groups (13-,14-, and 15-year-olds) formed their own respective categories		• These results indicate that older youth perceived teams as less cohesive than others on their teams.
Examining the views of providers in HIV care centres on the transition process for youth living with HIV	Publication date: 2019 Jurisdiction studied: U.S. Methods used: Focus groups	24 (11 pediatric and 13 adult) providers at a comprehensive HIV care centre	This study aimed to gain a more comprehensive understanding of both pediatric and adult provider perspectives on the HCT process for youth living with HIV.	• Providers agreed that the most important determinant of successful engagement in adult-oriented care appeared to be consistent prior engagement while in pediatric care. • The study suggests that interventions aiming to improve transitions should be more tailored, focusing on youth with difficulty maintaining consistent engagement in pediatric care.
Exploring the concerns and needs of patients with tuberous sclerosis complex and their parents during their transitional period	Publication date: 2018 Jurisdiction studied: The Netherlands Methods used: Semi-structured interviews	Six patients (17 to 30 years of age) and 12 parents	The aim of this study was to explore the concerns and care needs of young adult patients with TSC in medical, psychological, and socio-economical domains.	Key concerns highlighted during transition were: • mental and physical health; • participation; • self-management skills; • family planning; and • side effects of medications. Patients expressed the need for multidisciplinary care that is well-informed, easily accessible, and focused on the patient as a whole, including his/her family. Parents also reported high stress levels themselves.
Identifying the perspectives of pediatric nurse practitioners on the needs of youth, caregivers,	Publication date: 2018 Jurisdiction studied: U.S.	PNPs (N = 170) participated in a luncheon for those interested in transition at an annual conference	This study examined the perspectives of pediatric nurse practitioners (PNPs) regarding the needs of adolescents, parents/caregivers, clinicians, and institutions in the healthcare transition process.	Four categories of needs were identified. • Adolescent needs: Tailored education, timely and accessible healthcare, support through trusting relationships.

clinicians and institutions in supporting transition	Methods used: Small group discussions			• Parent/caregiver needs: Tailored education and communication, better coordination in the healthcare system, and support in helping letting go. • Clinician needs: Education in knowing how to prepare for transition, information sharing within the healthcare system, and fostering holistic support with early communication. • Institutional needs: Better coordination across hospitals/clinics, multidisciplinary approaches, and clear policies and roles. PNPs also identified healthcare informatics and adolescents' use of technology as additional critical aspects to be considered in healthcare transition planning.
Identifying provider perspectives on the barriers and facilitators in transitional care in patients with inflammatory bowel disease	Publication date: 2014 Jurisdiction studied: U.S. Methods used: Interviews	12 pediatric and adult IBD providers from across the United States with experience caring for adolescents and young adults with IBD	The study objectives were to identify outcomes for evaluating transition success and elicit the major barriers and facilitators of successful transition.	• Providers reported evaluating transition success and failure using: o healthcare-utilization outcomes (e.g., maintaining continuity with adult providers); o health outcomes (e.g., stable symptoms); and o quality-of-life outcomes (e.g., attending school). • Providers identified patients' level of developmental maturity (e.g., their ability to organize their own care) as the most prominent determinant of transition success. • Other determinants were: o parental involvement (e.g., a helicopter parent versus optimally involved parent); and o provider support (e.g., care coordination).
Exploring the perception of young adults with Type 1 diabetes on their patient-provider relationships during the transitional period	Publication date: 2014 Jurisdiction studied: U.S. Methods used: Focus groups	26 emerging adults with Type 1 diabetes.	This study aimed to explore perceptions that emerging adults with Type 1 diabetes have of their patient-provider relationships across the transition from pediatric to adult care.	Three major themes emerged: • loss and gain in provider relationships across the transition-patients; • adult provider collaborative conversations can promote patient involvement and accountability; and • pediatric providers could aid the transition process by actively promoting emerging adults' autonomy while maintaining parental support, communication with adult providers, and follow-up with transitioning patients.
Exploring the experiences of young people with	Publication date: 2013	Young adults with CF who were listed for transfer in the child	The aim of this study is to explore and understand the experience of	Two themes and four sub-themes emerged: • preparing for the transition:

cystic fibrosis before and after their transitional care	Jurisdiction studied: Ireland Methods used: In-depth interviews	setting, or who had been transferred to the adult setting within the last two years	young people before and after their transitional care.	o sharing knowledge (better coordination and coordination), and o easing the transition process (helping patients deal with fear and apprehension); and • amorphous service o structured transition (patients achieving objectives and skills), and o focusing on the needs of the young adult (avoiding being too clinically oriented).

Appendix 3: Details of tools and clinics designed to support transitions from child to adult care for people with special needs in Canada

Organization	Program/tool	Description of program components	Relevance to CAPHC transition guideline recommendations
BC Children's Hospital	ON TRAC (35)	• The ON TRAC Model includes: o Transition clinical practice guideline, detailing important steps in transition o Healthcare provider tools, including medical transfer summaries o Youth and family toolkit, including quizzes and activity cards	• Emphasizes recommendations 1-15, 17, 18
British Columbia Pediatric Society	Youth Mental Health Transition Protocol Agreement (36)	• Designed for youth receiving Ministry of Children and Family Development Child and Youth Mental Health Service or Aboriginal Child and Youth Mental Health Services who are transitioning to adult care • Collaborative planning process engages youth and family, and decides best fit for future program	• Emphasizes recommendations 11, 15
	Transition Care Management Plans (37)	• Transition care management plans are accessible online, and are designed to: o Assist in knowledge transfer and promote continuity of care in transition o Provide guidance for healthcare providers on specific conditions o Provide guidance on responsibilities for tertiary providers	• Emphasizes recommendations 1, 2, 6, 10, 12, 14
	Transition Timeline Tool(36)	• Guide to available resources early in transfer process, as time of transfer nears, and at time of transfer	• Emphasizes recommendations 1-10, 12, 13, 17, 18
Sinneave Family Foudation(38)	Launch™ (38)	• Launch™ materials provide three programs to assist stakeholders with transition: o Launch + Skills: individualized transition planning o Launch into Life: workshops for individuals, parents, and professionals o Launch Online: Free online training	• Emphasizes recommendations 1, 2, 5, 6
Alberta Health Services	Well on Your Way: Helping Youth Transition to Adult Healthcare (42)	• Well on Your Way provides information for youth, young adults, parents/caregivers, and healthcare providers including: o Transition guidelines for independent and dependent youth o Transition Readiness Checklists o Planning resources o Health professional transition and screening tools	• Emphasizes recommendations 1-13

Organization	Program/tool	Description of program components	Relevance to CAPHC transition guideline recommendations
	Care Coordinator at Alberta Children's Hospital (49)	• Connects patients with complex care needs to care teams • Collaborates with community and hospital-based workers to support transition care plans	• Emphasizes recommendations 5 and 11
	South Health Campus Adolescent Transition Program (49)	• Prepares adult acute care site for the care needs of patients transitioning from pediatric to adult care • Patients work with staff to create transition plans and develop knowledge of care transfer	• Emphasizes recommendations 5 and 11
	Physician role (49)	• Recently established physician role created to address needs of high-risk patients transitioning to adult care	• Emphasizes recommendations 8, 9 and 11
	Alberta Health Services Connect Care (49)	• Online flowsheet allowing for healthcare providers to document patient transition activities	• Emphasizes recommendations 1, 2, 7, 8, 10, 11, 14, 17
	Alberta Health Services provincial transition website (49)	• All-encompassing and publicly accessible website on topic of youth-to-adult transition • Collaborative effort of institutions, healthcare providers, families and patients	• Emphasizes recommendations 1, 2, 7, 8, 10, 11, 14, 17
	Transition Navigator Trial (TNT) (49)	• Provincial randomized control research study evaluating impact of patient-navigator intervention on health outcomes	• Emphasizes recommendations 1, 2, 7, 8, 10, 11, 14, 17
Cerebral Palsy Alberta(39)	Youth Transitions (39)	• Activities for transitioning youth include one-on-one counselling, mentorship opportunities, workshops and group support	• Emphasizes recommendations 1, 2, 4
McMaster University	MyTransition App (33)	• App developed by McMaster University to help with transition from pediatric to adult care • Components include: o Tools to describe one's own health condition o TRANSITION-Q scale to measure transition readiness/self-management ability o Health passport for communicating information about medical history and treatment	• Emphasizes recommendations 1, 8, 18
	Rheumatology Transition Clinic (50)	• Patients attend a clinic to meet with both adult and pediatric rheumatologists • Clinic staff use Transition Questionnaire to measure and track skill development of patients • MyTransition app used to help patients aged 12-18 as they approach adult care	• Emphasizes recommendations 1-13, 15, 17, 18

Organization	Program/tool	Description of program components	Relevance to CAPHC transition guideline recommendations
	Michael G. DeGroote Pain Clinic (51; 52)	• Provider prior to transition, and assess client's readiness and supports • Transfers care from pediatric to adult provider through a comprehensive referral system	• Emphasizes recommendations 1-19
Children's Hospital of Eastern Ontario	Transition Toolkits (53)	• Toolkits designed to support individuals and families in transition to adult care • General and complex special-needs toolkits including skills list, transition-readiness checklist, and health passport guide	• Emphasizes recommendations 7 and 14
	Mental Health Services Transitional Age Youth program (54)	• Program designed to meet mental health needs of people aged 16-24 undergoing transition • Transition coordinator works with youth to enhance care in the community and connect with resources	• Emphasizes recommendations 1-4, 8, 9, 11, 16
St. Joseph's Health Care London(55)	Transitional and Lifelong Care (TLC) Program (55)	• Provides care to people with needs related to a childhood condition, such as spina bifida, Rett syndrome, cerebral palsy, developmental delay • Interdisciplinary service providers including a physiatrist, nurse practitioner, social worker	• Person centred and clinical recommendations • Emphasizes recommendations 1-13
Holland Bloorview Kids Rehabilitation Hospital	Transitions to Adulthood services(44)	• Programs designed to support youth with disabilities through transition into adulthood • Programs include camp programming, volunteering and employment programs for youth	• Emphasizes recommendations 2, 4, 5, 9
	The LIFEspan clinic (56)	• Living Independently Fully Engaged service • Weekly clinic for youth with cerebral palsy and neuromotor illness • Available to youth at least 14 years old, with services including school support, community engagement, health care knowledge	• • Emphasizes recommendations 2, 4, 5, 8-11, 17
SickKids	SickKids Resource Navigation Service (32)	• Supervised by the Social Work Department; coordinators work with families to connect them with resources • Assistance with form completion, document gathering, clinical care team supports • Engage with youth to plan care and promote self-advocacy	• Emphasizes recommendations 1, 3, 7, 8, 9, 12, 14, 17, 18
	Diabetes Clinic (57)	• Session run by clinic staff providing information for patients aged 17-18 years • Goal to provide information and support for transition to adult diabetes care	• Emphasizes recommendations 4, 5, 10

Organization	Program/tool	Description of program components	Relevance to CAPHC transition guideline recommendations
		• Topics include coping with change, choosing a doctor, health maintenance, transition changes	
	Marrow Failure and Myelodysplasia Program(58)	• Patients who reach the age of 18 years are seen by specialists in inherited or acquired bone marrow failure syndromes	• Emphasizes recommendations 5, 11, 18
	Thalassemia and Sickle Cell Disease Transition Clinic (59)	• Monthly Sickle Cell/Thalassemia transition clinic features education, resources, supports, readiness surveys with the MyHealth Passport • Dedicated role of Transition Specialist supports transition of patients between hospitals	• Emphasizes recommendations 1, 3, 4, 5, 12, 16
	HIV Clinic: Positively Good 2 Go (60)	• HIV-positive youth transitioning to adult care are supported with transition tools and resources, including: o Readiness checklists, o The three sentence summary, o MyHealth Passport (featuring an HIV/AIDS template), o Transition booklet and timeline	• Emphasizes recommendation 2
	iPeer2Peer (61)	• Program matches teenagers living with chronic diseases such as chronic pain, cancer, and arthritis with young adult mentors who have learned to manage the disease • Mentors and youth meet 10 times over Skype to discuss transition and disease management • Program currently under development	• Emphasizes recommendations 5, 10, 11
IWK Health Centre	Pediatric Rheumatology Transition Clinic (48)	• Transition clinic attended by at least one pediatric rheumatologist, an adult rheumatologist, pediatric rheumatology nurse, pediatric physiotherapist	• Emphasizes recommendations 3, 5, 6, 9, 10, 12, 13, 18
	You're in Charge (48)	• Free three-hour workshop focusing on transition to adult care • Youth and parents engage with medication, health history, summary of health, goal setting	• Emphasizes recommendations 1, 3, 4, 9, 10
Children's Hospital at London Health Sciences Centre	Cystic fibrosis (46)	• CF program breaks down transition into six stages, beginning at age 8 and ending at age 18 when patients transition to adult care • Each stage has a checklist, emphasizing key points such as understanding CF, airway clearance exercises, medication management, independent clinic visits	• Emphasizes recommendations 1, 8, 10
	Epilepsy clinic (62)	• One clinic run by Transition Specialist and Pediatric Social Worker; run for youth with epilepsy that are part of Neurology team to assist with transitioning to adult care	• Emphasizes recommendations 1-5, 8-10, 12

Organization	Program/tool	Description of program components	Relevance to CAPHC transition guideline recommendations
		• One clinic run for youth who have been diagnosed with drug-resistant epilepsy and are seen in the Comprehensive Epilepsy Clinic; attended by Adult Epileptologist, Transition Specialist, Pediatric Social Worker	
	Congenital heart defect clinic (46)	• Starting at age 15, physician discusses transition plan with patient • Every four months, physician meets with adult cardiologist to review patient chart • Patient transitions to adult care at age 18	• Emphasizes recommendations 1, 4, 5, 8, 10, 11
	Complex care clinic (46)	• Patients typically do not fit into a specific care group and see a range of practitioners • Transition process begins at age 17; parents receive transition-readiness kit • Supports from clinic include support in funding applications, guidance in setting up bank account	• Emphasizes recommendations 1, 2, 4, 5, 8, 10, 11
Montreal Children's Hospital (47)	Diabetes transition clinic (63)	• Supports adults with diabetes from care at Montreal Children's Hospital to adult care	• Emphasizes recommendation 3
	Young Adult Kidney Transplant Clinic (64)	• Patients are followed by an interdisciplinary adult and pediatric team • Transition to adult care meeting and presentations bring together members of transition team	• Emphasizes recommendations 3, 4, 10
Shriners Hospital for Children – Canada	Osteogenesis Imperfecta Transfer Summary Tool (65)	• Tool includes information including insurance information, psychosocial needs, medical history, activities of daily living	• Emphasizes recommendations 1, 2, 4, 9, 10, 17, 18
Stollery Children's Hospital	Pediatric Diabetes Education Centre (66)	• Youth age 15-17 are supported in diabetes education such as insulin management, clinic appointment booking	• Emphasizes recommendation 1, 4, 8, 9, 10, 12
	Comprehensive Epilepsy Program (67)	• Clinic runs a few times a year, and includes a nurse-led program, self-management workshops, transition questionnaires	• Emphasizes recommendation 4, 8, 10, 13, 18