# A Guideline for Transition From Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach

CAPHC National Transitions Community of Practice

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CAPHC

CANADIAN ASSOCIATION OF PAEDIATRIC HEALTH CENTRES
ASSOCIATION CANADIENNE DES CENTRES DE SANTÉ PÉDIATRIQUES

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# Executive Summary

Advancements in medical treatment and technology have increased the life expectancy of children with special health care needs, the majority of whom are now living into adulthood. This means a greater number of youth with special health care needs (YSHCN) are transferring to adult care, placing more demand on adult specialists to treat individuals with childhood onset conditions despite minimal knowledge and training with respect to these conditions [1]. Therefore, there is an increased need for planned programs for transition of youth with special health care needs from the paediatric system to adult health services.

Currently, there is limited literature that defines and identifies transition practices that produce positive outcomes. However, there is a significant amount of qualitative data available on the patient, parent and health care provider perceptions of barriers to successful transition[2] and a growing pool of quantitative data reflects poor clinical outcomes post transfer [3,4].

To address these issues, in January 2012, the Canadian Association of Paediatric Health Centres (CAPHC) established a national Community of Practice (CoP) in Transition from Paediatric to Adult Health Care. While ensuring engagement of multiple stakeholders and a national approach, the CoP developed: A *Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs*. Herein referred to as the Guideline, this document includes 19 recommendations to enhance and guide the care of YSHCN through adolescence into adulthood. Practice recommendations are based on published evidence as well as stakeholder consultation through a consensus building set of surveys. When possible, we adhered to the AGREE II [5] framework for development of practice guidelines.

The primary aims of the Guideline are:

1. To influence transitioning at the person and clinical level, prompting change over time to the system level;
2. To provide a framework for a supportive process for transitioning from paediatric to adult health services; and
3. To identify collaborative processes, tools and resources for all stakeholders in the transition of youth to adult healthcare.

With this national collaboration, a repository of tools and resources has been developed to support organizations and clinicians in the implementation of the recommendations in the Guideline. Evaluating whether a purposeful, planned approach to transition improves health outcomes or experiences for the youth and their family is imperative. Transition research is growing and numerous models of implementation and evaluation are emerging.

The CoP philosophy supports an implementation strategy, such that knowledge continues to be shared as lessons are learned and new knowledge is created. Through this supportive network, the Guideline will be updated and improved through the continued sharing of resources, time, expertise, and research.

The following is included in this document:

1. An introduction to the topic of transition to adult care and the unique health and psychosocial needs for YSHCN;
2. A brief review of the need for transition support and measurement of outcomes;
3. A description of the purpose and scope of recommendations, target population and users;
4. Information on our review and adherence to AGREE II [5], formulation and methodology of recommendations, and access to tools for further support and operation;
5. A summary of the literature on implementation and evaluation of transition programs; and
6. Next steps for the Transitions CoP.

## Disclaimer

This Guideline represents the views of the CAPHC Transitions CoP and was prepared after careful consideration of the available evidence as well as a consensus building process. The Guideline does not override the responsibility of individuals and organizations to make decisions and provide the most appropriate care to children, youth and emerging adults in consultation with the patient and family/guardian.

## Funding

The CoP is supported by CAPHC through a generous contribution from BC Children's Hospital Foundation that pays for the coordination and management of the CoP's activities. The CoP members and their respective organizations have supported the Guideline development work through in kind contributions of time and expertise.

## Conflicts of Interest

The Guideline was developed by a National Community of Practice facilitated by the Canadian Association of Paediatric Health Centres. CAPHC and its member organizations have no conflicts of interest to declare.

## Guideline Management

The Guideline was completed in June 2016. Through the regular activities of the CAPHC Transitions CoP, the Guideline will be updated every three years to include new research and the inclusion of validated tools to support implementation as they become available.

## External Review

The Guideline was reviewed externally by individuals (listed below) not directly involved in the development of the recommendations.

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## *Glossary of Terms*

**Adult Services:** Inclusive of medical, nursing, allied health, educational, living, financial and complementary services after an individual leaves paediatric services (typically between 17 to 19 years of age).

**Attachment:** Establishing and forming relationships, following the transfer of care, to adult specialists or new care providers.

**Children and Youth with Medical Complexity:** Children with a unique combination of substantial family-identified service needs, characteristic chronic and severe conditions, functional limitations, and extraordinarily high health care use[6].

**Community Services:** Provided external to hospital settings including but not limited to: occupational and physical therapy, home care, educational/vocational counseling, behavioural therapists, social work, respite, and condition specific agencies.

**Complementary and Alternative Therapies:** Including but not limited to: acupuncture, Aboriginal healing, chiropractic care, herbal medicine, homeopathic care, massage, meditation, naturopathy, reflexology, and/or yoga.

**Developmentally–appropriate:** Ensuring teaching practices are appropriate to children and youth age and developmental status, attuned to them as unique individuals, and responsive to the social and cultural contexts in which they live.

**Family:** Those individuals who provide care, legal guardianship or whom the youth deem as important and vital in supporting their health.

**Health Summary:** A comprehensive letter written at the time of a youth's transfer from paediatric to adult services and which includes pertinent medical, emotional, and social content with appropriate assessments, reports and referrals.

**Lapses in Care:** Spaces and gaps in care between health care providers and or services–for various reasons.

**Lived Experience:** Includes understanding and giving value to each person's situation and history; evolves from sharing stories and direct communication.

**Natural Network:** Individuals, identified by the youth and family, who provide support and may include family members (extended or honourary), caregivers, neighbours, teachers, coaches and others.

**Navigation:** Locating, finding and accessing health care services and resources.

**Paediatric Services:** Services provided from birth until adulthood or a specific age determined by the province or health service (typically between 17 and 19 years of age).

**Primary Care:** Services provided by a qualified Family Physician and/or Nurse Practitioner, and which include age appropriate health surveillance and interventions (e.g., vaccinations), care coordination, counseling/emotional support, and referrals to specialty care.

**Readiness:** A rating of the level of capacity that a youth (or with the help of others) has to engage in behaviours and/or activities required by the adult health care system.

**Resources:** Includes people, time, space and funds.

**Self-management:** Relating to the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management, and emotional management[7].

**Specialty Care:** Services provided by health professionals with advanced training in a particular health concern or illness, and may be provided in community, paediatric or adult settings upon referral from primary care.

**Stakeholders:** Youth, families, their natural networks, community, paediatric, and adult care providers.

**Transfer:** A one-time event that occurs when a youth is transferred out of the child health system and into the adult care system.

**Transition:** A purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care[8] that is supported by individualized planning in the paediatric and community settings, a coordinated transfer of care and secure attachment to adult services.

**Youth:** A person between 12 to 25 years of age.

**Youth-focused Care:** Placing youth as the central member of the health care team, ensuring care, decision-making and language at the youth's level.

**Youth with Special Health Care Needs (YSHCN):** A youth requiring specialized health care and services for physical, developmental and/or mental health conditions.

# Introduction to Transition

There is an increased need for direction in the development of programs for the transition of YSHCN from the paediatric system to adult health services as a result of various emerging concerns and barriers in this field. These barriers include the psychosocial concerns of adolescents and young adults with special health care needs; documented by outcomes related to poor transfer experiences and changes in health care environments.

## *Psychosocial and Unique Health Needs of YSHCN*

As transitions occur at all points in the health care trajectory for Canadians, transition care planning is not exclusive to YSHCN. However, transition care can be particularly complex and challenging for YSCHN as these young people are at risk for additional psychosocial difficulties. This includes difficulties with social functioning[9], anxiety disorders[10], depression[9–12], suicidal ideation[10,11,13], and suicide attempts[11,13]. In addition, adolescents with chronic health conditions are as likely or more likely, to engage in risky behaviours (e.g., dangerous sexual activity, and tobacco, alcohol and illicit drug use) compared to peers without medical conditions[11,14,15]. A 2007 review suggested that “a chronic health condition in adolescence can represent a major psychosocial burden”[16]. Risk factors such as these can increase the complexity involved in transitioning from paediatric to adult care, place a higher burden on families and reduce the individual’s quality of life in the short term. This could also lead to the establishment of harmful long term behaviours that result in adverse health outcomes[17].

An adolescent's transition from paediatric to adult health care can also be a stressful time for parents/caregivers, and may place a toll on their health or psychological well-being [18]. Parents may experience competing demands, such as needing to provide care for their child with special health care needs, as well as themselves and other family members [18]. Psychological distress in parents is associated with poor adolescent health outcomes. For instance, caregiver depressive symptoms, as mediated in part by perceived caregiver burden, were found to be related to poor glycaemic control in adolescents with type 1 diabetes [19]. In addition, adolescents with cystic fibrosis were more likely to report psychological symptoms themselves if their parents reported symptoms of depression or anxiety [20].

Research indicates that adolescence and young adulthood (often referred to in the literature as “emerging adulthood”) is a physically, socially and neurologically unique developmental period, and the attainment of adult-like behaviors now often extends to 25 years and beyond [21]. This results in young adults remaining at home longer and reliant on their parents for support. While young people recognize that certain attributes are necessary to become an adult, the timing of acquiring these attributes differs [21]. Therefore, a “one size fits all” model for preparing youth to transfer to adult care is not possible. Transition needs to be an individualized, coordinated and collaborative process between the youth, family and paediatric and adult care providers, occurring over time and spanning both adolescence and early adulthood [22]. Understanding of this unique developmental period, by paediatric and adult providers, can help to facilitate transition for those with special health care needs [23].

## *Barriers for Transition*

Advancements in medical treatment and technology have increased the life expectancy of children with special health care needs, most of whom are now living into adulthood. This means a greater number of YSHCN are transferring to adult care, placing more demand on adult specialists to treat individuals with childhood-onset conditions despite minimal knowledge and training with respect to these conditions [1].

Youth and families also find themselves coordinating care in a new and more fragmented system, often lacking the skills and support required to navigate the system. Adult specialists and primary care providers identify the lack of knowledge and/or training they receive regarding childhood onset conditions, their long-term complications, and the surveillance requirements, as contributing to these poor outcomes in patients [1,24]. Further, adult care providers report concern with the inadequate transfer of information and medical documentation [25]. Hence, increase in stress and anxiety is reported by all parties involved in the transition of YSHCN from a paediatric to adult care setting.

Additionally, a growing pool of quantitative data reflects poor clinical outcomes post transfer. For example, prior to initiating a transition program in Manitoba, 40% of young adults with type 1 diabetes dropped out of adult health care [3] resulting in an increased risk of amputation, blindness and even death. Another study found that prior to initiating a transition program in British Columbia kidney transplant patients had worse health outcomes, including a 24 percent incidence of graft loss and/or death within two years of transfer [4]. Youth with chronic health conditions may also experience gaps in care during the years immediately following transfer [26]. Data show transitioning from paediatric to adult care is associated with decreased clinic attendance [27], impeding the management of a chronic health condition and leading to an increased risk that young adults will not receive care until after complications arise [28].

When youth and their families face barriers and challenges as they transfer from paediatric to adult services, care can be disrupted, and financial costs can be incurred not only by the patient and family but also by the health care system. For example, patients may use health care resources like emergency departments more frequently, and experience increased hospitalizations and longer inpatient stays [29].

The lack of preparation for and awareness of the differences between paediatric and adult care are identified as common barriers to successful transition [30]. The paediatric model of care is usually multidisciplinary and holistic in nature, with attention to psychosocial functioning, development, and navigational support. Paediatric care is also family centred, and parents or caregivers are actively involved in making medical decisions and delivering care. In contrast, in adult health care, the patient is seen as responsible and self-reliant, and expected to advocate for themselves, manage their own health and make informed, independent treatment decisions [31]. Young adults who are not prepared for the more autonomous environment of adult health care or who require psychosocial or navigational support often struggle to adapt. One of the reasons YSHCN may lack the personal responsibility and self-managed health care behaviours required in the adult medical system is that parents are expected to be highly involved in their care in paediatrics. This often leads to decreased opportunities for YSHCN to meet with health care providers on their own or practice self-directing their care as they approach the age of transfer [32,33].

In addition, youth and their families often struggle with the transfer to adult care because of their emotional attachment to paediatric health care providers and the grief and loss they experience when these trusting relationships end [34]. Fear of the unknown and uncertainty about the future are also commonly experienced by youth and their families during this time [18,35,36].

Of note, transition (which includes transfer) is more complex and generally more difficult for youth with medical complexity or who have multi-system issues, co-morbidities and physical and/or cognitive challenges. The difficulties in transition among such youth can be related to fragmentation in care, a decreased level of resources and support available for young adults, and difficulty finding a primary care provider to coordinate their care [18,37]. Increasing patient complexity requires parent/caregiver involvement in transition planning and often requires support with navigating the adult health care system [18]. Accessing navigational support during the transition to adult health care can be a challenge and additionally risky for this fragile population.

## *Statement of Need*

While a significant amount of qualitative data is available related to patient, parent and health care provider perceptions of barriers to successful transition and related transfer outcomes, there is a lack of research to definitively define and identify transition practice outcomes. This further supports the need for a review of both the published research literature and descriptions of current practices to determine common principles to foster a national Guideline with recommendations for transitioning from paediatric to adult health care.

# Guideline Development Methodology

## *Guideline Development Members - Community of Practice (CoP)*

The Guideline and recommendations were developed through CAPHC's national CoP. Communities of Practice are defined as "a type of informal learning organization"[38,39]. CoPs are established in order to address a certain issue and bring together people from different backgrounds and professions. These people share concerns, problems and a passion about a specific issue. The concept of CoP is shaped by three dimensions. The first dimension is *mutual engagement* which describes the social interaction between individuals in order to create a shared meaning. The second dimension is called *joint enterprise* and refers to the process of people working together towards one goal. Lastly, *shared repertoire* which is based on the use of common resources during the process of decision making[38]. Finally, while CoPs are an evolving concept, four key characteristics of CoPs: social interaction, knowledge sharing, knowledge creation and identity building exist [39].

In January 2012, a CAPHC Community of Practice in Transition from Paediatric to Adult Health care was established. This group of stakeholders from across the country includes front line clinicians and allied health professionals from adult and paediatric settings, researchers, administrators from all levels of care, homecare, rehabilitation, community and tertiary hospitals, as well as other community based care settings. Most significantly, families and youth who had previously transitioned are welcomed members. The CAPHC Transitions CoP has all of the dimensions and characteristics described by Wenger et al [38].

For a complete list of all participants and organizations in the Transitions Community of Practice (at the time of publication) click here

Through monthly meetings, a strong network of individuals and organizations was established to work toward the common goal of national standards to optimize the transition of YSHCN from paediatric to adult care. Knowledge sharing occurs via formal presentations and through informal exchanges between individuals and organizations. The sharing of resources; time, expertise, research and previously developed tools has enabled a process for guideline development at a much faster pace than a single organization can manage on its own. The shared decision making and consensus building process has ensured the voices of all stakeholders are heard equally.

While ensuring engagement of all stakeholders, the CoP aims are:

1. To develop national Transition Clinical Practice Guidelines and recommendations to enhance and guide the care and health of YSHCN through adolescence into adulthood.
2. To create strategies for sharing and implementation of transition tools, materials and resources at a national level with clear guidelines for use and collaboration.
3. To suggest opportunities for partnerships and collaboration in providing 'best practice' standards in clinical, education, evaluation, and research.
4. To ensure the voice and needs of youth and young adults involved with and experiencing transition are included at each stage of development of these objectives.

This CoP model aligned interprofessional learning with integrated knowledge translation. The Transitions CoP established a framework for decision making and determined how these decisions can be implemented in clinical practice. Having a strong CoP supports an implementation strategy as knowledge continues to be shared, lessons learned and new knowledge created.

The ***Guideline Development Group*** included a smaller group composed of members of the CAPHC Community of Practice for Transition from Paediatric to Adult Health Care. Members included young adults, families, health care providers, researchers and administrators from across Canada representing paediatric, adult, rehabilitation, community and mental health organizations. The CoP met frequently, providing a forum for knowledge exchange and relationship building.

## *Strengths and Limitations of Evidence*

The Guideline Development Group conducted a literature search for practice guidelines, global programming, policy statements, systematic reviews, and relevant research studies related to the transition to adult care from Canada, US, Australia and the United Kingdom. Medline, Cumulative Index to Nursing and Allied Health (CINAHL) and PUB Med were used to search for relevant articles (English only) using key words (adolescent, adolescence, young adult, parents, families, transition, transfer of care, health care, chronic health conditions, chronic illness, and complex care, policy statements, medical home, emerging adulthood, continuity of care, clinical guidelines and youth engagement). Results were limited to publications from 2006 to 2015 (with exceptions of foundational work of an earlier date) from primary and secondary sources.

All evidence found in the literature was critically appraised. Specifically, the quality of evidence from each source was rated using the following scheme:

| | |
|---|---|
| I | Evidence obtained from one or more randomized trials with clinical outcomes; |
| II | Evidence obtained from research, meta-analysis, systematic review, policy statement; or |
| III | Expert opinion. |

Of note, given the limited number of research articles with random controlled trials, our evidence body is composed of some quantitative studies, but mainly qualitative studies, reviews, case reports and systematic reviews. The literature scan and review was an ongoing process, as new articles and guiding papers were published annually.

A quick reference guide outlining the quality of evidence scale for each recommendation is available in: Appendix 1: Quick Guide to Recommendations and Levels of Evidence.

## *Formulating the Recommendations*

Using the literature, research and a review of 21 published transition guidelines/policy statements, guided by the experience of the working group, eight themes referred to in this document as “core domains” emerged as integral to the transition process at the individual, clinical and system levels.

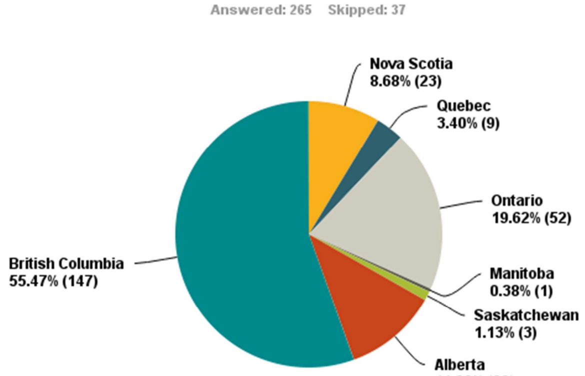
| | |
|---|---|
| Domain 1 | Youth Focused and Family Centered |
| Domain 2 | Youth, Family and Support Networks Engagement |
| Domain 3 | Documentation and Process Change |
| Domain 4 | Education: Building Capacity of all Stakeholders |
| Domain 5 | Attachment to Adult Services |
| Domain 6 | Roles and Care Coordination |
| Domain 7 | Service Planning & System Change |
| Domain 8 | Evaluation Strategies |

Once the domains were identified, the Guideline Development Group extracted evidence statements and developed related recommendations. These recommendations were vetted by the CoP members and it was agreed that they should be evaluated by a larger group of stakeholders who were not directly involved in the recommendation development process. To reach a broader audience, CoP members invited their networks to be part of a consensus building process. A list of 525 individuals from across Canada, who were identified as stakeholders in the transition process, was compiled. These included youth, families, health care providers, administrators, researchers from paediatric and adult settings—in acute, community and rehabilitation settings. The purpose of this national reach was also to ensure a Canadian-wide consensus on recommendations.

## *Consensus Survey Process and Results*

The survey consisted of two rounds where recommendations were presented and respondents were asked to rate them with a scale ranging from *Essential*, *Very Important*, *Accessory* or *Unnecessary*. Participants were encouraged to provide comments or suggestions for improvement to each of the statements. In round one, an electronic-based survey was sent to the list of 525 identified stakeholders, with a total of 260 (49.5%) completed. Demographic information was collected on stakeholders including, academic degrees, current position, organization, and province at round one.

| Discipline of Participants | Number of Participants |
|---|---|
| Nursing: RPN, Bachelor, Masters | 60 |
| MD/FRCPC | 28 |
| Social Work | 17 |
| Youth or Family Member | 23 |
| Allied Health (OT/PT/RT) | 13 |
| Education | 12 |
| BA/BSc MA/MSc | 14 |
| Business/Health Administration | 9 |
| Psychology BA/MA/PhD | 7 |
| PhD | 6 |
| Other | 4 |



Of note, majority of respondents were from one province and three provinces were not represented.

In total, 39 recommendations were presented. Seventy percent of the respondents agreed that five of the recommendations were *Essential*. When *Essential* and *Very Important* were combined all 39 recommendations were agreed on by more than 70% of participants.

Responses were overwhelmingly positive regarding the intent of the recommendations and the goal of the work. Numerous comments were collected for each recommendation statement and the overall collection. Of concern, was that some of the recommendations were seen as overarching statements and principles. Respondents remarked that the recommendations did not provide guidance on who would be responsible for the recommendation. Finally, there was concern on the number of total recommendations with a suggestion for reduction in the total number. Consequently, the Guideline Development Group reviewed the results of the survey and reworded many of the statements to provide clarity, reduce redundancies, and attempt to address these initial concerns. This resulted in 29 recommendations.

A second survey was conducted; 149 of the original 260 (57%) individuals responded. Again five recommendations were ranked *Essential* by 70% of respondents. When the scores for *Essential* and *Very Important* were combined 27 of the recommendations were agreed on by more than 70% of respondents.

The Guideline Development Group examined each recommendation, individually considering its ranking and all of the related comments and reduced the total to 19. Respecting the eight Core Domains and reflecting on the goals of the CoP the 19 recommendations were categorized as principles, clinical, system and good practice points. These were eventually re-organized into three categories: Person Centred, Clinical and System-level recommendations. A table outlining the development of the key recommendations, as compiled from September 2013 to December 2015, is available in Appendix 2: Evidence Table for Recommendations.

List of references reviewed to compile recommendations is available in Appendix 3: References List for Evidence Table and Recommendations. Of note, each of the references is graded as to strength of influence in writing the recommendations, using the following scale:

| | |
|---|---|
| A | Strong influence on recommendations |
| B | Moderate influence on recommendations |
| C | Optional or used to provide general background information. |

# The Guideline for Transition from Paediatric to Adult Health Care

## *Purpose and Scope of Guideline*

This Guideline was developed to address the CoPs' definition of *transition* as a purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care [8] that is supported by individualized planning in the paediatric and community settings, and results in a coordinated transfer of care and secure attachment to adult services. As such, the objective of the Guideline is to support a successful transition framework from paediatric to adult care that results in individuals who are better equipped to navigate the system and better able to manage their own health.

These five key questions influenced the development of subsequent recommendations:

1. What are the key components necessary for a successful transition/transfer?
2. How can clinicians support families and youth through the transition process?
3. How can the system support clinicians in providing a successful transition process?
4. How do we know when a clinical group or system has adopted and integrated transition/transfer processes?
5. How do we evaluate and monitor a successful transition?

### Aims

1. To influence transitioning at the person- and clinical-level, prompting change over time to the system level;
2. To provide a framework for a supportive process for transitioning from paediatric to adult health services; and
3. To identify collaborative processes, tools and resources for all stakeholders in the transition of youth to adult healthcare.

## *Target Population*

Youth (aged 12 to 25 years) with special health care needs including physical, developmental and/or mental health conditions, and their families, requiring ongoing health surveillance and care to maintain optimal health into their adult years.

## *Target Users*

This Guideline is aimed at the professional groups, allied health providers, families and caregivers who are involved in the care and transitioning of YSHCN. This Guideline is to be integrated into all areas of health care practice and policy; paediatric and adult, tertiary and community hospitals, rehabilitation, community and homecare services, administration and research.

# *Guideline Recommendations*

## Person Centred Recommendations:

1. Transition planning is youth-focused and family-centred, inclusive of personal choice and is adaptable to the abilities and complexities of the youth's needs.
2. Transition of youth and their families address the youth's physical, developmental, psychosocial, mental health, educational, lifestyle, cultural and financial needs.

## Clinical Recommendations:

3. Transition for youth is supported by individualized planning in the paediatric and community settings, a coordinated transfer of care and secure attachment to adult services.
4. Healthcare providers engage, educate and build capacity of youth and their families regarding transition.
5. Collaborative respectful communication between stakeholders (youth, families, their natural networks, community, paediatric, primary and adult care provider(s) supports the flow of information and ensures safe, caring and effective transition.
6. All youth have a primary care provider to support care coordination.
7. A developmentally appropriate individualized transition plan is prepared and documented in collaboration with the youth and family.
8. Paediatric and primary providers assess the youth's readiness for adult care, identifying gaps in skills and knowledge requiring intervention.
9. Healthcare providers and family members support youth at their appropriate developmental level to understand their chronic condition, treatment plan, and level of self-management.
10. Care providers educate the youth and family about transfer of care, at least one year prior to transfer, encouraging them to share in the responsibility of accessing community and adult services, and if needed, provide additional navigational support.
11. Priority for care coordination is given to youth with complex needs and their families.
12. Each transferring program is responsible to provide a comprehensive health summary at the time of referral, to the adult health care provider(s), primary care provider(s), youth and family.
13. Transfer of care to adult services includes monitoring of youth's attachment to adult services, attendance at adult appointments in an expected timeframe, ongoing communication between paediatric, primary and adult providers, and shared responsibility for management of youth with lapses in care.

## System Level Recommendations:

14. All services have a written policy for the provision of transition.
15. Develop efficient and accredited health information systems to support transfer of information and collaborative communication among sectors.
16. Organizations designate transition champions within their paediatric and adult settings to facilitate and evaluate transition.
17. Organizations provide ongoing transition education, training, and knowledge translation for all stakeholders.
18. Researchers and clinicians develop a method for consistent data collection at an individual and systems level, including qualitative narratives of lived experiences and quantitative data, to be used by clinical teams, decision makers and researchers for quality improvement and evidence based practices.
19. Involve youth, young adults and families, policy and decision makers, administrators, researchers, and government agencies, to jointly identify system barriers, system enablers and future development opportunities for the responsible transitioning of youth.

# Implementation and Evaluation of Transition Programs

In this section, we first review resources that can be used in the development or implementation of recommendations. Next, a summary of the current state of affairs in the transition field is provided, with a focus on key reviews, challenges in conducting research as it relates to outcomes, and newly emerging frameworks to better support outcome related studies.

## *Transition Tools and Resources*

To support implementation of the 19 recommendations for transition, a repository of tools and summary of programs has been built on the CAPHC Knowledge Exchange Network. This includes, but is not limited to tools for assessing self-management, health summaries, readiness checklists, health care skills for youth, parents and caregivers, and transfer summaries.

The Inventory of Transition Tools and Resources/Websites is freely available on the CAPHC Knowledge Exchange Network. The repository will be updated as new relevant tools, resources and programs emerge. Please contact info@caphc.org if you would like to any resources included.

## *Implementation and Quality Improvement Strategies*

Implementing the recommendations for transition into practice will require a systematic process. At a minimum, this will require a process to evaluate transition-related outcomes at the individual and clinical level, identify facilitators and barriers to transition, and allow for refinement and improvement overtime. The CoP promotes the use of an identified framework or model, which includes tracking of improvement goals, for all users of these recommendations.

The Registered Nurses' Association of Ontario [40] provides a comprehensive best practice implementation toolkit, providing recommendations and templates that support the development, implementation and sustainability of a project. The toolkit is available free on their website. Another valuable model for directing continuous quality improvement of tools and processes is the Plan–Do-Study-Act (PDSA) cycle [41,42]. In brief, the PDSA cycle involves identifying objectives, clearly defining the healthcare practice to be improved and developing the process (*Plan*), implementing the practice and associated processes (*Do*), evaluating the desired outcome (*Study*) and using evaluation data to drive changes (*Act*). The process is repeated via the PDSA cycle as new information emerges. Such a model is appropriate in the application of transition recommendations, tools and strategies, as the field and research is continually developing at a rapid rate.

The Got Transitions/Center for Health Care Transition Improvement [43] provides a framework to support improvements in transition at the clinical level through the use of strategies for health professionals, youth and families. Got Transitions' *Six Core Elements of Health Care Transition 2.0* defines the basic components of health care transition support and include establishing a policy, tracking progress, administering transition readiness assessments, planning for adult care, transferring, and integrating into an adult practice. Specific descriptions for each element are operationalized. A qualitative self-assessment measurement guide is also provided (*Current Assessment of Health Care Transition Activities*). In addition, an objective system to measure transition process and monitor the implementation of these core elements is available (*Health Care Transition Process Measurement Tool*).

Attempts to validate this tool are underway. In addition, increasing examples of the application of a transition improvement process are being published [44].

## *Measurement and Outcomes*

The number of publications on transition from paediatric to adult care for YSHCN is developing at a rapid rate. Early publications focused on the principles required to support transitions (e.g., [45,46] and directions for the enhancement of the field). A 2011 publication [47] using a 3-phase Delphi method, identified research priorities in adolescent transition for Canadian youth. Clinicians and academics initially reviewed questions emerging from earlier research (2004-2009) to conclude on five pressing areas for researchers in this field:

1. What skills and knowledge do adolescents need to learn in order to better manage their chronic illness and enable successful transition to adult health care and adulthood? How do they best like to learn these skills and knowledge?
2. How do we measure a successful transition or evaluate a transition program?
3. What are the factors that influence healthcare transitions (not just adherence) and also how do those various factors influence each other?
4. Does "successful transition" lead to improved health outcomes?
5. What are the potential successes or risk factors for successful transitions (i.e. type of illness, age of child, family involvement, level of support systems, and progression of illness)?

Of note, the definition and measurement of a "successful transition" was a key area for investigation in 2011 and continues to be so. In 2015, Suris and Akre attempted to determine agreement on the key elements for a transition program and quantifiable indicators to measure its success using an international Delphi study amongst transition experts. Consensus (over 70% agreement) was reached on six key elements that focused on assuring good coordination between paediatric and adult professionals, starting early and including youth's views and preference. Only one indicator of a successful transition from paediatric to adult health care was identified as essential; "patient not lost to follow-up." Additional indicators were identified as important; such as "patient building a trusting relationship with adult partner" and "patient and family satisfaction with transfer of care." This highlights the need to develop consistent measurement tools that can be used across conditions and sites, and the importance of including both qualitative and quantitative approaches. Of note, while there is agreement on including quantifiable indicators such as "number of ER visits for regular care," as an outcome measure, this requires consideration of the specific characteristics of chronic conditions and adaptation to local practices and resources.

Tools to assess the individual for transition readiness and for the individual to monitor their own progress have also been growing over time. A systematic review in 2014 of 14 transition readiness tools concluded that there was a lack of psychometric evidence supporting available tools and new measures were needed [48]. This was echoed from survey data from YSHCN highlighting the need for better assessment of transition preparation [49]. Two Canadian self-assessment tools for health-related knowledge, self-efficacy and skills for transition validated for psychometric properties, are available for use across a range of chronic health care populations; TRANSITION-Q [50] and Am I ON TRAC [51].

In parallel to research focused on trying to understand key elements for transition outcomes and measurement of its success, several models and interventions to improve transition and transfer experiences have emerged in the last 15 years. Many studies show promising results, however considerable challenges exist in the intervention focused field. Of note, few studies comprehensively evaluate efficacy [46,49,52–55], consistently report outcome data [47] or use validated tools or a common measurement framework [52]. Additional shortcomings include small number of participants per published studies and/or a single paediatric site, limiting generalizability. Designs often lack randomization or control groups, typically using either a pre-post transfer design or a historical cohort of those previously transitioned before an intervention. When measures are included, the focus is on access to care and not the transition process itself. Stakeholder viewpoints in measurement are often focused on the medical view perspective, such as uninterrupted co-ordinated care [52]. In contrast, from a person-centered perspective, the young adult may look at daily functioning and participation in education, housing, meaningful relationships and employment as equally important in the transition process [55–57].

Transition models that are condition specific or focused on a single chronic health condition, lead to an additional challenge in translation of knowledge. This is a particular concern for application to youth with complex or developmental disabilities, who may be excluded from studies or require more intensive, personalized and relationship based approach in terms of self-management, and autonomy [58]. Longitudinal studies are sparse, in spite of recognizing the chronic and ongoing nature of the special health care needs of these youth [59]. Finally, given the diversity of the transition interventions studied, there is difficulty in comparing efficacy of transition models [52]. As the field develops, the CoP reinforces the importance of moving the transition field forward by supporting the inclusion of rigorous and scientifically-sound research studies when implementing the identified recommendations in practice.

## *Frameworks for Evaluation*

In the face of the challenges that have emerged in the transitions field, there has been progression in improving knowledge on the use of consistent frameworks and reducing discord on measuring transition success. While it was agreed that transition is an active process with a comprehensive set of care and support processes that ideally begins well before and extends after transfer—transition is complex and requires multifaceted measurement. In this section, we review three emerging frameworks for measurement in this field.

### Triple Aim Framework

The Triple Aim developed by the Institute for Health Care Improvement [60]has been proposed as a framework for evaluation of transition efficacy and impact. The Triple Aim consists of three measures: patient experience of care, population health and cost. Patient experience of care includes satisfaction, enablers and barriers to care. Population health includes adherence to care guidelines, disease specific outcomes, mortality, patient-reported outcomes of quality of life and functional status, self-care skills, and process of care. Cost measures include service use, short term and longitudinally, gaps in care, cost of no shows, and cost per patient accessing outpatient care versus emergency care versus inpatient care. In a systematic review of 2282 studies of transition interventions, only 33 met inclusion criteria of using any measures of the Triple Aim, with disease specific measures being most commonly reported [52]. Fifteen reported cost in terms of service utilization and only eight measured experience of care. Only three studies reported on all three Triple Aim categories. The need for consensus on a core set of transition measures involving consumer, clinical and research expertise is acknowledged.

## International Classification of Function Framework and Transition

The importance of advancing past measuring “transfer or transition success” to capturing health related quality of life and personalized outcomes as it relates to the transition of YSHCNs has been proposed. The International Classification of Functioning, Disability and Health (ICF) of the World Health Organization moves beyond the health condition (body functions and structures) to understand that a person’s functioning (activities and participation in society) are dynamically influenced by interaction between personal factors and environmental factors [61]. This can include the physical environment, such as access, but also social attitudes, relationships and service availability [62]. These factors can be barriers or facilitators to function. The ICF provides a clear profile of the individual’s situation and can point to areas of strength and need.

Multiple researchers have integrated the psychosocial outcomes of the ICF framework to develop outcome measures and corresponding instruments to use in understanding the transition experience of youth [55,56,59,63–65]. In a qualitative study of lived life experiences of youth in transition, complex interactions between the person and environment were identified [59]. Gorter and colleagues used a knowledge synthesis approach of the developmental disability literature to identify outcomes, person-environment interactive factors and the developmental process or trajectory [55]. The importance of a life course view—not just one point in time—and how relationships, opportunities and experiences impact outcomes has also been identified as important. This study pointed to the interconnected, overlapping and contextually sensitive components of the system, including the impact of environmental and personal factors on the outcome of participation and function.  The lack of rigorous longitudinal data about youth with disabilities to inform recommendations for services supports and policy was noted. Several recommendations for research and for policy as it relates to transition youth are summarized in this study.

## Quality of Life Outcomes

A systems dynamic model for transitions has also been proposed. This includes looking at how the system components interact, as an evaluation tool, and identifying points of intervention [66].  A need to have instruments that can measure patient reported outcomes of quality of life and health related quality of life was identified.  These instruments are needed in evaluation of a process or interventions aimed at maintaining or improving patient reported outcomes.  In examination of 15 instruments that propose to measure patient reported outcomes, Fayed and colleagues also found that the instruments were variable with respect to reflecting the ICF domains [63].  Another finding was that the majority of studies using patient reported measures were based on cross sectional research and individuals were not tracked over time to identify what services or supports made a difference in their transition experiences. When evaluating interventions, the responsiveness of a patient reported outcome needs to detect changes. The need to select the right instrument to measure the intended purpose was raised as a caution, as the acceptance and rejection of instruments can be based on which instruments are included. This reinforces the need to include systematic approaches to evaluation of transitions [63].

In summary, at the present time, evaluation is recognized as a key factor to advance transition practice. However, evaluation is an emerging science both in terms of determining the efficacy of transition programs at a population health and cost benefit level, and at the impact at the individual patient level.

Current studies have concluded the need for collaborative research to identify measures for evaluation and to implement these tools longitudinally into practice.

## Next Steps

As dissemination of the Guideline is underway across Canada, the Transitions CoP's work will continue in key areas, including:

1. National dissemination of the Guideline through a multipronged approach, including electronic channels, use of Transition CoP champions, incorporating both a bottom-up (users) to top-down (organizational) approach.
2. Attention will be on increasing awareness and membership for the CoP (in particular for youth, family and adult-provider stakeholders).
3. Supporting opportunities for knowledge exchange as it relates to implementation of recommendations through formal and informal channels. The CoP model allows for input of all stakeholders in both knowledge creation and sharing in this domain.
4. Ongoing contribution to knowledge exchange via recurrent updates to the repository of information (programs, tools and resources) in our Transitions Tools and Resources online inventory.
5. Promoting research collaborations across sites and disciplines to better support the transition for Canadian YSHCN through evaluation of outcomes and processes. In particular, the next generation of research needs to address current challenges with small sample sizes, non-generalizability due to diagnosis specific studies, inclusion of youth with medical complexity, and limited number of randomized control trials. Evaluation of implementation must also be a significant focus of newly developing research initiatives.
6. Involve Accreditation Canada in this quality improvement initiative for transition.

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# Links

CAPHC CoP Membership list

Inventory of Transition Tools and Resources/Websites

# Appendices

Appendix 1: Quick Guide to Recommendations and Levels of Evidence

Appendix 2: Evidence Table for Recommendations

Appendix 3: Reference List for Evidence Table and Recommendations

# Appendix 1: Quick Guide to Recommendations and Levels of Evidence

| *Area of Focus* | Level of Evidence |
|---|---|
| **Person Centred** | |
| 1. Transition planning is youth-focused and family-centred, inclusive of personal choice and is adaptable to the abilities and complexities of the youth's needs. | II |
| 2. Transition of youth and their families address the youth's physical, developmental, psychosocial, mental health, educational, lifestyle, cultural and financial needs. | II |
| **Clinical** | |
| 3. Transition for youth is supported by individualized planning in the paediatric and community settings, a coordinated transfer of care and secure attachment to adult services. | II |
| 4. Healthcare providers engage, educate and build capacity of youth and their families regarding transition. | II |
| 5. Collaborative respectful communication between stakeholders (youth, families, their natural networks, community, paediatric, primary and adult care provider(s) supports the flow of information and ensures safe, caring and effective transition. | II, III |
| 6. All youth have a primary care provider to support care coordination. | II |
| 7. A developmentally appropriate individualized transition plan is prepared and documented in collaboration with the youth and family. | II |
| 8. Paediatric and primary providers assess the youth's readiness for adult care, identifying gaps in skills and knowledge requiring intervention. | II |
| 9. Healthcare providers and family members support youth at their appropriate developmental level to understand their chronic condition, treatment plan, level of self-management. | II |
| 10. Care providers educate the youth and family about transfer of care, at least one year prior to transfer, encouraging them to share in the responsibility of accessing community and adult services, and if needed, provide additional navigational support. | II |
| 11. Priority for care coordination is given to youth with complex needs and their families. | II |
| 12. Each transferring program is responsible to provide a comprehensive health summary at the time of referral, to the adult health care provider(s), primary care provider(s), youth and family. | II |
| 13. Transfer of care to adult services includes monitoring of youth's attachment to adult services, attendance at adult appointment in an expected timeframe, ongoing communication between paediatric, primary and adult providers, and shared responsibility for management of youth with lapses in care. | I, II |
| **System** | |
| 14. All services have a written policy for the provision of transition. | II |
| 15. Develop efficient and accredited health information systems to support transfer of information and collaborative communication among sectors. | II |
| 16. Organizations designate transition champions within their paediatric and adult settings to facilitate and evaluate transition. | II |
| 17. Organizations provide ongoing transition education, training, and knowledge translation for all stakeholders | II |
| 18. Researchers and clinicians develop a method for consistent data collection at an individual and systems level, including qualitative narratives of lived experiences and quantitative data, to be used by clinical teams, decision makers and researchers for quality improvement and evidence based practices | II |
| 19. Involve youth, young adults and families, policy and decision makers, administrators, researchers, and government agencies, to jointly identify system barriers, system enablers and future development opportunities for the responsible transitioning of youth. | II |

# Appendix 2: Evidence Table for Recommendations

The following table outlines the development of the key recommendations, as compiled from September 2013 to December 2015. Initial recommendations were compiled as of Spring 2014 and Final Recommendations as of Fall 2015.

| Domain Name | Initial Recommendations | Final Recommendation |
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| **Domain 1: Youth Focused and Family Centred** | | |
| **Person-centered, Holistic Approach**<br>Health care transitions are experienced by youth and young adults as developmental, biological, clinical, living, social and psychological changes – all creating different strengths, concerns and obstacles (Alberta 2007; Gorter 2011; Steinbeck 2007).<br>Best practice for this population requires a combined holistic, medical, psychosocial, developmental, lifespan approach to transition (Canadian Pediatric Society 2014; Kingsworth 2011; Price 2011; Schwartz 2011; Stewart 2009).<br>All transition planning should be **patient-centered** and adaptable to the **youth's developmental level and capacity for learning** (American College of Pediatricians & Physicians 2011; Blum 2002; Kaufman 2006; Racine 2014; van Staa 2015; White 2009).<br>A patient–centered approach for the support and health management of a person with special health care needs is recommended across the lifespan ensuring access to care, health information and care coordination (American College of Physicians 2005; American College of Physicians 2010). | The implementation of best practices for transition of YSHCN and their families requires a holistic approach. This approach should address medical, psychosocial, and developmental and /or mental health issues across their lifespan, in health care and natural environments. | **[1, Person Centred]**<br>**Transition planning is youth-focused and family-centered, inclusive of personal choice and is adaptable to the abilities and complexities of the youth's needs.** |

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| Within the definition of the **developmental transition**, there is an explicit acknowledgment of the importance of the developmental age of the client or patient. Understanding the impact of the developmental needs of youth in transition will better inform coordination of care requirements (McGorry, 2007).<br>Transition can be expected to be more **complex** and generally more difficult for youth with multi-system issues, co-morbidities and physical and or cognitive disabilities. Increasing **complexity** will require **parent/family/ care givers** involvement in all levels of transition planning and identify areas for extended support (Alberta 2007; American Academy of Pediatrics - Committee on Disabilities 2005; Antle 2009; British Columbia Government 2009; Binks 2007; Racine 2014; Sable 2011).<br>**Focus Approach on Adolescent Development**<br>Formation of **personal identity and psychological stability** for youth with chronic health conditions, may be significantly altered by their health condition, family environment, health care providers and the availability of services (Canadian Pediatric Society, 2006). In addition to their health condition, young people are more at risk to experience depression, emotional distress, self-harm, STD's, social disconnectedness, and experimentation with alcohol, drugs and smoking (Greenley, 2010; Sawyer 2007).<br>External factors can impact a youth's acquisition of skills and knowledge and impact health care behaviors such as; social skills, connectedness, educational attainment, self-efficacy, exposure to role models, school attendance, family involvement, and social integration (Kaufman 2006). | All transition planning should be youth-focused, involve personal choice whenever possible and be adaptable to the abilities, capacities and complexities of the person's health care needs. | **[2, Person Centred] Transition of youth and their families addresses the youth's physical, developmental, psychosocial, mental health, educational, lifestyle, cultural and financial needs** |

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| Childhood chronic conditions not only bear physical consequences, but also carry secondary **psychological issues** and an increased risk of developing depression and anxiety-related disorders, having significant impact on individual quality of life (Caplan, 2005; Pinquart 2011; Shaw 2004; Smith 2010). Adolescence demonstrates a higher level of psychological morbidity, and described as a time when more serious disorders such as psychosis emerge. Not only is the transition age a period of heightened risk for the onset of psychological disorders but, for young people with existing mental health concerns, it is also the time when the development of co-occurring disorders, including substance abuse (Davidson 2011; Smith 2010). Coupled with a chronic illness or disability, youth through the transition from adolescent to adulthood are at great risk for mental health issues.<br>A **lack of personal responsibility and self-managed health care behaviours** by youth with chronic conditions may be due to; limited opportunities for the youth to advocate for themselves without parental involvement and the lack of knowledge and opportunities to discuss their health conditions with others (Lugasi 2011; Peters 2011).<br>Establishing **meaningful social and peer relationships** is an important developmental milestone for all individuals. Youth with chronic illnesses often demonstrate social withdrawal and peer conflicts, problems with adaptive behaviours and peer relationships (Shaw 2004).<br>Developmentally-appropriate, youth-focused care should include sexual health guidance for health condition, risk screening, pregnancy planning and genetic counselling (New York 2011; Peters 2011). Lack of access to appropriate, condition-specific sexual health information may lead to misinformation and lack of guidance on | | |

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| fertility (New York 2011).<br>Seeking **vocational training or employment** are important in developing self-worth and self-sufficiency (White 2009). | | |
| <u>**Scope and Timeframe for Transition**</u><br>Studies on '**emerging adulthood'**, biological and neuro-imaging studies (Colver & Longwell, 2013), **extend the attainment of adult-like behaviors to 24 years and beyond** resulting in young adults remaining at home and reliant on their parents for support (Arnett 2000; Arnett 2004; Dovey-Pearce 2005). While young people recognize that certain attributes are necessary to become an adult (such as the ability to accept responsibility for one's self, the ability to make independent decisions, and, the ability to become financially independent) the timing of acquiring these attributes differs (Roisman 2004).<br>Further, emerging adulthood is also a time of considerable living and work instability (Arnett 2004). This erratic lifestyle can be exceptionally taxing on the management a chronic health condition - erratic schedules, limited finances impacting food choices, and absence of family and social support (Weissberg-Benchall 2007) increasing the risk for not receiving care until complications arise (Lotstein 2005).<br>Transition is a **coordinated and collaborative process** between the youth, family and care providers that occurs overtime through adolescence into young adulthood (Miller 2009; Peters, 2011, Amaria, 2011). While most formal programs are aimed at young people of entry to high school age, the health behaviors should be encouraged gradually in childhood, perhaps as early as diagnosis (Leung, 2011; Osteogensis Imperfecta Foundation 2006, Amaria, | A transition timeline for YSHCN (ages 12-25 years) requires a prolonged process that encompasses effort in the paediatric, community and adult settings including individualized planning, coordinated transfer and secure attachment into adult care. | **[3, Clinical] Transition for youth is supported by individualized planning in the paediatric and community settings, a coordinated transfer of care and secure attachment to adult services.** |

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| 2011).<br>The **timeline for transition** suggested by the Canadian Pediatric Society (2014) and supported by many consensus statements follows normal adolescent development categorized into content areas for early, middle and late adolescence with counselling and teaching starting at or around 12-14 years of age (American Academy of Pediatrics & Physicians 2002; American Academy of Pediatrics & Physicians 2011; Sable 2011). Care should be **developmentally appropriate, flexible** and responsive to the cognitive abilities of the youth (Huang 2011; Racine 2014; Royal College of Nursing 2004; Society for Adolescent Medicine 2003; White 2009), and in some cases, may extend later into the patient's second decade of life (American Academy of Pediatrics & Physicians 2011; Arnett 2004; Canadian Pediatric Society 2003; Hait 2006).<br>Some argue transfer to the adult system should not occur during a stressful time; medical instability, graduating high school, or entering college (Hait 2006).<br>A recent international Delphi survey showed consensus to start planning transition at an early age (at least one year before transfer boundary) and if developmentally-appropriate, see adolescent alone at least for part of consultation (Peters 2011; Suris 2015). Studies on readiness to transfer also recommend; relatively stable disease/ conditions; youth has a relationship with a community-based physician; and demonstrates independence in health care visits (Tuchman, 2010).<br>**Youth themselves** recognize the importance to express their feelings and attitudes towards transfer; the need to be involved in making a plan: information about the transition and the transfer event well ahead of time; clear dates for transfer that signal the termination of | | |

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| the pediatric relationship (Chatuverdi, 2009; Hait 2009; Pacaud 2005; Reiss 2005; Rutishauser 2011; Shaw 2006; Van Staa 2011).<br>Algorithms can be produced to delineate points for decisions making and outline specific indicators or questions that work toward desired goals and outcomes for transition (American Academy of Pediatrics & Physicians 2002; Huang 2011).<br>The initiation of transition planning, across all conditions, can take place at the clinic visit offering an opportunity to address the changing needs of the adolescent and promote skills and knowledge necessary for adult care and health planning into the future (Rosen 2003; Weiner 2007).<br>The process is complete once the young adult not only transfers to the adult system but is actively participating (to the level of his/her ability) in activities, appointments, health care surveillance, self-management and decision making (Leung, 2011; Telfair 2004). | | |
| **Domain 2: Youth, Family and Support Networks Engagement** | | |
| **Stakeholder Engagement**<br>Collaboration and engagement of all central stakeholders (youth, families and care providers) is essential for the success of transition strategies, processes and models (AAP 2002; Rosen 2003; Van Staa 2015, Amaria 2011).<br>Engagement of youth and their families is essential to understanding their skill and knowledge requirements, capacity and willingness to participate in the transition process (Fletcher-Johnson 2011).<br>A **strength-based approach** – focusing on the youth's personal | Engagement must include the immediate family of the youth (extended or honorary), all caregivers, personalized support systems, natural networks (e.g. teacher, coach or neighbour), paediatric and adult health care providers, and community-based services.<br>Engagement should extend through all aspects of the youth's | **[4, Clinical] Healthcare providers engage, educate and build capacity of youth and their families regarding transition.** |

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| talents and strengths and how these can be supported by health care providers is a recommended approach for youth by youth and families (Freeman, 2014).<br>Youth should be identified as emerging **young adult health consumers** and supported by parents and health care providers by building their skills and personal capacity (Paone 2006; Stewart 2009; Viner 2008).<br>**Beyond person-centered engagement** is the engagement of community groups, condition-specific organizations and groups where youth with special care needs and their parents look for support and guidance. Bridging to community for this population improves awareness, access to services and opportunities for engagement (Wynn 2006).<br>The ideal situation from the **family's perspective** is that health care providers facilitate continuity of care through communicating with each other and discuss the patient's clinical situation and the information that would be helpful for ongoing care (Miller 2009).<br>When young people are asked about **youth-sensitive services** they want active management of their transition process; involvement in service design and delivery; to have a trusted professional who acts as an advocate for them; and professionals on either end who understand adolescent / young adult issues (Viner 2008).<br>**Parents as partners** is a well-recognized quality improvement approach to engage parents of children and youth with special care needs and include them in care and service planning (Aquino 2010). | life (health, education, living and leisure), and requires understanding and support from administrators, policy makers, researchers, government agencies and leaders.<br>Foster the ability of youth to transition, through focusing on youth-centered and family-focused readiness and by developing a deeper understanding of the youth and family's needs, providing access to learning opportunities and resources.<br>Build on natural and personal support networks and identify whether a key point person for navigation beyond the family is needed.<br>Ensure care coordination through open communication with the youth, family, community, family physician, paediatric and adult care providers before, during and after transfer.<br>Facilitate collaborative, mutually supportive and respectful interactions between all groups, agencies and services to ensure | **[5, Clinical] Collaborative respectful communication between stakeholders (youth, families, their natural networks, community, paediatric, primary and adult care provider(s) supports the flow of information and ensures safe, caring and effective transition.** |

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| | flow of information and best care for the youth, at the centre of the process. | |
| **Domain 3: Documentation and Process Change** | | |
| **<u>Requirements for Transition Plans</u>**<br>The written transition plan is based on a formal assessment to identify individualized goals to gain independence and areas in need of support, including potential barriers, and solutions (New York 2011; Mills 2011). Research about the **young adult** (19-24 years) emerging into adulthood shows an interest in developing guidelines for this population to ensure that they are maintaining health care in the adult setting (Sable 2011; Telfiar 2004).<br>The transition plan spans several years with concrete goals and a timeline. Whenever possible, a written transition plan should be developed at least 3 years before the transfer of care is planned to occur and should be updated at least annually (New York 2011).<br>It is essential for **youth to be actively involved** in creating the transition plan including their needs, views and preferences. The plan needs to be accurate and up to date, as well as serve as a flow of information between the youth and health care providers. (BC Medical Association 2012; Alberta 2007; Leung 2011; Suris 2015; Tuchman 2010).<br>It is imperative that the youth recognize the importance of expressing their feelings and attitudes towards transfer (Van Staa 2011); the need to be involved in making a plan; information about the transition and transfer date well ahead of time (Royal College of Nursing 2004; Pacaud 2005; Shaw 2006) to help provide clarity for the youth about the termination of the pediatric relationship (Hait | | **[7, Clinical] A developmentally appropriate individualized transition plan is prepared and documented in collaboration with the youth and family.** |

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| 2009).<br>**Effective transition plans** should be part of the health care record and include: dates, services, health education goals, identification of adult services and providers; (American Academy of Pediatrics & Physicians 2011; Rosstad 2013) goals for social leisure, education, vocation, finances, living arrangement; (Alberta 2007; BC Government 2009;) sexual health and assessment of risk behaviors; (New York 2011). The plan should be developmentally-appropriate providing a holistic approach to the youth's ongoing health care needs (Alberta 2007; McDonagh 2006; Mills 2011; Paone 2006; Peters 2011; SAM 2003) including short and long term lifestyle choices and goals (Dovey-Pearce 2005).<br>Specifically, for transition, clinical pathways have effectively been used to guide care, measure readiness, identify adult care providers and requirements prior to transfer (Gravelle 2015; Paone 2006; Registered Nurses Association Ontario 2014). It is recommended pediatric health care providers **track progress**/achievement of transition and modify, especially, for those with disabilities (Amaria 2011; Canadian Pediatric Society 2011). Generic transition care plans or pathways bridging specialty and primary care can be modified to include condition specific information (Gravelle 2015; RNAO 2014). | | |
| **<u>Readiness in the Transition Process</u>**<br>The term 'readiness' is used in the acquisition and measurement of **self-management skills,** decision-making and self-care skills expected by the adult system (Brumfeild 2004; Fredericks 2010; McLaughlin 2008;; Tuchman 2010).<br>Assessment of readiness is important as youth who demonstrate skills in **self-reliance, decision making** and **self-care** transfer more | Readiness, defined as the knowledge and self-management skills necessary for functioning in the adult healthcare system, should be assessed at appropriate increments (sometimes even annually) through checklists or assessments, completed by youth, family, and/or healthcare | **[8, Clinical] Paediatric and primary providers assess the youth's readiness for adult care, identifying gaps in skills and knowledge requiring intervention.** |

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| successfully and have better health outcomes (Binks 2007; Holmes-Walker 2007; Fletcher-Johnson 2011; Lugasi 2011; McPherson 2009; Peters 2011; Prestidge 2012; Price 2011; Reid 2004; Wong 2010; Van Staa 2011).<br>**Readiness questionnaires and assessments** compile a list of desirable skills and educational targets which the patient should ideally meet before the transfer to an adult clinic. Readiness indicators may include; ability to describe condition, medications, symptoms, complications; how to make appointments and obtain test results; knowing who to call for symptom management; understanding the expectations of the adult health care system; and their role in providing consent and accessing health information (Dudman 2011; Ferris 2012; Fredericks 2010; Gorter 2011;Klassen 2014; Moynihan 2015; Robertson 2006; Sawicki 2009; Sawyer 2005; Telfair 2004; Tuchman 2010; Williams 2010).<br>A key indicator for readiness, supported by youth and health care providers, has been for youth to be able to express their health care needs which has been linked with the skill set of **meeting with care providers on their own**, greater youth responsibility and less parental involvement (American Academy of Pediatrics & Physicians 2011; Cooley 2011; Court 2009; Gilleland 2010; Gorter 2011; Reiss 2005; Rutishauser 2011; Shaw 2004; Shaw 2006; Suris 2015; Tuchman 2008; Paine 2014). | providers, shared in an accessible repository. | |
| Readiness scales of specific skills and knowledge requirements for health management can provide a sequential framework to assess the youth’s needs and provide **targeted areas for intervention** (Gilleland 2011; Klassen 2014; Lugasi 2011; Moynihan 2015; Sawicki 2009; Schwartz 2011; Stinson 2013; Williams 2010).<br>Youth and their families have shown a keen interest to participate in readiness self-assessment scales (McDonagh 2006; Rutishauser | At the point of transfer, the referring clinician is responsible to provide a health summary including medical, emotional and social content with appropriate assessments and reports. Copies should be sent to the youth, family | |

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| 2011; Williams 2010) and not unexpected, youth report having a higher level of self-management skills than perceived by their parents (Moynihan 2015; Williams 2010).<br>**It is important to identify the starting point by assessing** the client, their family and caregivers for factors known to affect the ability to learn self-care strategies before, during or after a care transition enables the nurse, collaborating with the inter-professional team, to implement interventions that take into consideration the factors affecting their ability to understand and follow through on **self-management strategies** (RNAO 2010; Suris 2015).<br>Parents/ legal guardians should be included in transition discussions, to determine how they can support their youth's readiness behaviors and encourage independence and self-management skills (Baldassano 2002; Suris 2015).<br>It is recommended that the **results of the readiness** assessment be used as part of the **transition plan** and **reviewed annually** to: track progress towards self-management; identify areas for education, intervention, psychological and emotional support; assess other targeted efforts, and have dedicated time to develop and implement written action plans that include timelines for review (Betz 2004; Cincinnati 2008; Flume 2004; McCurdy 2006; McLaughlin 2008; Reiss 2005; Schwartz 2011).<br>Identification and management of factors known to impact learning for self-management enhances client satisfaction before, during and after the care transition. Further research is required to standardize and test the number of self-described measures for readiness available (Schwartz 2014; Swinton 2014; Zhang 2014, Schwartz 2013, Moynihan 2015, Pierce 2015). | members as chosen by the youth, family physician and adult care providers.<br>To ensure attachment, and as a method of closing the loop, accepting adult care providers should send a summary of the youth's first adult visit to the referring paediatric provider and family physician. | |

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| <u>**Health Summary at Transfer to Adult Care**</u><br>**Sharing of health information** and patient history is essential for young adult's ongoing care as they transition from the pediatric health system (Amaria 2011, Kovacs 2012).<br>Primary health care providers and adult specialists receiving youth from the pediatric setting request improvements in transfer of information (Robertson 2006; Hait 2009).<br>Documentation should be portable, accessible, and written in collaboration with youth (American Academy of Pediatrics & Physicians 2011; Society for Adolescent Medicine 2003).<br>Collaboration may result in an increase of the skills and knowledge required for the youth to self-manage and navigate the adult health system. (Stewart 2006; UK Department of Health 2006).<br>Whenever possible, medical summaries should be **available electronically** with access for all the patient and health care providers in case of emergency and when transferring care. (Amaria 2011).<br>Youth should have a **portable, accessible and current copy** of their health care records, transfer summary and transition plan. This provides coverage should the documents not be available electronically or are not transferred to the adult care providers prior to the youth's first visit and encourages patient engagement and management of information. (Canadian Pediatric Society 2014; Dovey-Pearce 2005; Hait 2009; Society for Adolescent Medicine 2003).<br>The American Association of Pediatrics (2011) recommends that the **transfer of information and documentation** be available to primary health care providers, specialists and youth; including, the ***transition plan,*** youth completed ***readiness checklist***, and a ***comprehensive*** | | **[12, Clinical] Each transferring program is responsible to provide a comprehensive health summary at the time of referral, to the adult health care provider(s), primary care provider(s), youth and family.** |

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| ***medical summary***". It is essential for continuity that there is an accurate and up to date flow of information between the youth and health care providers (New York 2011; Suris 2015).<br>Health care providers involved in the care of youth transitioning to an adult healthcare provider/setting should use a **standardized formal discharge/transfer summary.** Transfer of patients is a medical legal requirement of care that requires documentation, the official transfer of care and acceptance of care by the referred to physician (BC Medical Association 2012, CPS 2014, College of Physicians & Surgeons BC 2009, College of Physicians & Surgeons of Ontario, 2008).<br>Documentation on transfer should include: a written summary (Baldassano 2002; Peters 2011; Sable 2011; Sawyer 2007) medical history, allied health/nursing summary (Robertson 2006; Hait 2009) psychological and social history, problem lists, medications, condition-specific information, co-morbidities, laboratory and imaging diagnostic results, sexual and reproductive health issues, immunization history and risk, mental health referrals and future health considerations (Baldassano 2002; Peters 2011; Sanci 2005; Suris 2015).<br>Adult care providers require specific health-related information, areas for screening and surveillance, and 'anticipatory guidance' as part of the transfer information (American Academy of Pediatrics & Physicians 2011; Baldassano 2002; Kovacs 2012; New York 2011; Roberstson 2006). | | |
| **Domain 4: Education: Building Capacity of all Stakeholders** | | |
| **<u>Content Areas for all Stakeholders</u>**<br>Developmentally-appropriate and patient-centered care strategies | Ensure that youth, families/caregivers and all who are involved in the youth's care are (i) | |

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| are identified by youth, families and care providers are essential for transition planning and preparation for adulthood (Betz 2004; Sable 2011; Racine 2014; Tefair 2004).<br>These include teaching on condition-specific information, **health care self –reliance/management skills** (BC Medical Association 2012; New York State 2011; Sebastian 2012; Stinson 2013); life skills, self-advocacy, peer support, psychosocial support, educational and vocational planning (White 2009), sexual health information, drugs and alcohol, fertility, and genetic counseling; (Royal College of Nursing 2004; Rosen 2003); decision-making, informed consent and power of attorney (Suris 2015; Tuchman 2010).<br>Parents and health care professionals involved need **'time' to learn** these new concepts and support each other in the process (Reiss 2005). There needs to be a gradual shift from focusing on the strengths and skills of the family to self-management skills and abilities in the youth/young adult (Sawyer 2005). For youth with neurological, cognitive and developmental disabilities, this information and guidance may have to be provided by another professional, thereby requiring education and support (Alberta 2007; American Academy of Pediatrics - Committee on Disabilities 2005; British Columbia Government 2009; Binks 2007; Racine 2014; Sable 2011).<br>Youth who develop self-reliance and confidence in skills of self-care and navigation are demonstrating better health outcomes. (Van Staa 2015).<br>**Youth-Focused Education**<br>**Youth- focused education** should be initiated at an early age (by the age of 12 for youth with the cognitive capacity) to allow sufficient | educated about the transition process, including organizational or system processes; criteria for accessing adult services; and youth's changing roles and responsibilities, and (ii) engaged in the process through meaningful and respectful interactions.<br>All those involved in the transition process should view emerging adults and/or transitioning youth as a unique population with unique needs, and build capacity to facilitate developmentally appropriate knowledge acquisition and skill development.<br>Initiate transition conversations at an early age (by the age of 12 for | **[9, Clinical] Healthcare providers and family members support youth at their appropriate developmental level to understand their chronic condition, treatment plan, and level of self-management.**<br>**[17, System Level] Organizations provide ongoing transition education, training, and knowledge translation for all stakeholders** |

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| time for youth to gradually acquire new knowledge about their chronic condition and develop self-management skills. Youth need to attain skills in communicating medical information to adult healthcare providers; making and keeping appointments; identifying when they need medical attention and how to get it; seeking and negotiating care in an adult setting; obtaining health care benefits and making life choices adding to, and critically assessing, the quality of their lives (Alberta 2007; New York 2011; Paone 2006; Sawyer 2005).<br>Youth are more likely to follow treatment plans and attach to adult healthcare service when they have understanding of their condition, reasons for treatments (Gurvitz 2013, Heery 2015), and family (social) support (Young 2009).<br>Educational tools and interventions for youth should be engaging, interactive (Rehm 2012) and in if possible, **designed by the youth** themselves (Kingsworth 2011; Kovacs 2012; Murphy 2005; Price 2011; Wolfstadt 2011). **Self-management** skills and **behavioral interventions** delivered by digital technology are more readily used by youth and young adults (Huang 2011).<br>Different **environments for transition preparation** have shown to be effective for youth's learning and outcomes. The integration of transition planning and discussions into **regular clinic visits** and or additional **transition clinics** provide an opportunity for assessment, education and skill building (American Academy of Pediatrics & Physicians 2011; Binks 2007; Canadian Pediatric Society 2014; Dovey-Pearce 2005; Huang 2011; Royal College of Nursing 2004; Wolfatadt 2011).<br>Youth or family-focused **transition workshops** with special content to support youth's knowledge, skills and readiness for adult health | youth with the cognitive capacity) to allow sufficient time for youth to gradually acquire new knowledge about their chronic condition and develop self-management skills (e.g., communicating medical information to adult healthcare providers and negotiating care in an adult setting).<br>To meet the needs of key stakeholder groups (youth, young adults, families and professionals) and to ensure appropriate delivery and uptake of information, a variety of educational media are recommended, such as social media, workshops, mentoring, online presentations or chat forums. It is important that each group be involved in the development and delivery of the resources. | **[10, Clinical] Care providers educate the youth and family** |

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| care have also shown to be effective (Mahood 2011; Moore 2009). Youth and family workshops and camps also offer opportunities to foster positive peer relationships and networking (Alberta 2007; Kovacs 2012).<br>**Adult specialists and family physicians** need the opportunity to acquire the clinical knowledge and skills to treat and care for this 'new' population of youth patients with chronic health conditions entering their system (Binks 2007; Miller 2007; Murphy 2005; Peter 2009; Royal Autralasian College of Physicians 2007).<br>Evidence-based education and training should include: chronic & complex condition-specific management of newly emerging young adult populations; adolescent development; transfer processes and accessing services in the adult system; understanding the differences for eligibility and functioning of adult services; and how to engage youth in change behaviors (Dovey-Pearce 2005; Grant 2011; Shaw 2004; While 2004).<br>A significant barrier is that family physicians and adult care providers may lack the needed expertise in caring for youth and young adults with special care needs. Adult specialists and primary health care providers have identified a lack of knowledge, exposure and training to pediatric onset conditions, long-term complications, and surveillance requirements of specific diseases (Lam 2005; Murphy 2005; Peter 2009; Reiss 2005; Borlot 2014).<br>This can be counteracted by offering specialty education programs on topics of specific disease conditions and treatments and developmentally-appropriate care (Sanci 2005). Developmentally-appropriate education and planning is essential for effective transition planning and should be a certified component of resident, physician, nursing and social work training (American | Build capacity across all disciplines by providing evidence-based education and training including: chronic & complex condition-specific management of newly emerging young adult populations; adolescent development; transition and system processes; accessing services into adulthood; and interdisciplinary, youth and family roles and responsibilities. | **about transfer of care, at least one year prior to transfer, encouraging them to share in the responsibility of accessing community and adult services, and if needed, provide additional navigational support.** |

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| Academy of Pediatrics & Physicians 2011; Canadian Pediatric Society 2014; Royal College of Nursing 2004; UK Department of Health 2006). | | |
| **Domain 5: Attachment to Adult Services** | | |
| **<u>Continuity of Care</u>**<br>Early referral, engagement and attachment to adult services is important for relationship building and to the establishment effective adult management (New York 2011).<br>Regular continuous medical care with ongoing monitoring and adjustments that extend beyond pediatric care and into adult care are major factors in improving health and quality of life (Robertson 2006) and maximizing life-long functioning (Stewart 2007; Stewart 2009).<br>Continuity of care requires an uninterrupted flow of clinical care, consultation, information, and services across pediatric, adult and community jurisdictions (Baldassano 2002; Sable 2011; Suris 2009; Van Walleghem 2008).<br>Youth with greater complexity - such as persons with complex physical needs, mental health difficulties or substance abuse issues – may require more time for development of the relationship with the primary health care provider (West 2011).<br>Best practice for this population requires inter-agency collaboration (Alberta 2007).<br>Assuring a good transfer includes identification of an adult point person before transfer and remaining available as a consultant between pediatric and adult professionals (New York 2011; Suris | Early referral, engagement and attachment to adult services are crucial to relationship building and to the establishment of safe, caring, effective, uninterrupted health management from paediatric to adult services.<br>There are youth whose developmental age requires a unique communication and care style such that caregivers may require special training and consideration.<br>Paediatric care providers should instil confidence in their youth with regards to their adult counterparts - understanding that attachment to adult care providers builds overtime – reflective of the paediatric relationship they are leaving.<br>Special consideration may be required to link YSHCN and their families with appropriate services and contact persons in | **[13, Clinical] Transfer of care to adult services includes monitoring of youth's attachment to adult services, attendance at adult appointment in an expected timeframe, ongoing communication between paediatric, primary and adult providers, and shared responsibility for management of youth with lapses in care.** |

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| 2015).<br>**Family Physician as Medical Home**<br>The family physician (FP) has a unique opportunity to address a youth's primary health care needs and act as a referral agent and 'gate keeper' to secondary and tertiary care providers – a coordinator of care into and through adulthood (American Academy of Pediatrics & Physicians 2011; Canadian Pediatric Society 2014; College of Family Physicians of Canada, 2011, Sable 2011).<br>Attachment to a community-based, primary care provider who will provide access to and coordination of care for youth with chronic illnesses is an important component of coordinated adult care (Dovey-Pearce 2005).<br>It is recommended that young people with chronic conditions have a '**Medical Home'** - a community-based family physician who will ideally have an interest in young adults and is able to provide centralized medical surveillance, and ongoing management in collaboration with specialist clinicians (American Academy of Pediatricians & Physicians 2011; American College of Physicians 2010; College of Family Physicians of Canada 2011; Cooley 2011).<br>**Accessing Adult Specialists Care and Services**<br>A joint visit or access to the adult specialist/office prior to transfer has been recognized as a beneficial intervention and may facilitate attachment to the new care providers (Anthony 2009; Brumfeild 2004; Dabadie 2008; Malbrunot-Wagner 2009; McCurdy 2006; McPherson 2009; Peter 2011; Stabile 2005; Tuchman 2008). | communities that are not within easy physical access to a health-care centre.<br>The identification of and annual visits with a community–based family physician are essential for ongoing care and referral access to specialized services.<br>A mechanism (referrals and documentation) should be in place to ensure ongoing access to community clinicians/therapists & services (including OT, PT, SLP, school, behavioral, nurse and social workers) with experience in addressing the unique needs of | **[6, Clinical] All youth have a primary care provider to support care coordination.** |

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| Youth have voiced an interest and are shown to have reduced concerns and fears when able to meet adult practitioners prior to leaving pediatric services such as in a joint transition clinic or cross-over visit (Annunziato 2007; Busse 2007; Dabadie 2008; Fair 2010; Kovacs 2012; Shaw 2004; Steinbeck 2007).<br>**Adult services** for youth and young adults requires health care provider skills within an environment that is developmentally-appropriate; fosters openness, advocacy and support; maintains trust and confidentiality; and demonstrates an interest in the youth as a whole – beyond the medical condition (Dovey-Pearce 2005; Miles 2004; Moons 2009; Reiss 2005; Steinbeck 2007; Colver 2013).<br>**Identification of adult specialty** professionals/services should occur prior to transfer of care with written information and orientation about the new providers, location, medical care and expectations of the patient's role (Huang 2011; Moons 2009; New York 2011; Stabile 2005; Suris 2009; Wray 2008).<br>The ideal situation from the **family's perspective** is that health care providers facilitate continuity of care through communicating with each other and discuss the patient's clinical situation and the information that would be helpful for ongoing care (Chatuverdi 2009; DiFazio 2014).<br>**<u>Attachment</u>**<br>Youth may not be actively attending appointments in the adult setting because youth attending physician's appointments depended on the urgency/ stability of their health care needs and physician effectiveness. (Mitchell 2015).<br>Successful transfer of care will involve assuring a good coordination | these clients, without a gap in service.<br>Identify and inform the youth and family of whom the adult specialty care team will be and what services will be available at least one year prior to transfer. Facilitate measures to allow the youth and family time to become familiar with their future adult health care providers | |

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| (such as timing of transfer, communication, follow-up, remaining available as a consultant) between pediatric and adult professionals; identifying an adult provider willing to take on the young adult patient before transfer; making sure that at least one appointment with adult provider after transfer is scheduled; and putting in place mechanisms/ resources to ensure patient attended the first adult visit and how to contact patients lost to follow-up (Suris 2015). Youth with fragile or changing care needs should be seen within 6 months of transfer to adult care (Peters 2011). | | |
| **Domain 6: Roles and Care Coordination** | | |
| **Stakeholder Roles**<br>**Key stakeholders i**n the transition to adult care are the youth, family/legal guardian for the youth and health care providers (Canadian Pediatric Society 2014).<br>***Role of Youth***<br>Adolescents who have been 'cared for' since the time of their birth may have false assumptions that their condition is the responsibility of others (Blum 2002). Youth need to develop the knowledge and skills to interact with adult health care providers effectively- ask questions about their condition, medications, side effects, complications from use of other substance, and how to access additional services (Robertson 2006).<br>***Role of the Family***<br>Care of the adolescent occurs within the context of the family or social group influencing health behaviors, future goals, compliance and outcome (Reiss 2005).<br>Families have acknowledged their need to develop skills that encourage their youth's autonomy, independent ownership of their | Priority should be given to YSHCN and their families who require multiple services and appointments. Flexibility in complex cases needs to be built into the system where, if necessary, a clinical case review may be required to identify the services that best address the complexity of the presenting issues.<br>Transition planning (care coordination) should be integrated into all levels of service and between sectors/ teams to clearly establish responsibilities in the handing over of the youth. Information protocol should be met for planning across systems (i.e. consent to exchange of client information). | **[11, Clinical] Priority for care coordination is to be given to youth with complex needs, and their families.** |

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| condition, skill building and knowledge in and trust in the adult system (Huang 2011; Malbrunot-Wagner 2009; Reiss 2005; van Staa 2011). Families also request time and support in 'letting go' and encouraging independence in their youth (Gray 2015, van Staa 2011).<br>Parents have requested transitional networking resources for physical and emotional support including peer groups, web sites, workshops, public health nurses, lay groups, social services, and home health providers (Kingsworth 2011; Moore 2009; Murphy 2005; Towns 2011).<br>***Role of Primary Care Physicians***<br>The Family Physician provides **entry into the health care system**, first medical contact and forms the initial bond with the patient requiring ongoing care. When referral is indicated, the family physician **refers** the patient to other specialists or caregivers but should remain the **coordinator** of the patient's health care, preventing fragmentation (American Academy of Family Physicians 2011).<br>The Family Physician addresses primary care needs and can facilitate the transition process by providing continuity and access to adult care – the FP role in transition needs to be encouraged and supported (Dovey-Pearce 2005; Miles 2004;<br>Role of physicians at each end of the continuum need to have practice skills to enhance self-management skills and behaviors in the youth; meet alone with adolescent patient, communication, and sharing documented information (Suris 2009).<br>***Role of Pediatric Health Care Providers (Sub-Specialty Team Members)*** | Implementation of a central individual (navigator) who is familiar with services is important for access to: referrals, medical and community resources, and explanation of services in a non-medical easy to understand language.<br>Involve the youth/family in transition by increasing transparencies in process and services, empowering them to share in the responsibility of accessing services to meet their needs.<br>Both paediatric and adult programs and services should designate key contact people (transition champions) who will be responsible for liaising within their organization to facilitate transition. When possible, multi-disciplinary care should occur in one location.<br>All persons involved in health services (clerical, allied health, medical, educators and administrators), have the opportunity and responsibility to be involved in the transition of | |

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| The integration of transition planning into the pediatric clinic visit offers an opportunity for the pediatric team to address the changing needs of the adolescent and promote skills and knowledge necessary for adult care and health planning into the future (New York 2011; Paone 2006; Reid 2004; Reiss 2005; Rosen 2003; Viner 2008).<br>Depression, anger, risk taking behaviours, and non-adherence to treatment are all important issues. It is important for professionals either to address these or to have access to colleagues with the necessary expertise (Busse 2007; Caplan 2005; Greenley 2010; Pinquart 2011; UK Department of Health 2006).<br>***Role of Adult Health Care Providers***<br>Adult health care providers' openness to understand the concept of adolescent development, engaging youth in discussions, and willingness to promote a collaborative approach to the patient's care and helping them build confidence in their new setting (McDonagh 2007; McLaughlin 2008; Reiss 2005; Shaw 2004; Tuchman 2008).<br>There is a need to acknowledge the youth and **family's perceptions and real differences** between the pediatric and current adult system such as experiences that may have offered a reduced time for the patient visit, seeing different physicians at each visit and extended wait times (Busse 2007; Dovey-Pearce 2005).<br>Skills in caring for youth include being sensitive, non-intrusive, non-judgmental, flexible, supportive and interested in all aspects of the youth's life outside his/her condition (Miles 2004; Shaw 2004).<br>Adult care providers should develop methods to assess young adult's skills and knowledge in self-management and any barriers to care or keeping appointments (Stabile 2005; New York 2011). | youth by supporting youth voice, decision-making, consent, education and funding of clinical programs and youth-oriented policies. | |

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| ***Role of Care Coordinator/ Navigator***<br>Studies have indicated improved efficacy and success when there is a **designated care navigator or program coordinator** to oversee the transfer process (Anthony 2009; Betz 2005; Brumfeild 2004; Dabadie 2008; McCurdy 2006; McDonagh 2005; McDonagh 2007; Reiss 2005; Rosen 2003; Shaw 2004; Van Walleghem 2008; Holmes-Walker 2007). This is a specialized role that requires dedicated time (UK Department of Health 2006).<br>Care coordination and case management, assigned to a nurse, social worker, hospital, or community-based health care professional, is required for complex and unattached patients in order to ensure access to adult care and coordination of services (New York 2011; Van Walleghem 2008). The role of this professional can be diverse and may include required skills of a clinical expert, consultant, educator, researcher and/or change agent as well as providing youth and families with information and access to resources to support the process through writing the action plan as well as monitoring and evaluating the progress (BC Government 2009; Gorter 2014; Royal College of Nursing 2004; Steinbeck 2008; Stewart 2009).<br>Youth that are **medically fragile** may also require transitional support for ongoing care and end of life issues (Binks 2007; Peter 2009).<br>***Role of Transition Coordinator (Organizational)***<br>Transition coordinators are recognized as valuable to organizations in developing transition programming, to organize and ensure collaboration advocates for necessary resources and promote change (West 2011). Transition coordinators have been shown to contribute to physical wellbeing as measured by biomarkers and to quality of life as measured by QOL questionnaires (Annunziato | | **[16, System Level] Organizations designate transition champions within their paediatric and adult settings to facilitate and evaluate transition.** |

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| 2013). | | |
| **Domain 7: Service Planning & System Change** | | |
| **Models and Transition Programming**<br>Transition models and interventions have been studies amongst different patient groups demonstrating some success in achieving better outcomes for their population (Crowley 2011; Koshy 2009; Prestidge 2012; Nieboer 2014; Tuchman 2010).<br>Through development and research over the past 20 years, standard components of transition models have been suggested to include;<br>• An organizational timeline, policy or guideline for transition;<br>• Coordinated tools and interventions (readiness preparation) for all stakeholders (youth/ families and care providers);<br>• Standardized care processes and transfer documentation;<br>• Tracking patients requiring, utilizing, and lost to follow-up;<br>• Monitoring impact and evaluation (patient health outcome, patient experience and cost savings); and<br>• Experience of youth and families for further improvements (Canadian Pediatric Society 2014; Brodie 2010; Grant 2011; Nieboer 2014; Mcmanus 2015; Joly 2015; Suris 2015; Tuchman 2010; Van Staa 2015).<br>**A Shared Management Approach**<br>These components can only be operationalized through a shared management approach between the youth themselves, families and care providers (Amari 2011; Gall 2006).<br>The transition process (preparation, transfer and successful attachment) across health care systems, clinical requirements and meeting the need of all stakeholders, is complex and has not been | Involve policy and decision makers in order to jointly identify system barriers, system enablers and future development opportunities for transitioning youth responsibly. Consideration of these guidelines should be taken in relation to the social cost of investment as well as healthcare economics.<br>Where adult services do not exist, the development of a provincial strategy is required to create medical and allied health services for newly emerging paediatric populations<br>Required Organizational Practices (RoP) and accreditation standards should be modified to address the transitional needs of YSHCN and their families based on evidence-informed recommendations. | **[19, System Level] Involve previously transitioned young adults and families, policy and decision makers, administrators, researchers, and government agencies, to jointly identify system barriers, system enablers and future development opportunities for the responsible transitioning of youth.**<br>**[14, System Level] All services have a written policy for the provision of transition.**<br>**[15, System Level] Develop efficient and accredited health information systems to support transfer of information and collaborative communication among sectors.** |

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| adequately evaluated to ascertain ‘best practice’ for the transition to adult care (Fair 2010; Fletcher-Johnson 2011; Prior 2014; Watson 2011, Betz 2014, Joly 2015).<br>**System Change**<br>At the systems level, the transfer of youth with special health care needs from pediatric to adult care is often based on a policy and age limitations for services- an administrative event. Aging out is an example of the institutional transition process, whereby an event results in a change in status that renders the individual ineligible for the previous service and displacement from that service environment follows (Brown 2011).<br>**Transition is a complex and dynamic system** addressing interconnected, overlapping and contextually sensitive components. When viewed as a system, transition includes interacting stakeholders (youth and family members, healthcare providers, administrators and policy makers), services (pediatric and adult health organizations, community/ natural system supports), and actions (transition related interventions (Hamdani 2011).<br>A systems approach to transition can be used to understand the complexities of transition of youth using the International Classification of Functioning (ICF) framework;<br>1) Personal factors: developmental readiness, self-determination skills, self-management skills, autonomy<br>2) Health factors: condition severity and stability, activity limitations, and<br>3) Environmental factors: family and peer support, coordinated transfer process, training of service providers, health policy, organizational policy, inter-organizational communication, resources for services and programs to support transition | | |

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| and the adult system, supportive physical environment (Mitchell 2015).<br>Two areas identified to enhance system change include public policy (health, social and economic) resource allocation and service approaches at an inter-organizational level and training of health care providers at all levels (Hamdani 2011; Nguyen 2013).<br>There is general agreement that in order to improve health care transitions for youth, further requirements should be met including consistency and collaboration across different systems, the need to move current evidence into practices, and the need to develop policy and models of funding that are sustainable and supported by evaluation of long term outcomes (Gorter 2011; McLaughlin 2008; Nieboer 2014; Tuchman 2010; Van Staa 2015 ). Not engaging policy makers was identified to be a barrier to sustained funding for transition systems following positively evaluated pilots (Hepburn 2015).<br>At an organizational level, it is key that the resources and efforts put in to developing a transition program are accepted by staff to integrate changes in their practice (McManus 2015). | | |
| **Domain 8: Evaluation Strategies** | | |
| **Lack of Evidence for Transition Models and Programs**<br>There is consensus on the definition, purpose and principles of transition as outlined by a number of professional organizations and condition-specific associations (American Academy of Pediatrics 2011; Canadian Pediatric Society 2014). Also, the concept and responsibilities of 'transfer of care' is well documented and can be effectively measured – thus being able to report the numbers and percentage of youth who do not effectively transfer to adult care | Identify and clearly define key measures of transition such as; transition readiness, tools for transition, training provision across disciplines, and goal setting for successful transition. This should ultimately lead to outcome measures for transition not just for health but for quality of life | **[18, System Level] Researchers and clinicians develop a method for consistent data collection at an individual and systems level, including qualitative narratives of lived experiences and quantitative data, to be used by clinical teams, decision makers and researchers for quality** |

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| (Reid 2004). Currently the lack of outcome data prevents the development and implementation of evidence-based transition programs, however there is data to support a comprehensive approach to transition care (American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians 2011; Canadian Pediatric Society 2014; Lugasi 2011; McLaughlin 2008; Prior 2014; Sable 2011; Tuchman 2010; West 2011).<br>**Clinical-system levels for evaluation** include developing frameworks, indicators or benchmarks to determine changes in practice, process adoption, skills and behaviors.<br>Benchmarks have been identified to improve the transition experience for stakeholders. The authors recommend that clinical teams use the indicators to inform system level strategies as well as program evaluation (Aldiss 2015).<br>The study identified 8 factors needed for successful transitions;<br>1. youth moving to manage health condition as an adult<br>2. support for gradual transition<br>3. coordinated child and adult teams<br>4. services are young people friendly<br>5. written documentation<br>6. parents gradually transferring responsibility to the youth<br>7. assessment of readiness<br>8. involve the primary health care provider<br>Outcomes of health care transitions (HCT) need to be clearly defined, measurable, validated and used as a standard index of HCT. However, there needs to be longitudinal studies to determine the predictive validity of currently used HCT measures such as readiness and of specific HCT interventions on short and long term outcomes (Mitchell 2015). | participation (International Classification of Functioning). Create a list of transition outcome measures at all levels: youth and family, clinical, organizational and provincial.<br>Health authorities should develop a method for the identification and ongoing tracking of YSHCN (numbers & ages of youth accessing care and where), to evaluate successful transitions and long-term health outcomes; making the data and analysis accessible to both decision makers and researchers in order that they may contribute to quality improvement and evidence based practices.<br>Establish a process of development, implementation and evaluation using process change methodology and qualitative input, including stories, from all stakeholders throughout the process of transition. | **improvement and evidence based practices.** |

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| **Personal- level forms of evaluation** include readiness, skills/ knowledge assessments, and health outcomes measures. Readiness assessment tools provide information on the youth's reported skills to be ready for transition but do not reflect the outcome of transition (Pierce 2015, Schwartz 2013, Paul 2015, Annuziato 2013). Health outcomes are multidimensional and can be influenced by subjective factors such as knowledge, beliefs, motivations, social supports and relationships, self-efficacy and other person advocacy, psychosocial functioning. These subjective factors can be potentially modified through interventions (Pierce 2015).<br>A recent scoping literature review and realistic evaluation qualitative study of longitudinal data provided further evidence (Mitchell 2015). Facilitators to informed choice for youth with disability in transition were identified to be: supportive family, peer network, professional network that was collaborative, advocacy, accessible and accurate information, experiential knowledge, positive expectations. Barriers were: low expectations, negative attitudes, poor collaboration between child and adult services, bureaucratic organizational and cultural differences, lack of accessible information and services, individual's capacity and respect by others.<br>There are numerous transition programs and interventions reported in the literature, yet few comprehensively evaluate efficacy (Prior 2014;, McManus 2015; Davis 2014, Gorter 2011;Sheehan, 2015; Canadian Pediatric Society 2014). The models have common transition components developed through consensus processes but outcome data is not consistently reported or even agreed upon (Fletcher-Johnston 2011).<br>**Evaluation Frameworks**<br>**Triple Aim** focuses on three goals which are to improve the health of | | |

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| a population, the providers and patients' experience of care (including quality, access, reliability) while lowering the cost of care (Berwick 2008). These results can be achieved through health system integration and redesign. By redesigning transition health care processes, such as implementing standardized components for transition (Tuchman 2010), the goal would be to improve youth and family preparation and engagement, streamline transfer processes and encourage a completed transfer, safely into the adult system – improving patient experience and reducing costs to the health care system. The Triple Aim framework has been applied to the transition of youth to adult services yet effectiveness of transition interventions has not been well validated (Prior 2014).<br>Testing transition clinical guidelines, tools and interventions can be evaluated for efficacy and usefulness by **Plan, Do, Study, Act (PDSA)** cycles to achieve spread, uptake, and sustainability of strategies and interventions (Brown 2011, Varkey 2007). The Center for Health Care Transition Improvement suggests PDSA cycles as a method for continuous quality improvement of care processes (IHI 2009).<br>**Components for Evaluation**<br>**Got Transition** is a national leader (US) in identifying core transition components and uses the Triple Aim Framework for measuring transition impact and efficacy using a quality improvement process and are validating a measurement tool for auditing the integration of transition components into practice (Prior 2014). The Got Transition framework includes six core element: 1) transition policy; 2) method for tracking and monitoring patients; transition preparation/ readiness self-care assessment tool; 4) written transition plan; 5) transfer processes and documentation to adult care; and confirmed transfer completion /attachment to adult services with stakeholder feedback. Health care providers and organizations following these | | |

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| steps showed improved transition processes (McManus 2015).<br>**Key areas of evaluation** should include 1) improvement in documentation of the transfer process; transition plan as part of health care record, transfer medical letter, 2) developmentally-appropriate counselling and guidance, and 3) confirming attachment to adult care provider(s), and long-term health outcomes (Robertson 2006; VanWalleghem 2008).<br>**Data collection systems** must be developed that address these needs to measure processes (interventions) structures and outcomes and these data collection systems must be functional, inter-connected, capable and flexible to generate reports in a timely and "as need" manner at policy, program and patient/provider level (McDonagh 2007).<br>Qualitative evaluation should include **stakeholder's perceptions** including youth and family experiences, **satisfaction** and **perceptions** (Fletcher-Johnston 2011; Lugasi 2011). | | |

# Appendix 3: Reference List for Evidence Table and Recommendations

All of the sources identified in the Evidence Table are outlined below. The following scale was used to rate the quality of the evidence.

| **Scale** | **Quality of Evidence** |
|---|---|
| I | Evidence obtained from one or more randomized trials with clinical outcomes |
| II | Evidence obtained from research, meta-analysis, systematic review, policy statement |
| III | Expert opinion |

The degree of influence on the recommendation development is outlined by a letter grade, as indicated below:

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| A | Strong influence on recommendations |
| B | Moderate influence on recommendations |

| Author/ Year | Reference | Grade | Scale |
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| Alberta Children & Youth Initiative (2007) | Transition planning protocol for youth with disabilities: your guide to reaching new heights. Accessed at: http://www.adhdfamilies.ca/sites/default/files/resources/pdf/transitionplanningprotocol1_3.pdf | A | II |
| Aldiss, S., Ellis, J., Cass, H., Pettigrew, T., Rose, L. & Gibson, F. (2015) | Transition from child to adult care- "It's not a one-off event": Development of benchmarks to improve the experience. *Journal of Pediatric Nursing,* 30, 638-647. | A | II |
| Amaria, K., Stinson, J., Cullen-Dean, G., Sappleton & K., Kaufmann M (2011) | Tools for addressing systems issues in transition. *Healthcare Quarterly*, 14: 72-76. | A | III |
| American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, American Society of Internal Medicine (2002) | A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110(6), 1304-06. | A | II |
| American Academy of Pediatrics, Committee on Children with Disabilities (2005) | Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics*, 116, 1238-44. | A | II |
| American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians (2011) | Supporting the health care transition from adolescence to adulthood in the medical home. *Journal of the American Academy of Pediatrics*, 128, 182-202. | A | II |
| American College of Physicians (2005) | The advanced medical home: a patient-centered, physician-guided model of health care. Position Paper. Philadelphia, PA. Accessed at: www.acpoline.org/hpp/adv_med.pdf | A | II |
| American College of Physicians (2010) | The patient-centered medical home neighbor: the interface of the patient-centered medical home with specialty/ subspecialty practices. Philadelphia, PA. | A | II |
| Annunziato, R., Emre, S., Shneider, B., Barton, C., Dugan, C. & Shemesh, E. (2007) | Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatric Transplantation*, 11(6), 608-614. | A | II |
| Annunziato, R., Baisley, M., Arrato, N., Barton, C., Henderling, F., Arnon, R. & Kerkar, N. (2013) | Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. *Journal of Pediatrics*, 163, 1628-1633. | A | I |

| Author/ Year | Reference | Grade | Scale |
|---|---|---|---|
| Anthony, S., Kaufman, M., Drabble, A., et al. (2009) | Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation*, 9, 614-9. | A | II |
| Antle, B., Montgomery, G. & Stapleford, C. (2009). | The many layers of social support: capturing the voices of young people with spina bifida and their parents. *Journal of Health & Social Work*, 34, 97-106. | A | II |
| Aquino, E., Bristol, T., Virginia Crowe, V., DesGeorges, J. & Heinrich, P. (2010) | Powerful partnerships: a handbook for families and providers working together to improve care. National Initiative for Children's Healthcare Quality. Boston, MA. www.nichq.org | A | III |
| Arnett, J. (2000) | Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychology*, 55, 469–80. | A | III |
| Arnett, J. (2004) | Emerging adulthood: the winding road from the late teens though the twenties. New York: Oxford University Press. | A | III |
| Baldassano, R., Ferry, G., Griffiths, A., Mack, D., Markowitz, J. & Winter, H. (2002) | Medical position statement: transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the north American society for pediatric gastroenterology, hepatology and nutrition. *Journal of Pediatric Gastroenterology and Nutrition*, 34, 245-248. | A | II |
| Berwick, D., Nolan T. & Whittington J. (2008) | The triple aim: care, health, and cost. *Health Affairs,* 27, 759–69. | A | III |
| Betz, C.L. (2004) | Adolescents in transition to adult care: why the concern. *Nursing Clinics of North America*, 39, 681-713. | A | III |
| Betz, C.L. & Redcay, G. (2005) | Dimensions of the transition service coordinator role. *Journal of Special Pediatric Nursing,* 10(2), 49-59. | A | III |
| Betz, C., Ferris, M., Woodward, J., Okumara J., Jan, S. & Wood, D. (2014) | The health care transition research consortium health care transition model: a framework for research and practice. *Journal of Pediatric Rehabilitation Medicine* 7, 3-15. | A | II |
| Binks , J., Barden, W., Burke, T. & Young, N. (2007) | What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medical Rehabilitation*, 88, 1064-1073. | A | II |
| Blum, R. W., Hirsch, D., Kastner, T.A., Quint, R.D. & Sandler, A.D. (2002) | A consensus statement on health care transitions for young people with special care needs. *Pediatrics*, 110(6), 1304-1306. | A | II |
| Borlot, F., Tellez-Zenteno, J., Allen, A., Ali, A., Snead, O. & Andrade, D. (2014) | Epilepsy transition: challenges of caring for adults with childhood-onset seizures. *Epilepsia*. 55(10), 1659-1666. | A | II |

| Author/ Year | Reference | Grade | Scale |
|---|---|---|---|
| Brink, S.J., Miller, M., & Moltz, K.C. (2002) | Education and multidisciplinary team care concepts for pediatric and adolescent diabetes mellitus. *Journal of Pediatric Endocrinology*, 15, 1113-1130. | A | II |
| British Columbia Government (2009) | Cross ministry transitional planning protocol for youth with special needs. Accessed at: http://www.mcf.gov.bc.ca/spec_needs/pdf/transition_planning_protocol.pdf | A | II |
| British Columbia Medical Association (2012) | British Columbia Medical Association (2012). Closing the Gap: Youth Transitioning to Adult Care in BC. Accessed at: https://www.bcma.org/files/1984-BCMA%20Youth%20Transitions.web_.pdf | A | III |
| Brodie, L., Crisp, J., McCormack, B., Wilson, V., Bergin, P. & Fulham, C. (2010) | Journeying from nirvana with mega-mums and broken hearts: the complex dynamics of transition from paediatric to adult settings. *International Journal of Child & Adolescent Health*, 3(4):517-526. | A | II |
| Brown, J., Rounthwaite, J. & Barwick, M. (2011) | Implementing evidence based practices: a transformational organizational change process. *International Journal of Knowledge, Culture and Change Management,* 10(7), 33-53. | A | II |
| Brumfeild, K. & Lansbury, G. (2004) | Experiences of adolescents with cystic fibrosis during their transition from pediatric to adult health care: a qualitative study of young Australian adults. *Disability & Rehabilitation*, 26(4), 223-34. | A | II |
| Busse, F. Heirmann, P. Galler, A., et al (2007) | Evaluation of patients' opinion and metabolic control after transfer of young adults with Type 1 diabetes from a pediatric diabetes clinic to adult care. *Hormone Research,* 67, 132-8. | A | II |
| Canadian Pediatric Society (2003) | Age limits and adolescents. *Pediatric Child Health,* 8, 557. | A | II |
| Canadian Pediatric Society (2006) | Care of adolescents with chronic illness: position statement*. Pediatric Child Health,* 11(1), 43-38. | A | II |
| Canadian Pediatric Society; Adolescent Health Committee (2007/2014) | Transition to adult care for youth with special health care needs: position statement. *Pediatric Child Health,* 12(9), 785-788. | A | II |
| Caplan, R.S. (2005) | Depression and anxiety disorders in pediatric epilepsy. *Epilepsia*, 46(5), 720-730. | A | II |
| Chaturvedi, S., Jones, C. Walker, R. et al. (2009) | The transition of kidney transplant recipients; a work in progress. *Pediatric Nephrology*, 23, 1055-1060. | A | II |
| Cincinnati Children's Hospital Medical Centre (2008) | Best evidence statement: readiness for transition to adult care. Pediatric Kidney Transplant Patients. Cincinnati Children's Hospital Medical Centre. | A | II |

| **Author/ Year** | **Reference** | **Grade** | **Scale** |
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| College of Family Physicians of Canada. (2011) | A vision for Canada: family practice. The Patient's Medical Home. Accessed at: http://www.cfpc.ca/uploadedFiles/Resources/Resource_Items/PMH_A_Vision_for_Canada_abridged.pdf | A | II |
| College of Physicians & Surgeons of BC (2009/2015) | Expectations of the Relationship between Primary Care / Consulting Physician and Consultant Physician. College of Physician and Surgeons of British Columbia. Accessed at: https://www.cpsbc.ca/files/pdf/PSG-Expectations-of-the-Relationship-Between-Physicians.pdf | A | II |
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