Care in the Long Term for Youth and Young Adults with Complex Care Needs

Jennifer Major (Canadian Foundation for Healthcare Improvement)
Deb Stewart (McMaster University)
Khush Amaria (The Hospital for Sick Children)
Tram Nguyen (McMaster University)
Jenna Doig (The Hospital for Sick Children)
Sherri Adams (The Hospital for Sick Children)
Catherine Giroux (Canadian Foundation for Healthcare Improvement)
Matt Freeman (McMaster University)
Stephen Samis (Canadian Foundation for Healthcare Improvement)
Miriam Kaufman (The Hospital for Sick Children)
Jan Willem Gorter (McMaster University)
Jan Burke Gaffney (Family Alliance Ontario)
Lindsay Wilson (Canadian Foundation for Healthcare Improvement)

This work was produced with funding from the Ontario ministries of Education, Health and Long-Term Care, Children and Youth Services, and Community and Social Services. The views expressed are those of the authors. No inferences should be drawn with respect to the views or endorsement of content by the funders.
# Table of Contents

EXECUTIVE SUMMARY ................................................................................................................................. 5

BACKGROUND ..................................................................................................................................................... 10

PHASE I: ............................................................................................................................................................. 10

Definition of complex care needs ..................................................................................................................... 10

PHASE II: ............................................................................................................................................................. 12

Information about youth with complex care needs to facilitate transition to adult services ...................... 12

Profile Characteristics and Service Needs of Youth and Young Adults with Complex Care Needs ............... 13

Interventions that promote successful transition to the adult service system ................................................. 16

Client-centred decision-making frameworks (legal or other) designed to include clients and/or their family/caregiver in the decision-making process ................................................................. 18

PHASE III: .......................................................................................................................................................... 22

Ensure continuity and portability of funding so that it stays with the person as they move from pediatric to adult services (so funding never abruptly stops) and allows clients and families greater control and choice over the services they obtain ................................................................. 23

Enact processes to facilitate active collaboration among the main “sectors” of services, community, families and youth to improve preparedness and efficiency of transition planning for all stakeholders. ......................................................................................................................................................................................... 26

Increase availability and accessibility of medical, social, and community-based care and support services ........................................................................................................................................................................... 30

Improve information sharing during the transition from pediatric to adult services ....................................... 34

Enhance education and training of all service providers about transition issues (in both adult and child/youth systems) .............................................................................................................................. 36

EDUCATION AND TRAINING OPTIONS ........................................................................................................... 37

LIMITATIONS OF THE PROJECT ....................................................................................................................... 38

CONCLUSIONS AND FUTURE WORK ............................................................................................................. 39

REFERENCES ....................................................................................................................................................... 41
APPENDICES........................................................................................................................................46

Appendix 1: Summary of phase I: Comprehensive scoping review to inform development of a
definition of complex care needs..............................................................................................................46

Appendix 2: Report on one-on-one interviews........................................................................................54

Appendix 3: Pre- and post-roundtable surveys.........................................................................................60
Executive Summary

The Canadian Foundation for Healthcare Improvement (CFHI) was commissioned by the Ontario ministries of Health and Long-Term Care, Children and Youth Services, Community and Social Services, and Education to conduct work to:

- develop a better understanding of the profile of youth and young adults with complex care needs
- better understand the required interventions for youth and young adults with complex care needs to successfully transition to adult services that will continue to meet their needs

Methodologies and associated results of each of the three phases of the work

Phase I:

A comprehensive scoping review and consensus meeting with health and community-based care professionals, researchers, patients and families, and policy experts was conducted to develop a definition of complex care needs. The draft definition was finalized according to feedback from the ministries to be the following:

*Care refers to the constellation of individualized services, supports and resources, both formal and informal, provided within the environment* by families and caregivers, service providers, communities, and funders with the goal of optimizing the health and functioning* of the person and their family/caregivers over the life course. In this definition, health is defined as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1948), while medical needs are supports required to maintain higher levels of health and functioning.*

Care needs become complex by virtue of their breadth and depth. Breadth of these needs is characterized by multiple needs for care in diverse areas of functioning* that require comprehensive and coordinated care across multiple sectors and services. Depth of these needs is characterized by their intensity and/or frequency and their chronic and often lifelong nature that must be supported by people and/or resources (e.g., technology) to optimize functioning* and fulfillment of youth and adult roles. A person’s complex needs fluctuate over time.

* Note: In this definition, the terms “functioning” and “environment” are defined holistically by the World Health Organization’s International Classification of Functioning, Disability and Health (ICF). The ICF framework describes three categories of functioning (and disability): body functions and structures (impairments), activity (activity limitations), and participation (participation restrictions). The ICF framework depicts functioning and disability as an interaction between an individual’s health condition and contextual factors, including factors that make up the physical, social and attitudinal environment in which people live and conduct
their lives. The ICF framework describes five categories of environment: 1) products and technology; 2) natural environment and human-made changes to the environment; 3) support and relationships; 4) attitudes; and 5) services, systems and policies.

Phase II:

A comprehensive scoping review of both unpublished and published literature from Canada and other jurisdictions was conducted to better understand the following:

- profile characteristics (e.g., functional limitations) of youth and young adults with complex care needs
- service needs of youth and young adults with complex care needs
- interventions that promote successful transition to the adult service system
- client-centred decision-making frameworks (legal or other) designed to include clients and/or their families/caregivers in the decision-making process

Phase II also included six one-on-one interviews to explore the experiences and perceptions of transition from caregivers of young people with complex care needs.

Key results of phase II:

- A single profile that can describe youth with all types of complexities (i.e., diagnoses, disabilities, specific complex care needs) does not exist. Profiles exist to describe subpopulations of those with complex care needs (e.g., medically fragile, medically complex, more complex versus less complex), and some evidence suggests service needs can vary based on profile characteristics. There is no consensus regarding how to assess individuals’ service needs according to the various sub-profiles.
- Much research has indicated that a diagnosis is not a reliable indicator of service needs or service utilization. This observation was one of the factors that led to the creation of the ICF. This classification tool can be used to measure service needs based on a person’s experience of functioning and disability within the context of that person’s specific environment and is strongly endorsed in the literature.
- The review identified 14 transition-specific programs across Canada; most are hospital-based but a few are community-based. Key principles of the transition models include: youth and empowerment of youth, with inclusion of family; multi-disciplinary, coordinated care which should include both adult and youth agencies; the use of a “shared management model” where care management is shared among service providers, youth, family and community.
- Very few evaluations of transition program effectiveness or impact exist. Where data are available, the focus is on patient/parent perspectives, satisfaction and changes in knowledge; medication/treatment adherence; improved continuity of care (i.e., decreased dropout in adult system); improvement of health-promoting/self-management behaviours; decreased morbidity; and suspected financial savings.
Evidence on the effectiveness of shared, client-centred decision-making models is limited for several reasons, partly because the models are difficult to research (e.g., there are often no “right or wrong” decisions; individual differences in providers, treatment options, clients and families make it difficult to measure effectiveness). Second, our research revealed no controlled studies of the effectiveness of the models. Evidence that does exist suggests that shared decision-making is associated with lower costs of care for medically complex clients (through significant decreases in hospitalizations, emergency department visits and office visits) and higher caregiver satisfaction. Evidence also suggests that clients and caregivers do not always want shared decision-making, usually with respect to decisions regarding potentially fatal scenarios.

**Phase III:**

Further research and consultation activities were conducted to create a prioritized list of recommendations for improving the transition to adult health and social services and facilitating community participation for youth and young adults with complex care needs. Activities included a one-day facilitated roundtable with 60 Ontario stakeholders (including clients and family members). Pre- and post-roundtable surveys were also emailed to all stakeholders, asking for their feedback in ranking the top three interventions or practices that could result in a successful transition to adult services for youth and young adults with complex care needs who require care in the long term. Based on the evidence synthesized from these sources, the following list suggests recommendations in order of priority to improve the transition to adult health services and facilitate community participation for youth and young adults with complex care needs:

1. Ensure continuity and portability of funding so that it stays with the person as they move from pediatric to adult services (so funding never abruptly stops) and allows clients and families greater control and choice over the services they obtain.
2. Enact processes to facilitate active collaboration among the main “sectors” of services, community, families and youth to improve preparedness and efficiency of transition planning for all stakeholders.
3. Increase availability and accessibility of medical, social and community-based care and supports.
4. Improve information sharing during the transition from pediatric to adult services.
5. Enhance education and training of all service providers about transition issues (in both adult and child/youth systems).

**Key considerations for the recommendations:**

- All of the recommendations are viewed by the project team to be interrelated, such that improvements in one will lead to improvements in another.
- The importance of empowering youth/young adults and families to have more authority to choose the services and supports they need to improve their transition and care in the long term was a strong message heard from all families and clients during our consultations. This message is also prominent in the literature. Evidence suggests that empowering patients and families is associated with improved patient experience and quality of care.
While some recommended changes to improve care in the long term for those with complex care needs will require considerable time and demonstration projects/evaluation to enact, other recommended changes will require much less time and resources. For example, excellent community support programs that currently exist within community centres could be further strengthened (e.g., through hiring a personal support worker or training volunteers) to better accommodate those with complex care needs. This approach would provide much needed respite for families while promoting community participation and improved mental health for the young adults.

Differences within jurisdictions and contexts (urban and rural) and within different organizations will complicate how these recommendations can be enacted.

**Additional key conclusions and future work**

Many youth and young adults with complex care needs and their families are in crisis because there are not enough of the right services and supports to facilitate their transition to adult services and their care over the long term. This work, led by CFHI, demonstrates that there are tangible solutions to reduce this state of crisis. Many of the recommended solutions are inexpensive and could be implemented in short order (e.g., increasing community supports). Others will require significant resources to support further research, policy analysis, demonstration projects and evaluation to determine how best to enact and tailor the improvements to local contexts and conditions (e.g., individualized funding models). An example of a solution that could be enacted in fairly short order in Ontario to reduce any crisis in families during the transition process is to mandate the provision of services by a pediatric provider to provide ongoing care until appropriate adult care can be found. This solution has recently been enacted by the Ministry of Health in British Columbia.

To set the stage for real transformative change that will enable improved transition and improved care over the long term, it is critical that all of the ministries involved in providing services and supports to this population work together to improve the overall collaboration of the service providers, communities and clients/families. The recently established cross-ministry, inter-ministerial partnership in British Columbia to improve services for people with developmental disabilities and their families is a good example of how such inter-ministerial collaboration can work to design, implement and evaluate improvements in service delivery specific to population groups. Through this inter-ministerial partnership, extensive community, family and stakeholder consultations were hosted across the province that led to the formulation of a new integrated service delivery model that will serve people with developmental disabilities. Components of the new integrated service delivery model, including testing navigators to support people aged 16–24 through periods of transition, are being tested and evaluated in 2013–2014. The Ontario ministries responsible for providing services and supports to youth and adults with complex care needs are encouraged to talk to the inter-ministerial committee in British Columbia to find out if their integrated service delivery model could be applied to the complex care needs population more generally and whether testing of this model in Ontario is warranted.
Further research and policy analysis (that includes interviews with families and stakeholders) and demonstration projects are required to design, implement and evaluate initiatives to facilitate improved care in the long term for youth and young adults with complex care needs in Ontario. Such work would also address one of the major limitations of this project, which is the limited amount of published scientific studies regarding evidence-based best practices for improving the transition to adult services, and even of unpublished literature (such as that found on ministry websites and in our cross-jurisdictional scans). Interviews with families and stakeholders are therefore a critical source of evidence that can be used to inform the design, implementation, evaluation and spread of initiatives to improve transition and care in the long term for youth and young adults with complex care needs.

CFHI and the project team welcome the opportunity to collaborate further with the ministries to clarify the next steps for enacting the recommendations outlined in this report. In addition to the further analysis suggested within the report, some of these recommendations could be piloted through CFHI’s 14-month EXTRA Program for Healthcare Improvement. In this program, teams within and/or across organizations (such as from multiple ministries) undertake quality improvements and system change initiatives within pilot sites (e.g., a community care access centre). Through the EXTRA program, CFHI could support the ministries and healthcare professionals in developing, implementing and spreading the improvements suggested here (e.g., single access point for information sharing and funding models that promote continuity and portability of funding).
Care in the Long Term for Youth and Young Adults with Complex Care Needs

Background

Transition to adulthood is associated with various milestones, chief among them obtaining adult employment, realizing fulfilling roles in the adult community, living independently, and experiencing satisfactory personal and social relationships. The extent to which such outcomes of transition to adulthood are achieved is impacted by a multitude of factors, including the care needs of the individual and the availability of services and supports within the community. For patients with complex care needs and their families, the transition from pediatric care to an adult care system is especially challenging. Not only are they entering a new stage of life in adulthood, they are also tasked with learning how to manage their health, medical and social needs within an adult health system and community that is not designed to address their unique needs. Unsuccessful transition from pediatric to adult services in young adults with complex care needs has been associated with deteriorated health status and acceleration of mortality (through lack of appropriate follow-up care, for example; Fredericks, 2009). Successful transition programs can significantly reduce both the quality and the cost of healthcare by reducing emergency department visits, increasing continuity of care, and increasing patient and physician relationships (British Columbia Medical Association, 2012).

The Canadian Foundation for Healthcare Improvement (CFHI) was commissioned by the Ontario ministries of Health and Long-Term Care, Children and Youth Services, Community and Social Services, and Education to develop a better understanding of the profile of youth and young adults with complex care needs and the required interventions to ensure a successful transition to adult services that will continue to meet their needs. The aim of our research project was to understand how the transition to adult services could be improved for youth and young adults with complex care needs. The project proceeded in three phases.

Phase I:

Definition of complex care needs

In phase I, we defined the concepts related to complex care needs through an extensive interjurisdictional scan and unpublished literature/online review of current provincial and
international definitions of special needs and a published literature review of these definitions and related terms. The research team synthesized the results of the reviews before consulting with key stakeholders at a consensus meeting to formulate the following definition of complex care needs (see Appendix 1 for a more in-depth summary of phase I and a list of commonly reported functional characteristics and limitations):

**Care** refers to the constellation of individualized services, supports and resources, both formal and informal, provided within the environment* by families and caregivers, service providers, communities, and funders with the goal of optimizing the health and functioning* of the person and their family/caregivers over the life course. In this definition, **health** is defined as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1948), while **medical needs** are supports required to maintain higher levels of health and functioning.*

Care **needs** become **complex** by virtue of their **breadth** and **depth**. **Breadth** of these needs is characterized by multiple needs for care in diverse areas of functioning* that require comprehensive and coordinated care across multiple sectors and services. **Depth** of these needs is characterized by their intensity and/or frequency and their chronic and often lifelong nature that must be supported by people and/or resources (e.g., technology) to optimize functioning* and fulfillment of youth and adult roles. A person’s complex needs fluctuate over time.

*Note: In this definition, the terms “functioning” and “environment” are defined holistically by the World Health Organization’s International Classification of Functioning, Disability and Health (ICF). The ICF framework describes three categories of functioning (and disability): body functions and structures (impairments), activity (activity limitations), and participation (participation restrictions). The ICF framework depicts functioning and disability as an interaction between an individual’s health condition and contextual factors, including factors that make up the physical, social and attitudinal environment in which people live and conduct their lives. The ICF framework describes five categories of environment: 1) products and technology; 2) natural environment and human-made changes to the environment; 3) support and relationships; 4) attitudes; and 5) services, systems and policies. Functioning can also be assessed more broadly to consider an individual’s ease with learning and applying knowledge; managing general tasks and demands; communication; mobility; self-

---

1 Please contact CFHI for more information from our Interjurisdictional Scan and Published Literature Review.
The consensus meeting participants agreed not to include examples of possible profiles of complex care needs directly in the definition because of the concern that a particular sub-profile would be left out inadvertently. The consensus definition would apply to those with a disability as defined by the *Ontario Disability Support Program Act*, whereby the individual has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more; the direct and cumulative effect of the impairment on the person’s ability to attend to his or her personal care, function in the community and function in a workplace results in a substantial restriction in one or more of these activities of daily living; and the impairment and its likely duration and the restriction in the person’s activities of daily living have been verified by a person with the prescribed qualifications (Ministry of Community and Social Services Toronto, 2013). Those with complex care needs may also have serious incapacities that are associated with serious and/or palliative illness, behavioural issues (that can result in criminal behaviours and conflict with the law), severe learning disabilities, or substance abuse. Research does support the notion that there are different sub-profiles of complex care needs (that are associated with different levels of functioning); however, this research is discussed as part of phase II in this report.²

Phase II:

**Information about youth with complex care needs to facilitate transition to adult services**

Phase II of the project focused on identifying and describing strategies to facilitate the transition to adult services for youth with complex care needs. We conducted a review of unpublished and published literature using a non-categorical approach to identify the following:

- **Profile characteristics (e.g., functional limitations) of youth and young adults with complex care needs**
- **Service needs of youth and young adults with complex care needs:**
  - Family impacts and experiences regarding service needs were noted when identified (e.g., impact of service provision on the “adult roles” of the family members; family role in service provision).
- **Interventions that promote successful transition to the adult service system:**
  - Interventions were conceptualized as evidence-based models (programs, service system, cross-sectoral), best practices and/or lessons learned from other jurisdictions that provide services, with a focus on transition

² For more information, please contact CFHI and inquire about our Summary Table of Profile and Service Needs for Youth and Young Adults with Complex Care needs.
planning, resulting in youth and young adults with complex care needs having their needs addressed in the adult system. Wherever possible, information gathered regarding the interventions was organized to provide a description of the models/practices and the target population, key elements of the program/practice, information about program inception and management, and information regarding the impact on outcomes.

- client-centred decision-making frameworks (legal or other) designed to include clients and/or their family/caregiver in the decision-making process

A summary of the results of phase II of this project are illustrated next.

Profile Characteristics and Service Needs of Youth and Young Adults with Complex Care Needs

- A single profile that can describe youth with all types of complexities (i.e., diagnoses, disabilities, specific complex care needs) does not exist in the literature.

- Much research has indicated that a diagnosis is not a reliable indicator of service needs or service utilization. This observation, in part, led to the creation of the International Classification of Functioning, Disability and Health (ICF). This classification tool can be used to measure service needs based on a profile that is defined by a person's experience of functioning and disability within the context of their specific environment, which includes the family, based on assessment of three levels: body function/structure, activities and participation. The ICF can and has been used to inform service planning in the education system. For example, a process was being undertaken in Switzerland starting in January 2011 to implement a multidimensional, context-sensitive procedure to establish eligibility criteria for special education programming in education systems using the ICF-CY model and classification system (Hollenweger, 2011).

Most descriptions of youth with complex care needs appear to be organized into components of the following:

- Health status (or medical complexity), with some articles describing diagnostic groupings and others describing health comorbidities and hospitalizations
  - Conditions were chronic and lifelong in nature.
  - Co-occurring conditions were commonly reported.
  - More than one body system was often impaired.
  - High utilization of health services and resources was portrayed (e.g., one article about youth with medical fragility described involvement of five or more medical specialists and two or more hospitalizations the year before a program admission; Aruda et al., 2011).
• **Functional characteristics** that describe the ongoing limitations in the ability to perform activities that other children of the same age can do because of the presence or absence of an ongoing medical, behavioural or other health condition. **Functional characteristics change with development and age, which implies a need for flexibility in profiling and determining service needs, including during transition to adulthood** (Cobb & Alwell, 2009). Refer to Appendix 1 for a list of commonly reported functional characteristics and limitations.

• **Family characteristics** and outcomes. For example, parents are less likely to work full time, often experience financial problems and are required to provide medical care at home. Several articles highlighted the need for families to collaborate with other service providers to create tailored service provision plans.

• The Ministry of Education website cites typical profile characteristics of a student with complex needs. This profile includes one or more of the following characteristics: more than two comorbid diagnoses; a mental health diagnosis or concern; significant concerns regarding the safety of self and others; requires significant medical needs; inability to cope with typical school setting or frequent attendance in a variety of settings; out of school or limited attendance; receiving or requiring support from outside community agencies; history or risk of encountering difficulties with law enforcement; typical school interventions identified as ineffective; and/or treatment (medical or behavioural) as a necessary component of the student’s success plan (Ontario Ministry of Education, 2001). Tailored educational management plans that include information about the child’s medical, behavioural, learning and social abilities have been recommended to improve service delivery within schools.

• **Service needs during the transition** is a theme in the literature. Some examples of recommendations for improved services during transition are improved education curricula that can better prepare youth for transition from school to post-school activities and vocational training that includes employment experience (Cobb & Alwell, 2009); inter-ministerial structures that support implementation of best practices in transition (Morris, 2003); palliative care, emergency care and advanced care planning; mental health assessments and counselling services to address the normal social, physical and psychological developmental processes; assistance with learning to live independently, if possible; and nutrition counselling.

• Profiles exist to describe subpopulations of those with complex care needs (e.g., medically fragile, medically complex, more complex versus less complex, more severe versus less severe), and research suggests that different service needs are associated with different profiles (in terms of functional characteristics). A few examples of this follow, but note that many of these
studies have not been replicated and there is no consensus regarding how to precisely assess individuals’ service needs according to the various sub-profiles.

- Several studies have used the *Children with Special Healthcare Needs (CSHCN) Screener* to create sub-profiles of youth with complex care needs and found that service needs differed based on the sub-profiles. For example, one study found that those who endorsed more CSHCN Screener questions generally had higher healthcare needs and higher medical expenditures compared with those who endorsed fewer items (Bramlett et al., 2009). The same study showed that those who endorsed the question that specifically assessed the presence of functional limitations had the most complex care needs (e.g., greatest amount of outpatient emergency care; health conditions placed greatest care and financial demands on family members) and the greatest amount of “unmet needs” compared with those who did not report functional limitations.
- “More complex” health needs have been associated with higher prevalence of certain diagnoses, such as mental disabilities, emotional problems, seizure disorders, autism, cerebral palsy and joint problems (Kuo et al., 2011), and of developmental diagnoses, such as learning disabilities and problems with speech or stuttering (Bramlett et al., 2009).
- Some articles reported high incidence of unmet need for specific services, for example, prescription medication, specialty care, mental health services, physical therapy, medical supplies, durable medical equipment and communication aids. Condition severity was a strong predictor of unmet need (Houtrow et al., 2011). We did not uncover any articles that discussed the relationship between unmet need and geographic location (e.g., rural versus urban settings).

- Access problems for mental health services were frequently reported. Results from one study showed that less than half the parents of children with behavioural diagnoses reported the need for mental health services, suggesting that perhaps parents do not seek help for children’s behavioural issues within the health system (Warfield & Gulley, 2006).

- A notable service need is **high coordination of care needs**. This relates to the multiple services and providers often required by the youth and their families. **Service coordination** was identified as an important need and often an unmet service need in most articles. For example, one study cited deficiencies in management across sectors, agencies, teams and administrative service sectors as commonplace. Such deficiencies include education plans that do not contain information about the medical issues of the child and non-holistic care provision (e.g., service for a physical diagnostic condition but not mental health) (Warfield & Gulley, 2006).
Interventions that promote successful transition to the adult service system

- The review identified 14 transition-specific programs across Canada. These programs serve a various jurisdictions, including Vancouver, Edmonton, Winnipeg and London. The Toronto area is particularly well represented, with a wide variety of transition programs originating there, including the Good 2 Go program, Growing Up Ready and the LIFEspan clinic. The Canada-wide perspective is represented by the National Educational Association of Disabled Students (NEADS), which offers resources to youth across the country.

- Most services are hospital/healthcare institution-based (e.g., Good 2 Go, YARD Clinic, OnTrac, Growing Up Ready). Few are community-based (e.g., Maestro, Transition Residences).

- The target population is youth, typically aged around 14 with service up to 25 (some inception for late childhood around age 10 and up).

- Eligibility criteria are either broad (not well defined) or disease-specific:
  - Broad: special healthcare needs, complex care, any condition, physical disabilities, acquired brain injury, mental health, rehabilitation, developmental disabilities
  - Specific: rheumatologic conditions, cardiac conditions, diabetes, cystic fibrosis

- All programs have identified goals for youth related to:
  - improving chronic health condition knowledge and skills for self-management in some domain (e.g., medication management)
  - improving/preparing for transfer into adult health system or adult community system

- Key shared principles of transition programs include the following:
  - Focus on youth and empower youth, with inclusion of family (e.g., age-appropriate care and tasks; parent information and support)
  - Multi-disciplinary, coordinated care is essential, including both adult and youth agencies. (Programs stress the importance of including a designated transition coordinator to bring two service systems together and prevent loss of engagement.)
  - Adopt a “shared management model” (e.g., management is shared among service providers, youth, family and community).

- Common partners and stakeholders include:
  - youth, parents and family

3 Please contact CFHI for more information on interventions that lead to transition to the adult system.
CARE IN THE LONG TERM FOR YOUTH AND YOUNG ADULTS WITH COMPLEX CARE NEEDS

Op pediatric providers
- adult healthcare providers (less common)
- parent/family facilitators or mentors (in formal roles)
- hospitals or organizations (secondary and tertiary care services)
- family physician, in terms of encouragement (not commonly integrated)
- rarely, community organizations such as schools

Core components and structures/techniques (tools) vary based on program goals/needs, but commonalities include:
- education, information and resources available in hard copies and on websites
- defined pathways for service from start to "finish," with the need for these pathways to be flexible and not age-dependent (i.e., rather, developmentally appropriate)
- individual counselling for support and overcoming obstacles and for managing emotional reactions to transfer (anxiety, depression)
- individual/centralized navigation via system (e.g., coordination of services program) or a coordinator/mentor
- traditional self-management training

Very few (if any formal) evaluations of program effectiveness or impact exist; where data (metrics) are available, the focus is on:
- patient/parent perspectives, satisfaction and changes in knowledge
- medication/treatment adherence
- improved continuity of care (i.e., decreased dropout in adult system)
- improvement of health-promoting/self-management behaviours
- decreased morbidity
- suspected financial savings

Published literature summary (key points)

- The needs or criteria for successful transition services were often defined by or based on research (e.g. study by Human Resources and Skills Development Canada) or key editorials, literature reviews or consensus statements in the transition field.

- Many guidelines or recommendations for transition services were made in the published literature. Common suggestions are listed below:
  - patient-centred approach with goal of improving self-advocacy and/or self-determination and resilience
  - coordination/collaboration among all services and systems, with ideally a single point of access
  - continuity between pediatric and adult services (e.g., reduce the gap)
• capacity building of youth, parents and community members
• enhancing capacity of all service providers (especially adult service providers) in adolescent, young adult and transition issues through education, training and direct capacity building (Consider modifications to remuneration given the time required for complex patients.)
• age-appropriate and accessible information and resources
• use of navigators and/or transition coordinators/liaisons and/or mentors (youth or parent)
• youth-friendly services (e.g., out-of-hours calling) and/or young adult clinics
• timing: starting early with lots of preparation
• providing opportunities and experiences to build self-management and “independence” (or “interdependence”); youth and family expected to be involved at all stages
• inclusion of more than “medical” transition—vocational, educational, social/recreational and financial—in transition planning, aiming for participation in life/society (requires engagement of all these other services from an early stage in transition planning and an emphasis on coordination of school, adult service agencies and natural supports in the community)
• reframing the idea of leaving pediatrics as an achievement
• commitment from organizations with dedicated resources

• The focus is often on youth with disabilities, single disease categories or “special healthcare needs,” yet there is a belief that comorbidity with mental health, developmental or complex medical needs is an additional risk factor.

• The importance of training of primary care physicians and adult healthcare providers at the medical school level is emphasized.

• Unique examples of transition services:
  o Mental health (Chronic Care Model): stressed the importance of building evidence-based care, coordination of care, information, linkages and community empowerment. Pilot project evaluation had positive results.
  o Medical Home Model (in the United States): early development of an individualized, comprehensive care plan that includes collaboration among youth, parents, and educational, social and health services using a primary care provider to coordinate activities and communication
  o Transition recreation camps: residential training approach to improve readiness skills
Client-centred decision-making frameworks (legal or other) designed to include clients and/or their family/caregiver in the decision-making process

Shared or patient-centred decision-making is the process by which a healthcare provider communicates to the patient personalized information about options, outcomes, probabilities and uncertainties of available treatment and service options and a patient communicates values and the relative importance of benefits and harms. It is important for providing care consistent with patient preferences and may improve satisfaction and adherence. Models may apply only when there is a clear decision to be made (Dy & Purnell, 2012).

According to these decision-making models, decisions regarding transition planning should be derived collaboratively, and recommendations by providers need to be informed by both clinical experience and patient preference. In the literature uncovered through this project, however, decision-making models have most often been discussed in the context of informing medically related decisions when there is a clear decision to be made (e.g., whether or not to have a medical procedure, designing treatment plans), whereby the providers collaborate with the client and family to present all options for treatment in the context of their knowledge of the client and family preferences and goals (e.g., Dy & Purnell, 2012; Fiks et al., 2012; Lipstein et al., 2012). Actions to increase client and family understanding of options, such as visual depictions of risk (in the case of medically related decisions) or interactive exercises for eliciting preferences, are postulated to enhance patient understanding and improve decision quality (Dy & Purnell, 2012). Examples of interactive exercises include having information shared in a structured manner (e.g., using written, verbal and video formats) and using such tools as computers, touch screens and question prompts (Trevena et al., 2006). These exercises help inform patient decisions, especially when they are tailored to the individual. Additional factors shown to increase the effectiveness of shared decision-making include trustworthiness of the provider from the patient’s perspective, cultural understanding, patient/family capacity to understand information and options, and lack of family conflict (Dy & Purnell, 2012).

Evidence on the effectiveness of client-centred decision-making models is limited for several reasons, partly because the models are difficult to research (e.g., there are often no “right or wrong” decisions; individual differences in providers, treatment options, clients and families make it difficult to measure effectiveness). Second, based on our research, there have been no controlled studies of the effectiveness of the models. Researchers have called for more research to address the best ways to give providers the skills needed to help guide client-centred decision-making with clients and families (Lipstein et al., 2012), to determine how best to engage children and less educated parents in the decision-making process (Fiks & Jimenez, 2010), and to better identify the needs of clients and families regarding involvement in decision-making processes (Gravel et al., 2006).

Evidence that does exist suggests that higher degrees of shared-decision making, where clients, families and providers participate jointly in decisions to design medical treatment plans, are associated with
lower costs of care for medically complex clients⁴ (through significant decreases in hospitalizations, emergency department visits and office visits; Fiks et al., 2012) and higher caregiver satisfaction (McKenna et al., 2010). Telephone-based case management that promotes more direct communication between doctors and clients/families, provides self-management skill guidance, and offers shared decision-making has also been shown to reduce treatment cost for medically complex adults and children. This decreased cost was attributed to a higher likelihood of clients/families opting for more conservative medical treatment plans following such telephone-based case management (Fiks et al., 2012). Evidence also suggests that clients and caregivers do not always want shared decision-making (Lipstein et al., 2012), usually in decisions regarding potentially fatal scenarios (Dy & Purnell, 2012), and the client/caregiver role varies according to the child’s diagnosis, the specific decision and the parents’ knowledge base (Lipstein et al., 2012). Thus, it is important for providers to assess the desire for clients and caregivers to be active participants in the decision-making process.

A description of some shared decision-making models and methods that could be appropriate for the population of youth and young adults with complex care needs include the following⁵:

- **Integrated Complex Care Model (ICCM)**, used to provide services to children with medical complexity: In this model, a family lead is nominated to empower the family to be central to the decisions made related to service delivery and transitions. By working primarily with a community care access centre (CCAC) care coordinator and a clinical lead (nurse practitioner), clients, families and providers work collaboratively to make decisions regarding service delivery and transitions. Through this collaboration, clients and families receive education about health and social support options and collectively derive transition plans and goals and receive the necessary guidance to implement the transition/care plan (e.g., by coordinating resources and developing relationships across the spectrum of care). Preliminary evaluation of this model (from pilot testing conducted in Ontario from March 2010 for 18 months) showed better care experience and outcomes (e.g., reduced stress) and a decrease in the number of visits per patient in acute care and rehabilitative settings, decreased acute care costs, decreased duplication of assessments, and reduced avoidable costs (Cohen et al., 2012). Further demonstration projects and evaluation of the ICCM model are warranted.

- **Best Journey to Adult Life (BJAL) model** (Stewart et al., 2009a): Much like the ICCM, core components of this model include active collaboration between clients, families and providers, on the one hand (with clients leading the collaborations where possible), and a navigator (which is the CCAC care coordinator in the ICCM), on the other. Critically, a navigator provides support

---

⁴ *Medically complex* in this study was defined as “those who have or are at increased risk of chronic physical, developmental, behavioural, or emotional conditions that require health and related services beyond those required by children generally” (Fiks et al., 2012, page 100).

⁵ Please contact CFHI for a summary table describing other decision-making models that may be appropriate for this population
to the client and family through the transition process, in part by assisting the clients and families to prepare early for transition by guiding them through the transition planning process. The BJAL model mandates collaboration between community, service providers, and clients and families to best specify service and community participation needs through collaboratively derived transition goals and plans. The BJAL model was devised via an evidence-based approach covering critical reviews of literature for the years 2000–2007, extensive environmental scans, and focus groups in Ontario with clients, families, and key ministry representatives and policy-makers. Extensive stakeholder feedback (including clients and families) indicates that application of this model helps smooth the transition to adult services, and many of its core principles (such as the need for collaboration and a client/family navigator) are present in the ICCM model (described above).

- Telephone-based case management that promotes more direct communication between doctors and clients/families, provides self-management skill guidance and offers shared decision-making has also been shown to reduce costs of treatment for “high risk” adults and children (as discussed above, Fiks et al., 2012).

- Patient decision aids and tools that explicitly outline the medical and treatment-related decisions that need to be made provide in-depth information about options and possible outcomes in the context of personal values (Children’s Hospital of Eastern Ontario, 2013; Ottawa Hospital Research Institute, 2013). Decision aids have been created for a range of specific medical conditions (e.g., autism, diabetes), but not for all possible complex care needs. An example of a decision aid used at the Children’s Hospital of Eastern Ontario (CHEO) is titled “Autism: Should My Child Take Medicine for a Challenging Behaviour?” The decision aid includes a wide variety of information, including the pros and cons of taking medication and not taking medication and checklists to help parents decide whether medicine is the right choice for their child. To our knowledge, use of these aids has not been formally evaluated, but the tools are perceived as a good way to increase client–family–provider collaboration in making medical and treatment-related decisions. Designing such tools to inform transition planning could be a promising way to increase client–family–provider collaboration in designing transition plans.

Below is a summary of client-centred decision-making frameworks that are designed to include clients and/or their family/caregiver in the decision-making process.

- There is no one model for using client-centred decision-making, yet multiple tools exist to help individuals/parents make decisions in medical settings (e.g., http://decisionaid.ohri.ca). These can likely be adapted to use by patients/parents.

- The most specific focus of shared decision-making appears to be on how to improve patient/parent involvement in decision-making when two or more options are available, with
the expectation that this will reduce morbidity (i.e., increase adherence, reduce harms) and improve satisfaction for the “client” (e.g., less frustration). In its broadest sense, shared decision-making/shared management requires developing the skills to be one’s own expert in self-management and life management.

- Some evidence is emerging that implementing frameworks that include clients, families and caregivers in the decision-making process in practice impacts healthcare expenditures and unnecessary hospitalizations; increases satisfaction with care, healthcare outcomes, client knowledge and more realistic expectations; and decreases conflict.

- Common barriers to implementing or using these types of models are:
  - time constraints for healthcare providers
  - lack of skills of patients/parents to make decisions (and also absence of training/coaching to improve this lack)
  - lack of skills in healthcare providers to use these frameworks (e.g., do not know how to find out family preferences) or lack of awareness of frameworks’ value (may not think they are necessary)

- A few practical ideas to improve client-centred decision-making are reported:
  - Healthcare providers and parents can increase children’s involvement in decision-making and their participation in healthcare. Parents need guidance from healthcare providers to know when to do this.
  - Parents want honest, credible information and to have their opinions and preferences valued.
  - The amount of involvement for a child varies by capacity and severity of decisions (not age), where capacity extends beyond traditional skills (e.g., motor or cognitive skills) to include more developed attributes (e.g., understanding and using one’s abilities, problem solving and decision-making, being in control of one’s life and directing others to provide supports). Everyone, including service providers, needs to build the capacity to promote positive, inclusive adult outcomes for all young people with disabilities. Rights to privacy must be respected.
  - The goal is for collaboration and negotiation among all parties, often with the focus on youth developing greater responsibility when appropriate (e.g., BJAL model).
  - The weight assigned to each stakeholder’s opinion in any one decision warrants discussion.
  - Education for families, clients and providers is necessary. This can help ensure that clients and families feel comfortable making decisions and contributing to decisions about their care and that providers offer the appropriate information to families to help inform their care decisions.
• Transition programs should include these components:
  o assistance for youth with decision-making, palliative or end-of-life care, and emergency planning
  o improvement in the decision-making support across the entire continuum of care, including both community and tertiary care levels

One-on-one interviews
In addition to the literature review described above, phase II included six one-on-one interviews to explore the experiences and perceptions of caregivers of young people with complex care needs regarding the transition from pediatric to adult healthcare. All participants were parents of adolescents or young adults with complex care needs who were current or former patients of the Complex Care and/or Good 2 Go transition programs at The Hospital for Sick Children, would be transferring or had transferred to adult care, and were within three years of their 18th birthday. Appendix 2 presents a more complete description of the interview methodology and a summary of the results of this portion of the project.

Phase III:

Once the research team synthesized the results of the second literature review and interviews, phase III commenced with the team hosting a facilitated discussion with key stakeholders at a one-day roundtable in Toronto on June 4, 2013. The plenary informed a set of prioritized recommendations for required interventions or practices for youth and young adults with complex care needs to successfully transition to adult services and continue to have their needs met over the long term. Key stakeholders included community and acute healthcare-based providers working with families and young adults with complex care needs and/or who had experienced the transition to adult services, caregivers and family members of clients with complex care needs, policy-makers, and researchers.

To further inform phase III, pre- and post-roundtable surveys were emailed to all stakeholders. The surveys asked the roundtable participants to choose their top three priorities for strategies to promote successful transition to adult services for youth and young adults with complex care needs who require care in the long term. A list of options, created from the literature review, was provided, and respondents were told they could also specify priorities other than those provided. Appendix 3 provides a summary of the survey results.

From our work in phase III of this project and using the evidence synthesized from all sources described above, we created the following list of recommendations in order of priority that can improve the transition to adult health services and community participation for youth and young adults with complex care needs.
Ensure continuity and portability of funding so that it stays with the person as they move from pediatric to adult services (so funding never abruptly stops) and allows clients and families greater control and choice over the services they obtain.

The recommendation for continuous and portable funding was ranked the highest priority by roundtable participants. Currently in Ontario, there is a "disconnect" of such funding for youth with complex care needs in Ontario when they turn 18 years old. They have to reapply for "adult" funding—a process often accompanied by a long wait period to access many required funding sources (e.g., passport funding). The delay leaves many parents worried and scared about the continuity of services for their youth (as stressed in the one-on-one interviews and roundtable discussions), because funding does not stay with their child as he or she moves from pediatric to adult services. Continuity and portability of funding would allow youth and young adults, and their families, to have greater control and choice over the services they obtain and could prevent dangerous gaps in the access to necessary supports (e.g., respite care, nursing support) that often result during and after transition (usually around ages 18–21). The need for continuous, portable funding is supported by evidence in recent literature about supports for adult transitions for youth with disabilities (Stewart et al., 2009a, b) as well as for youth with mental illness and/or addictions (Murphy & Eykens, 2013).

Individualized funding tied directly to children, youth and families is a support offered in many jurisdictions, including other provinces and countries. This funding can pay for services to address health and medical needs and can be used to facilitate community participation. Mounting evidence shows that this type of funding can make a significant, positive difference in supporting youth and young adults with all types of chronic conditions during the transition to adulthood (Provincial Council for Maternal and Child Health, 2013; Stewart, 2009). For example, in collaboration with the Ministry of Health and Long-Term Care, the Toronto Central Community Care Access Centre (TC-CCAC) recently tested Your Choice, an 18-month family-directed funding model, with two families with children with complex medical care needs. Through this funding model, families were given the power to choose the amount and type of services and supports they needed and wanted to access. This model operated according to responsibility and accountability agreements, and monetary entitlements were established based on a predetermined needs-based budget and care plan goals. The evaluation results demonstrated that the program:

- was safe and effective and afforded clients and their caregivers the flexibility to select and direct care services based on their individual needs
- ensured accountability and an appropriate level of transparency for the use of public funds
  - did not jeopardize health outcomes or exceed the normal cost of care for appropriate clients and caregivers

The promising results of the TC-CCAC pilot fits with other evidence that indicates that individualized funding can work well for parents and clients who want to take an active role in managing the delivery
of their own or their child’s services (Stewart et al., 2009a, 2009b). A project funded by the Ontario Ministry of Community and Social Services in 2001, the Opening Doors project, provided individualized funding to 10 young adults aged 18 and older, each with a developmental disability and at varied stages of transition from school to the adult community (Forhan et al., 2007). An evaluation of the project combined quantitative self-reporting measures with qualitative in-depth interviews to assess the effectiveness of individualized funding for youth with developmental disabilities. The evaluators concluded that “individuals benefit from having the autonomy associated with individualized funding through an increase in participation in their communities, schools, places of employment and recreation. The benefits realized by individualized funding go beyond the individual to the family” (Forhan et al., 2007, p. 19). Individualized funding models have the potential to provide families with better “peace of mind,” knowing that their child has funds and that they, as a family, have the power to choose what services they should and want to access to increase community participation. These models can also provide caregivers with the time and flexibility to tend to their own careers, health and social networks (Forhan et al., 2007). Further demonstration or pilot projects are needed, however, to ensure that different funding models work well for all families. Providers and families would need training to understand how different funding models worked, and an essential part of such demonstration/pilot work would be more analysis of the types of services and community supports families need and want to access (McConkey et al., 2007).

Personal health budgets have been implemented in some jurisdictions across Europe and are being piloted in other jurisdictions in the United Kingdom’s National Health Service (NHS) as part of reform efforts to increase the quality, cost-effectiveness and person-centredness of care for people with disabilities and long-term care needs and for those who require mental health services (NHS Confederation, 2009). Individualized personal health budget funding models have also been piloted in the United States. Through personal budgets, clients are given control over a direct cash payment or an indicative fund of money, either directly or through a caregiver or care coordinator. Recipients can use the budget to form care packages that suit their own health and social needs by purchasing, for example, personal care, assistance with domestic chores, and social, leisure and educational activities. Promising results of personal health budgets include less fragmented care, an accountability shift to clients rather than providers and empowerment to the service user. Results from 13 pilot studies of this individualized funding model found that young adults with a physical disability, as well as mental health users of varying ages, reported higher quality of life and overall satisfaction with the funding model when compared with standard services without individualized funding (Glendinning et al., 2008). Cost savings for systems have also been realized through use of personal health budgets in some jurisdictions. A study in Massachusetts revealed a decrease in clinical and social service spending of 78% between 2002 and 2006, for example. Another study has found, however, that the potential for cost savings via individualized funding models varies based on population subgroups and the length of time used (Manthorpe et al., 2011).
Critical elements of personal health budgets include these: 1) the choice to say “no” to a personal budget—in cases where the process of planning and managing personal support is too burdensome, as has been found more often in older populations compared with younger populations with mental health issues and physical disabilities; 2) robust information systems so individual choices are well informed, and the limitations of budget and administrative support are well understood; and 3) strong local leadership to support necessary cultural change in professionals that will empower professionals to work better with patients to accomplish things such as the co-creation of care plans. Implementing personal health budgets in Ontario is a potential long-term goal that would require much more research, planning and evaluation to execute, but designing, piloting, evaluating and refining their use is a promising strategy that may improve the quality, cost-effectiveness and person-centredness of care for youth and young adults with complex care needs.

Other individualized funding programs exist across Canada that may also improve transition to adulthood, where funding is provided directly to individuals and/or their guardians to arrange and manage their own support services. (However, the evaluations of these initiatives in terms of how they may improve transitions were not available for analysis, and these programs may differ significantly in terms of the eligible services for purchase—for example, community support services often may not be eligible). For instance, through the Ministry of Health in Saskatchewan, clients with long-term care needs can apply for individualized funding. If eligible, the recipients or their guardians receive direct funding that empowers them to arrange/hire and manage their own approved support services (e.g., personal care or home management) according to guidelines set out in an agreement they sign with their respective regional health authority.

A more extensive analysis of funding mechanisms that exist across Canada and beyond would be useful for identifying funding models relevant to youth with complex care needs during transition, particularly those that can provide access to continuous, portable funding throughout their care journey. Consumer-directed support has been identified as a potentially effective model for other populations with specific needs, such as adults with disabilities, those with Alzheimer’s disease and dementia, and the elderly (NDS, 2009; Alzheimer’s Australia, 2007; Timonen et al., 2006). The cost implications of implementing various funding mechanisms warrant considerable further research as well, and such research should consider specific population needs, the current costs associated with young adults with complex care needs transitioning into the adult system and the potential costs associated with individualized funding for these youth.

Enact processes to facilitate active collaboration among the main “sectors” of services, community, families and youth to improve preparedness and efficiency of transition planning for all stakeholders.

Collaboration should take place within and across sectors (intra-sector and inter-sector; figures 1 and 2).
In addition to suggestions in the literature, many roundtable participants voiced the view that, although multiple organizations and ministries within Ontario are working to improve the transition for youth to adult services, the service providers are often unaware of each other's programs and/or have areas of redundancy and/or contradictory practices, and services are also not connecting with community programs and supports. The Ontario ministries of Health and Long-Term Care, Children and Youth Services, Community and Social Services, and Education can be the catalysts for improving collaboration among the service providers, community and families by promoting and mandating processes that would promote active efforts for service providers, communities and families to work together to improve care and transitions for youth and young adults with complex care needs. Critically, families
and youth should be given the opportunity to lead the collaborations where possible and desired. The end goal of the collaboration is to improve the well-being of the clients and their families (and to ensure that all Canadians have an acceptable level of well-being), and research suggests that health outcomes, costs and satisfaction can be improved/optimized if care is patient-centred.

To increase collaboration and improve service coordination, some jurisdictions within and outside Canada have formalized partnerships among multiple ministry and community organizations responsible for providing care to complex care needs populations. For example, the HCN unit in New Zealand is an interagency unit comprising a small team of regionally based individuals that support staff and managers across Health, Disability, Education, and Child, Youth and Family ministries to identify, plan and better meet children's needs when these are high and complex (Ministry of Social Development, HCN Unit, 2013). The HCN unit has full-time, regionally based advisors who provide guidance to interagency members and provide tools, resources and information to support interagency working. Its members are responsible for managing information from a variety of stakeholders to support collaboration, encourage interagency working and promote best practices.

The province of British Columbia has made significant inroads in improving the care of and transitions for young people with developmental disabilities through a cross-ministry and inter-ministerial collaboration in that province. Specifically, it has a cross-provincial partnership with nine ministries or authorities to develop and implement system-wide changes within British Columbia to improve services for people with developmental disabilities and their families. Through this partnership, the province hosted community and family engagement sessions across the province in autumn 2012 and, also informed by other consultations, designed a new “integrated service delivery model” that can serve people with developmental disabilities.

This B.C. ministry collaboration has given life to 12 recommendations, including the need to “develop a one-government policy framework for people with developmental disabilities” and “support greater utilization of individualized funding.” A publicly accessible briefing note on the website of the British Columbia Ministry of Social Development and Social Innovation (2013) lists the 12 recommendations and the actions under way to implement them. For example, the province has now simplified application processes for some services and created an inter-ministerial team with representation from the nine ministries/authorities to ensure a “one-government” service delivery system for people with developmental disabilities. A call put out in July 2013 asks organizations and agencies from across British Columbia to submit expressions of interest to volunteer as early implementation sites, to test the new integrated service delivery model. Various components will be tested and evaluated, such as 1) navigators to support people aged 16–24 through periods of transition; 2) the implementation of common assessment platforms to centralize information and provide better service and support.

---

6 These include the ministries of Advanced Education and Labour Market Development; Children and Family Development; Education; Housing and Social Development; and Public Safety and Solicitor General.
planning for young adults and families; and 3) the technology and tools required to support an information-sharing platform among service partners. The provincial cross-ministry partnership has also supported the importance of improvements to transition and to services for people with developmental disabilities by signing the “Transition Protocol for Youth with Special Needs.” The purpose of this protocol is to promote cross-ministry commitment to a collaborative transition-planning process for individual youth and their families, which will lead to the development of an individualized transition plan for each youth. The protocol outlines the roles and responsibilities of the signatory ministries and organizations in supporting youth and their families through the transition process, and it will ensure that cross-ministry collaboration occurs for information sharing to support individual youth and their families through the transition process and system capacity planning. This provincial-level commitment to work together to improve transition builds on work by these organizations to develop protocols that can identify the necessary school, home and community support services for school-aged children with complex care needs.

Processes and ways that the Ontario ministries could promote or mandate active collaboration include the following:

- **A provincial network between pediatric physicians and adult care providers** (British Columbia Medical Association, 2012). Such collaboration could function to better prepare adult providers to provide care for young adults who are transitioning to their services (more training and education is also needed to prepare adult providers to provide medical care to the young adults, as discussed later in this report). The lack of such a provincial network in British Columbia has been identified as a barrier to strong collaboration at the program level for improving the transition to adult services in that province.

- **Transition resources, such as guidebooks, tool kits and transition checklists** can promote collaboration among clients/families, communities and services if service providers take the time to work with youth and families to create specific goals toward their transition plans. For example, the Youth KIT™ (“Keeping It Together” for youth: www.canchild.ca) has been developed collaboratively by researchers at CanChild Centre for Childhood Disability Research and youth with disabilities. The Youth KIT is a tool that encourages youth to give, receive and organize information about themselves that they will need to know as they make the transition to adult life (McMaster University and CanChild, 2013). Some regions in Ontario have developed guidebooks with local resources: for example, the Child Development Resource Connection Peel’s (CDRCP’s) Transition Checklist for students with disabilities in high school provides a timeline for transition as well as a list of links to appropriate adult services (CDRCP, 2012). A related recommendation put forward at the roundtable was to have a central repository of such tools for youth with complex care needs across Ontario. Tools will need to be adapted or developed for subgroups of youth who meet the definition of having complex care needs—given the diversity of the breadth and depth of their needs. Nonetheless, best-practice and promising practice tools exist and can be adapted.
• **Tools and initiatives to improve communication between service providers and youth/families** can also promote collaboration. For example, an Australian-based program requires youth to write letters outlining their goals and transition plan, which is used as the basis for developing a formalized transition plan in collaboration with providers. Common terms of reference, which have been established in at least some local regions (e.g., by the Transitions Advisory Committee of Peel Region), can also improve communication.

• **Community-based navigators** can promote collaboration between the youth and families they serve and the service providers/community members. An important point raised during the roundtable was the community-based nature of navigators, meaning that navigators would not be part of any specific service system: the unencumbered nature of community-based navigators would ensure that the needs of the youth and families came first (versus the needs of the service system). Navigators can provide individualized support and guidance to youth with complex care needs and their families to find and access services and community opportunities in the period of time leading up to and during the transition period. In the cancer care literature, navigators have been shown to increase patients’ access to providers, increase patient satisfaction and reduce stress, and they have created cost savings within the healthcare system. For example, an evaluation of the cancer patient navigator program in Nova Scotia conducted through patient interviews and analysis of patient medical records revealed a cost-savings outcome of allowing more efficient use of clinical time for physicians and more appropriate use of community health professionals (Cancer Care Nova Scotia, 2004).

• **Cross-ministry creation of common goals and timelines for specific improvement initiatives** to improve transition to adult services, actively informed by clients, families, providers, policy experts and community organizations. This approach relates to the message heard at the roundtable that a shared sense of understanding and commitment is required around the issue of improving transition to adult services to facilitate true collaboration and commitment to partnership and change. An *inter-ministerial committee* could be commissioned in Ontario to bring this forward. British Columbia is successfully enacting this recommendation through their formation of an inter-ministerial team that aims to ensure a “one-government” service delivery system for people with developmental disabilities and by creating publicly accessible information on their website that outlines the current actions toward realizing the 12 recommendations from the associated deputy ministers’ 2012 report to improve services for people with developmental disabilities.

• **Tools to improve client- and family-informed decision-making** are important resources to ensure that youth and families develop the skills needed to take the lead in collaborative activities. For example, in healthcare, patient decision aids can complement provider counselling by providing concise information about options and outcomes of treatment. Studies
show that use of such decision aids can decrease healthcare costs relative to costs incurred without decision aids, because of lower frequency of procedures/surgeries (e.g., Veroff et al., 2013). Further research is needed about the use of decision-making tools for youth and families working in collaboration with other service sectors and/or with communities.

Roundtable participants and the research team concluded that youth with complex care needs must receive enough support to be fully capable of participating in their own communities. In the short term, collaboration can be fostered through ministry incentives such as a recognition of models that work or testing different models through demonstration projects. At the individual level, walls between ministries should be invisible for youth and families, who should be able to access services via a common pathway.

**Increase availability and accessibility of medical, social and community-based care and supports.**

This recommendation covers a great deal of services and supports, so we organized the information into two main areas: a) availability and accessibility of services—medical, social and other, and b) availability and accessibility of community-based care and supports.

3(a) **Availability and accessibility of services—medical, social and other**

During the roundtable, it was evident that services still tend to be “silod” into physical and mental health, social, and developmental services. Many participants felt that collaboration, as discussed above, is needed to bring these services together in order to address the holistic needs of youth and young adults with complex care needs in a person-centred approach.

A key recommendation made was to mandate mental health and addiction assessment and support for all youth and families with complex care needs, irrespective of diagnosis or condition. Issues around the availability and accessibility of mental health services for youth with complex care needs were frequently reported in the literature, and echoed by participants of the roundtable, as a deterrent or risk factor for poor transitioning (Bloom et al., 2012; Murphy and Eykens, 2013). Results from one study showed that less than half the parents of children with behavioural diagnoses reported the need for mental health services, suggesting that perhaps parents do not seek help for their children’s behavioural issues within the health system (Warfield & Gulley, 2006). Initiatives to better promote the mental health wellness of clients and families pre- and post-transition could include ensuring that clients with complex care needs have mental health assessments (e.g., by mandating the use of short, standardized mental health and addiction assessment tools during primary healthcare visits).

Several methods provide examples for increasing the availability and accessibility of medical, social and other services for young adults:
- **Create incentives** (financial or otherwise) for community services to offer more placements for students with complex care needs. This would (likely) require increased capacity for such organizations to provide necessary medical and other supports (e.g., attendant provider environments that can accommodate toileting, specialized feeding and other personal support needs) required to meet—at a minimum—the basic needs of some clients.

- **Offer flexible age of eligibility for current child- and youth-oriented services.** For some clients and families, particularly those diagnosed with mental health conditions, developmental conditions, multiple diagnoses or intellectual disabilities, research suggests that age is not an appropriate indicator of the need for adult-oriented services. Developmental age will impact the transition process, and flexibility related to chronological age demarcations has been argued to be necessary at the level of policy planning and service provision (Davidson & Cappelli, 2011). Some clients can continue to benefit from pediatric-based services (e.g., family-centred care) until well into their twenties, longer or even indefinitely. In addition, transition plans need to be tailored to the developmental/cognitive needs of the clients and families, and if pediatric services are the most appropriate to fulfill needs, those are the services that should be accessed until no longer suitable. This does not mean that the person should be always cared for in the same place by the same people. Even for someone with a very significant cognitive delay, there are different medical and non-medical needs as the person ages that need to be addressed in a developmentally sensitive manner. The importance of engaging adult services and providers who are willing to learn, and of ensuring that there are enough providers who can provide this care, is a key component of this recommendation (discussed further in education section).

- **Create a single application and entry point to facilitate service access across organizational and ministerial boundaries** (Provincial Council for Maternal and Child Health, 2013). This has the potential to reduce the administrative burden faced by families to complete multiple application forms and can eliminate administrative processes and costs associated with having multiple points of service system access. Several roundtable participants indicated high satisfaction with at least one Ontario-based initiative—*Enhanced Respite Funding*—that is accessed via a single point of entry, and they advocated for other services to be administered in this way.

- **Connect youth/young adults and families with community-based navigators** who can help youth/young adults and families identify and access services and community opportunities to meet their transition goals and other needs (in addition to supporting collaboration as described above). Close connections between community navigators and CCACs in Ontario should be nurtured to promote service access. Implementation of navigators who can support young adults aged 16–24 are set to be tested soon in select sites across British Columbia (the call for test sites was released in July 2013).
• Establish peer and parent mentors who have experienced transition and/or have meaningful adult roles. These mentors can also provide a low-cost resource for youth/young adults and families to find available and accessible services. Research and feedback from roundtable participants suggest that such mentorship initiatives show promising positive impact on client and family satisfaction and acceptance with the transition process, and mentorship may also aid clients and families in identifying community participation opportunities. This finding also applies to the community-based services and supports (as described below).

During the roundtable, participants recognized that improving availability and accessibility of services should not necessarily mean increases in funding for adult services. It was suggested that service system redesign and implementation of different funding models (e.g., redesigning the Ontario Disability Support Program or implementing direct funding models) can potentially free up and/or create funds necessary for supporting available, accessible adult-oriented services for young adults with complex care needs.

3(b) Availability and accessibility of community-based care and supports

There is a need to develop and strengthen supports that already exist within everyday “natural” communities to facilitate the participation of young adults in employment, recreation, education and other local community activities. Further developing and strengthening of supports that exist within communities can be a promising, cost-effective way of facilitating the transition from pediatric to adult services and community opportunities. Such community activities should not be run by special service organizations, but rather operate under the stewardship of inclusive municipal programs that already exist. It can be difficult to be inclusive at the very start, but the ministry can reward and incentivize models that work in municipalities.

Relative to other changes that can smooth the transition to the adult community in the long term (e.g., changing funding models, implementing system redesign), some of the initiatives that can increase the capacity of communities to accommodate participation of people with complex care needs have the potential to be implemented within a short time period. Possible ways to increase supports in the community to facilitate the participation of young adults in their local communities include the following:

• Advance initiatives that will promote greater partnerships between community organizations, schools, and pediatric-based services and organizations. Regarding employment, for example (which will not be a realistic goal for all clients with complex care needs), research suggests that many local businesses would be open to providing “job shadowing” experience and offering job opportunities for young adults with complex care needs. Such opportunities need to be identified and shared with clients and families at various points in their transition process. Through the Ministry of Human Services and the Ministry of Health in Alberta, the “Employer Council” has recently been established to support the goal of more and better employment
opportunities for people with developmental disabilities. Through its Persons with Developmental Disabilities program, employment-supports funding is also available in the province of Alberta to train, educate and support individuals to gain and maintain paid employment. The amount of services that individuals can purchase through the Persons with Developmental Disabilities program is based on an assessment of support needs of the individual with developmental disability and is outlined in the Individual Service Agreement.

- **Mandate revisions to special education curricula to better prepare youth for transition to adult roles within the community.** The Ontario education system has some excellent curricula that teach life skills that can promote successful transition to adult services, but there is a need for greater ministry involvement to enhance these curricula. Research indicates that education curricula for people with complex care needs should be tailored to each individual student, be designed to develop the talents and interests of the youth, and ensure ample meta-cognitive instruction (i.e., learning “how to learn”) where necessary (Cobb & Alwell, 2009). Special education curricula should also include work experience in real jobs, particularly those that focus on socialization with co-workers. Studies have found that youth who are placed in adult employment positions while in the education system often lose their jobs after graduation (Cobb & Alwell, 2009). Therefore, researchers have recommended that job placements be connected with adult role models/mentors who can provide mentorship to increase the chances that the young people will maintain the employment position post-graduation.

- **Initiate or provide incentives for campaigns to reduce the stigma associated with people with visible/invisible disabilities and other complex care needs.** Reducing such stigma can increase a person's sense of inclusion in his or her community, in turn making them more likely to actively seek opportunities for community participation. Regarding employment opportunities, research suggests that employers are less likely to consider employment opportunities feasible for disabled applicants (Carter et al., 2009).

- **Increase support for existing organizations that aim to support clients and families with complex care needs.** Family-driven, non-profit organizations such as Family Alliance Ontario and local transition committees comprising individuals from local agencies that service youth and young adults (e.g., Transition Network Committee of Waterloo Region) are examples of organizations that can support the transition of clients and families, particularly by helping to identify and facilitate access to community opportunities. For example, PLAN Toronto is a family-driven, non-profit organization whose mission is to support families in planning and creating a meaningful life and safe, secure future for relatives with disabilities. One of the ways PLAN achieves this is through assigning clients to a facilitator who can help them to develop and realize goals for community participation. In one case, a facilitator was able to arrange for a client with complex care needs, stemming from cognitive impairments, to become involved in a full-time volunteer position that later translated into full-time employment at the same place.
(PLAN Toronto, 2013). Such a resource would be particularly valuable for youth who are not engaged in the educational system around the time of transition.

- **Increase supports that could promote full participation in communities** (e.g., availability of specialized support teams or support workers within organizations and workplaces to support adults with complex care needs). While some appropriate successful adult support programs do exist, the wait-lists for such programs are often unacceptably long, such that many clients and families can never access them in the appropriate timeframe (Toronto Rehabilitation Institute, University Health Network, 2012). For example, the *Family home program* of the Ministry of Community and Social Services provides independence with necessary supports and supervision, but there is so little turnaround in that program that many new young people are never able to access the services (Ontario Ministry of Community and Social Services, 2004). Similar, almost impenetrable wait-lists exist for many community employment opportunities. Through its *Persons with Developmental Disabilities program*, the province of Alberta has specific funding available to promote community access and participation. Through the *Provincial Disabilities Support Initiatives Centre* in Alberta, key community stakeholders are identified and contracts are developed to use the knowledge and experience of community agencies to enhance the supports available to persons with disabilities (it is unclear whether this initiative has been evaluated).

There is a definite shortage in Ontario of adult-oriented respite and day programs, which negatively affects the ability of both the clients and their families to be fully engaged in their communities. We suggest a national comparative analysis of the programs that do exist in Canada and elsewhere to successfully provide more respite and day program services (and the associated evaluations of such programs), to better understand promising ways that Ontario could improve the access and availability of respite and day programs for clients with complex care needs and their families.

One key outcome of improving the availability of health, social and community services would be the prevention and quick resolution of crisis in families—an unfortunate risk associated with transition from both an experience and a health outcome perspective. However, prior to actively seeking to increase the availability of services, further research into the most necessary services in each community across Ontario is required. For policy change to be effective, it must be equitable across the whole province but must also recognize that each region of the province has unique (and sometimes limited) needs and community opportunities.

**Improve information sharing during the transition from pediatric to adult services.**

A single, standard method for exchanging information is a critical part of any good partnership. A single portal where clients and families can input, update and track their goals and progress for all transitions and share this information with providers in a standardized fashion can improve transition planning,
preparedness and execution. The value of sharing information pre- and post-transfer is identified as a key element of healthcare transition in some transition programs (e.g., http://www.gottransition.org/), and the lack of a standardized method for sharing information has been pointed out by many youth and families as a barrier to smooth transition. Enabling better information sharing during transition can also lead to cost savings for families. For example, a young person who recently turned 18 has to complete a psycho-educational assessment (at a cost of $2,000 or more) to reconfirm a diagnosis of an intellectual disability and be eligible to receive funding from Developmental Services Ontario as an adult, despite the fact that this diagnosis has already been documented within the pediatric system. This process can actually put services offered through Developmental Services Ontario entirely out of reach for families who cannot afford to pay for a psycho-educational assessment, or it can lead to such assessments being paid for through tax dollars—an expense that could be spared with improved communication of information between child/youth and adult service providers.

Examples of how information sharing can be improved to facilitate the transition from pediatric to adult services include these:

- **Create and mandate the use of concise transition-planning templates and procedures, and share these completed templates with all of the client/family’s network of providers.** Transition-planning guides, completed by clients and families in collaboration with providers via a standardized procedure, have been used successfully to facilitate information sharing among the multitude of providers within some transition programs in Canada. Promising examples include Complex Care Plans and MyHealth Passport (developed at The Hospital for Sick Children), both of which show evidence of improving service satisfaction of clients and families and are believed to be associated with improvements in health outcomes. Research shows concise written complex care plans, which include information such as the goals of care, patient-specific emergency guidelines, updated medication lists, community- and hospital-based contacts, are associated with reduced hospital admission rates and reduced health system costs. Families who have used such complex care plans have reported that they are better empowered to use available resources and seek guidance when needed compared with when the plans were not used (Soscia et al., 2013). Another example of a transition-planning resource is the Youth KIT™ described above, which can be used by youth with any type of complex care need within any service system. Accountability for using, sharing and updating such transition plans should be shared among all key stakeholders (youth, families and care providers) because this would ensure that all parties were optimally informed and could then use this information more effectively for transition planning and diagnosis.

- **A centralized information-sharing resource in Ontario** would improve access of important information about transition supports and services for everyone involved—youth/young adults, family members, community members and service providers. One centralized resource, such as an Ontario-wide website that is continuously updated, would ensure that transition information was consistent across different regions and sectors and would promote collaboration across
sectors. Some online resources are available, such as the DOOR 2 Adulthood website, but these resources tend to be specific to one service sector, and current evidence supports a non-categorical approach to information about transition to adulthood for youth with all types of chronic conditions. The Canadian Association for Paediatric Health Centres’ Knowledge Exchange Network (CAPHC-KEN) is a wiki-based, interactive online community focused on sharing and growing knowledge in child and youth health service delivery. Initiated by the CAPHC Continuity and Coordination of Care Working Group, the CAPHC-KEN seeks to engage practitioners, patients, families, researchers and other stakeholders in a common, interactive knowledge exchange community. Such a site could help facilitate transition information sharing, but it would require extension and inclusion to the non-healthcare centres (i.e., community programs), and outcomes related to its use would need to be studied.

- Sharing of information can also be supported at the ministries’ level (when appropriate and consented to by youth and their families). From a policy perspective, there are programs in place (e.g., Developmental Services Ontario) that should assist in connecting families and community agencies. A standardized way for ministries to transfer information could help those agencies to quickly connect young adults and their families with appropriate adult services. However, information sharing is much more than the transfer of a file or receipt of a pamphlet for services. At the ministerial level, it might be useful to have the central file containing information about families and individuals with complex care needs equally accessible to all ministries involved, with the consent of individual families. In addition, when appropriate, the file of information and accommodation could follow the young person into adulthood. A shared repository could also facilitate a better understanding of gaps and facilitate research (as described below) by exploring the aggregate needs of these youth in the long term.

Enhance education and training of all service providers about transition issues (in both adult and child/youth systems)

Currently, there is little to no formal education in the area of transition supports and program development for pediatric or adult care providers. As the field of transitions develops, there is an expectation for training to be in the curriculum for both pediatric and adult care providers (e.g., medical association position statements). Although alternative opportunities for training are emerging (e.g., University of Florida’s Education Health Care Transition (EdHCT) Certificate Program; University of Florida, 2013), there is a gap in Canadian-based training. A policy paper released by the British Columbia Medical Association (BCMA) in December 2012, containing specific recommendations to increase training of adult providers who can provide care to adults with complex care needs, recommends that “in the case of patients with unique needs for which no specialist adult care provider is available, the Ministry of Health should ensure that support can be provided in order for a pediatric specialist to provide ongoing care until appropriate adult care can be identified” (BCMA, 2012, p. 4). Based on this recommendation, the Ministry has committed to work with pediatric specialists, in collaboration with the Ministry of Health and health authorities, to identify necessary supports for these
patients or provide ongoing care until appropriate adult care is identified (it is not clear from the paper how this may extend to necessary supports following the end of school life, if applicable).

**Education and training options**

- **Mandate training for healthcare professionals to enable them to better provide services for young adults and adults with complex care needs.** This includes training for general practitioners, who have limited training on how to care for people with complex care needs, despite the fact that many of these young adults need to access a family doctor for care when they leave child-oriented health and medical services. Many young adults with complex care needs are left without medical/health services when they are no longer eligible to receive pediatric services because there are few, if any, adult medical providers who are willing or able to attend to their complex care needs. A key recommendation in a report from the BCMA released in December 2012 states that “health authorities should provide ongoing resources and support for specialist and family practitioners to develop appropriate skills and to manage the care of pediatric patients who transition into their care” (BCMA, 2012, p. 4). Examples of training programs that exist and could be expanded include the following:
  - Education and training modules could be similar to those developed for the online workshop about developmental coordination disorder (McMaster University, 2013). These online learning modules could be used to educate and train youth, families and healthcare providers about the transition process and to help families identify medical and social service needs in preparation for adult services.
  - Free and easily accessible workshops and online webinars could be offered to identify and train specialized adult providers who could become a referral source for family physicians who need consultation. This should develop as a joint initiative of pediatric care providers and adult care providers.
  - Education is also necessary around the experiential aspects of living with complex needs and the biopsychosocial impact of this on the individuals, their family and communities. Short-term solutions may be to include vignettes of success stories to volunteer organizations in individual communities across the province to show how incorporating someone with complex care needs in a community-based role is successful and rewarding for both the individuals and those in their environment.

Critically, training needs to be supported by incentives for adult providers to deliver services for young adults who are transitioning to adult services. For example, there are few incentives for family doctors to accept clients who have complex care needs. These clients often require higher levels of consultation and service referral, and family doctors are paid on a fee-for-service basis, which creates a disincentive to provide for high-needs clients. We recommend the development of an interdisciplinary fellowship to train care providers (e.g., physicians, nurses, dieticians) on caring for young adults with complex care.
Education and training needs to be supported by solid evidence, and this is accomplished through research. Some recommendations follow:

- Dedicate funding for research. A centre of excellence for complex care needs research could spur research and innovation in this area, and, in conjunction with feedback from clients and families, could help to define the service needs.

- Commission further research to explore promising practices in the transition to adult services. This research should include interviews and consultations with providers and families across jurisdictions and internationally to better identify evidence-based and promising practices in this area. Although the current analysis uncovered some evidence-based and promising practices for transition, participants of the roundtable and other experts consulted noted that many of these practices were unpublished.

- Facilitate collaboration between researchers and care providers to support the implementation and evaluation of transition models across care programs (BCMA, 2012). The lack of long-term data tracking on clients who have transitioned makes evaluation of current programs impossible. Small sample sizes are a limitation to identifying promising results.

- Provide access to data to facilitate service system planning needs. For example, researchers and providers should be aware of the uptake and demand for services to be able to plan and prioritize service development and expansion. Researchers also need to ensure that the results of transition research are clearly translated into useful information for service providers.

- Enhance knowledge translation and dissemination by using patient-oriented and integrated knowledge translation approaches that partner youth and families, allowing them to take a lead role in the research process. Youth input can be used to identify knowledge gaps and move research results into clinical practice.

Limitations of the Project

We found limited published information (both in scientific publications and the grey literature domain) regarding evidence-based practices for improving the transition to adult services for youth with complex care needs. Many of the recommendations described above were collected through direct communication with stakeholders who shared their personal and clinical experiences. Although many of the transition programs and models have not yet been evaluated for effectiveness, they echo the sentiments outlines in our recommendations. Furthermore, the project’s short timeline resulted in limited accessibility and availability of stakeholders who could participate (e.g., participants we contacted from outside of Ontario could not participate due to cost and time constraints, and some key
stakeholders within Ontario were also unable to participate for similar reasons). In a future project, we hope to enhance recruitment strategies to include more stakeholders from across Canada and beyond.

Conclusions and Future Work

This report describes recommendations to improve transition to adult services for youth and young adults with complex care needs, as prioritized by 60 key stakeholders in Ontario, based on evidence from comprehensive reviews of the literature and stakeholder interviews. The project team considers that all recommendations interrelate; for example, collaboration across sectors would increase the accessibility of services and community supports. The concept of interactions between people and environments is now recognized as a key component of all developmental transitions and of a broader view of health as described by the World Health Organization. The project team therefore believes that these recommendations should be viewed as an integrative whole; each recommendation is integral to the functioning of the others.

Furthermore, the importance of empowering youth and young adults with complex care needs and their families in driving their care in the long term cannot be overemphasized in each of the recommendations. Empowerment of youth and their families emerges when youth are given choices about their care, have access to supports, make decisions and take responsibility for their transition planning—all functions expected of the normally developing young adult. As shown in figures 1 and 2, the ministries need to be the catalysts to improve the overall collaboration of the service providers, communities and clients/families to set the stage for real transformative change that will enable improved care in the long term. Improving collaboration would equalize the power imbalance that currently exists, such that clients and their families would have more control and accountability over the services and community supports they chose. To truly support the care of youth with complex care needs in the long term, there needs to be a shift in the culture of both pediatric and adult care providers and systems. This would be a philosophical change—a low- to no-cost initiative that could begin immediately across organizations and ministries.

Furthermore, it is clear that many of the proposed recommendations are most likely long-term in nature, as it would take some time to transform the current system to allow for some of the transformation (such as funding models that increase continuity and portability of funding, and increased collaboration via enacting a standardized information-sharing portal). The need to solve the current “crisis” facing many youth with complex care needs and their families (on whom the youth depend for their care) remains and cannot be overlooked. CFHI and the project team are able to articulate, support and evaluate demonstration projects across the province to enact some of the recommendations immediately. Longer-term solution implementation will require more research and policy analysis in other priority areas. For example, to better understand how to implement funding models that would ensure continuity of funding, an in-depth review based on interjurisdictional scans and interviews could be completed to describe ways to increase continuity and portability of funding.
and outline associated policy options and proposed implementation plans. Work to implement both short- and long-term recommendations needs to take place in collaboration with the ministries and/or with an inter-ministerial working group, so as to collectively assess the merits of solutions and to devise short- and long-term implementation plans and schedules.

Finally, the methods to enact these recommendations within specific local and system-level contexts are not yet clear, because we do not have sufficient evidence of the effectiveness of models and programs for youth with complex care needs. It is strongly recommended that any new initiatives should include an evaluation component to build evidence in this area. Some of the recommendations can feasibly be enacted over the short term within local contexts, while others will require long-term efforts. Differences within jurisdictions (urban and rural) and within different organizations (with differing governance structures, leadership, patient/family support and resources) will complicate how these recommendations can be carried out.

CFHI and the project team could collaborate with the ministries to further clarify the next steps for enacting the recommendations outlined in this report. In addition to the research and policy analysis suggested above, continued work to improve care in the long term for youth and young adults with complex care needs could be executed through CFHI's 14-month EXTRA Program for Healthcare Improvement. The EXTRA program provides focused support for teams of up to four people to undertake quality improvements and system change initiatives from within or across organizations and jurisdictions. Through the EXTRA program, CFHI could support the ministries and healthcare professionals in developing, implementing, testing and spreading the improvements suggested in the recommendations (e.g., single access point for information sharing, funding models that promote continuity and portability of funding, and development of online training modules for families and providers). For examples of how the EXTRA program could facilitate the implementation of programs and policies in this area, visit http://www.cfhi-fcass.ca/WhatWeDo/EducationandTraining.aspx.

CFHI and the project team welcome the opportunity to collaborate with the ministries to improve care in the long term for youth and young adults with complex care needs and to address the current crisis facing families of youth with complex care needs who are dependent on their families for care.
References


Davidson, S. & Cappelli M. (2011). We've got growing up to do: Transitioning youth from child and adolescent mental health services to adult mental health services. Ontario Centre of Excellence for Child and Youth Mental Health.


Murphy, A. & Eykens, A. (2013). Transitional Aged Youth (TAY) Environmental Scan. Hamilton Niagara Haldimand Brant Local Health Integration Network.


and best practice guidelines for the transition to adulthood for youth with disabilities. Hamilton, ON: McMaster University.


Appendices

Appendix 1: Summary of phase I: Comprehensive scoping review to inform development of a definition of complex care needs

Preamble and assumptions
The scope and methods used in the literature review were guided by the Request for Proposal (RFP) issued by the Ministry of Health and Long-Term Care (MOHLTC) and from our accepted proposal. In addition:

- The proposed definition of complex care needs was developed using two effective approaches: 1) a comprehensive interjurisdictional scan of current provincial and international definitions of special needs and an extensive review of published and unpublished literature for definitions of the terms "special needs" and "complex care needs" and related terms, and 2) an expert panel meeting with the project team members and five additional expert consultants.
- We adopted a non-categorical approach to defining complex care needs, meaning that we searched for definitions that encompassed youth and young adults with all types of special needs/disabilities/diagnoses.
- We were guided by current definitions of health that are biopsychosocial and functional in nature—health is viewed as a state of well-being (physical, emotional, social, etc.) for all persons and is not focused solely on a person’s medical condition. Furthermore, current definitions of disability are also functional in nature and consider the person and environment in interaction (versus focusing solely on a person’s condition/diagnosis).

Methods
Comprehensive literature review

- Comprehensive searches of both published (in past five years) and unpublished literature on definitions of the key terms "special needs" and "complex care needs" (and other related terms; please refer to Appendix 1.1 herein for a more complete description of the inclusion criteria employed in phase I of the present research).
- Review of current provincial and international definitions of special needs, including analysis of legislation and policy documents obtainable from ministry and other websites (including MOHLTC, Ministry of Children and Youth Services [MCYS], Ministry of Community and Social Services [MCSS], and Ministry of Education [EDU] in Ontario). In addition, following a joint meeting with MOHLTC, MCYS, MCSS and EDU on February 6, 2013, and subsequent bilateral meetings with each of the ministries, the following information was consulted:
  - specific information regarding the process by which school boards identify students with special and/or complex care needs and the associated definitions of “exceptionalities” (five-page document supplied by EDU)
  - the following websites: Autism Ontario, Bloorview Holland, Surry Place, March of Dimes, the Ontario Association of Children’s Rehabilitation Services, College Committee on
Disability Issues and Inter-University Disabilities Issues Association (note that individuals who work at these organizations were contacted to inform phase II and III of this research, but time constraints did not permit such interviews in phase I).

- Abstracts and information sources (websites) were compiled and reviewed by the research team, and summary tables including definitions and information that could inform the development of the definition of complex care needs were produced.

**Implications from the comprehensive literature review**

- There is no one clear and accepted definition of the term “complex care needs.”
- Many of the definitions/descriptions in the literature are of “children with special needs/special healthcare needs” and not simply of “complex care needs.”
- The term “complex care needs” is distinguished from “special needs” in terms of breadth (i.e., more than one need, interrelated/interconnected needs) and depth (severity, seriousness, intensity) (Rankin & Regan, 2004).
- Recent definitions and descriptions acknowledge/include both the person (youth) and the environment (care) in interaction, which fits with current models about disability, health and development. Furthermore, there is a call in recent literature to adopt a functional approach to understanding complex care needs, rather than focusing on specific conditions or categories of need.

**Consensus meeting**

Email correspondence and a half-day in-person consensus meeting hosted on March 12, 2013, at The Hospital for Sick Children were used to develop a definition of complex care needs. Participants included all 12 members of the core project team plus five additional experts purposely selected to yield a group with a variety of experience and expertise with the subject matter. Please refer to Appendix 1.2 for a list of the consensus meeting participants.

Fifteen participants were invited to review the summary tables produced from the comprehensive literature review and to submit their proposed definition of complex care needs and associated explanation. Participants were asked to consider phrasing their definitions neutrally or positively rather than negatively (e.g., instead of saying “lack of access,” say “access”). Thirteen participants submitted definitions. All proposed definitions and associated explanations were collated into a single document and recirculated to all participants via email by the project manager. Participants were asked to review all definitions and arrive at the meeting prepared to discuss their definitions and clarify, elaborate, defend and/or dispute any definitions or parts of definitions that were submitted. The participant who was not able to attend the meeting in person was asked to clarify, elaborate, defend and/or dispute any definitions or parts of definitions that were submitted via email to the project manager and, if applicable, email the project manager with a revised definition.

---

7 This excluded only the two core project team members Jennifer Major, project manager, and Stephen Samis, facilitator for the meeting.
Participants wrote their definitions on flip chart paper upon arrival at the consensus meeting. All definitions were posted to the wall of the conference room. In addition to the definitions, two pieces of flip chart paper were posted that contained the following considerations for developing the definition:

1. The proposed definition should also reflect that the youth/young adult is expected to:
   - have a chronic/lifelong need for service
   - utilize high levels of services, possibly in a residential setting
   - have care needs (medical, social, etc.) that require multiple service providers, often across many sectors

2. Suggested format of the definition:
   - neutral/positive language
   - non-categorical
   - functional view/not condition-specific
   - do not need to define the youth—only the needs

The facilitator asked participants to introduce themselves and briefly discuss their interest in the topic. Next, the co-principal investigator and the project manager reviewed the two aforementioned considerations for developing the definition and described in detail the purpose of the entire project as outlined in the RFPs from the ministries and from bilateral meetings with ministry representatives. Deb Stewart, the facilitator and the project manager answered questions from the participants to further clarify the scope of the work. In terms of the definition of complex care needs, it was clarified that the ministries were looking for a consistent definition of complex care needs that:

- could be used across ministries, potentially to develop eligibility criteria for programs
- included medically fragile or technology-dependent people, people with comorbid or multiple conditions, people with multiple exceptionalities in the education system and people with autism spectrum disorder

The facilitator and the co-principal investigator then led a general discussion to devise a list of critical considerations and components of the definition of complex care needs. In terms of critical considerations, the participants agreed that the proposed definition should not include examples to avoid the possibility that a person who should meet the criteria of having a complex care need be accidently excluded. For example, it was agreed that the phrase “possibly in a residential setting” would not be used in the definition.

The facilitator led an open discussion about all proposed definitions. The facilitator read each proposed definition, and the authors of the definitions and other participants identified components within the definitions they thought were critical to the final definition. The facilitator and the co-principal investigator recorded the agreed-upon core components of the definition. In terms of critical components of the definition, the participants agreed that:
A large component of care complexity is due to the nature of service delivery—services are delivered across sectors, locations and providers, through the support of various ministries and organizations, and are not always coordinated or interconnected.

Care can be formal (systems and services) but also informal, including the vast amount of caregiving provided by families and community members.

A definition of complex care needs must reflect the notion that complex care needs affect not only the person but also the family and caregivers.

A major goal of fulfilling complex care needs should be to optimize functioning of the person and his or her family/caregivers within their personal roles and within the community.

The definition should not exclude people with complex care needs that are medically related.

Both breadth and depth of needs (where depth is intensity and/or frequency of needs that are chronic and often lifelong and necessarily supported by people and/or resources to optimize functioning) are critical distinguishing factors between complex and non-complex care needs.

Following a short lunch break, the facilitator and co-principal investigator led a general discussion with the group to formulate the definition of complex care needs. A definition was formulated before the meeting convened at 1:00 p.m. The project manager circulated the definition to all meeting participants via email and asked them to submit final revisions and comments to the entire group no later than Friday, March 15, 2013, at noon. The project manager revised the definition according to the submitted comments and recirculated the definition for final review to the group before noon on March 15. No further changes were required by the meeting participants, and the project manager sent out an email to participants with the proposed definition and the report, indicating that a consensus on a definition of complex care needs was achieved.

Feedback meeting with representatives from the ministries of Health and Long-Term Care, Children and Youth Services, Community and Social Services, and Education

The proposed definition of complex care needs and the process for devising the definition was presented to representatives from the MOHLTC, MCYS, MCSS and EDU by Jennifer Major (project manager, CFHI), Linda Piazza (senior director, CFHI), Khush Amaria (co-principal investigator, The Hospital for Sick Children) and Deb Stewart (co-principal investigator, McMaster University) on March 19, 2013, at 9:00 a.m.

Representatives from the ministries suggested minor revisions to the definition of complex care needs. Specifically, representatives recommended 1) revising the statement “persons with complex care needs and their families/caregivers require comprehensive and coordinated care involving multiple sectors and services” to better reflect how comprehensive and coordinated care was an integral part of complex care needs, and 2) specifying what was meant by “communities.” The project manager revised the definition accordingly and circulated it to the participants of the March 12 consensus meeting for comments and suggestions. Several participants responded with suggested changes to the definition. The project manager revised the definition again based on their feedback and circulated it to the group.
Proposed definition of Complex Care Needs

DEFINITION of COMPLEX CARE NEEDS:

Care refers to the constellation of individualized services, supports and resources, both formal and informal, provided within the environment* by families and caregivers, service providers, communities, and funders with the goal of optimizing the health and functioning* of the person and their family/caregivers over the life course. In this definition, health is defined as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1948), while medical needs are supports required to maintain higher levels of health and functioning.*

Care needs become complex by virtue of their breadth and depth. Breadth of these needs is characterized by multiple needs for care in diverse areas of functioning* that require comprehensive and coordinated care across multiple sectors and services. Depth of these needs is characterized by their intensity and/or frequency and their chronic and often lifelong nature that must be supported by people and/or resources (e.g., technology) to optimize functioning* and fulfillment of youth and adult roles. A person’s complex needs fluctuate over time.

* Note: In this definition, the terms “functioning” and “environment” are defined holistically by the World Health Organization’s International Classification of Functioning, Disability and Health (ICF). The ICF framework describes three categories of functioning (and disability): body functions and structures (impairments), activity (activity limitations), and participation (participation restrictions). The ICF framework depicts functioning and disability as an interaction between an individual’s health condition and contextual factors, including factors that make up the physical, social and attitudinal environment in which people live and conduct their lives. The ICF framework describes five categories of environment: 1) products and technology; 2) natural environment and human-made changes to the environment; 3) support and relationships; 4) attitudes; and 5) services, systems and policies.
1.1 **Examples of Functional Difficulties among Children with Special Care Needs**

- Breathing or other respiratory problems
- Learning, understanding or paying attention
- Feeling anxious or depressed
- Behaviour problems: fighting, bullying and arguing
- Speaking, communications, or being understood
- Making and keeping friends
- Repeated or chronic pain, including headaches
- Coordination or moving around
- Taking care of self: eating, dressing and bathing
- Using his/her hands (age appropriate)
- Swallowing, digesting food, or metabolism
- Difficulty seeing even with glasses or contacts
- Blood circulation
- Difficulty hearing even when using hearing aids

**Terminology used in the literature for the three key words:**

<table>
<thead>
<tr>
<th>“COMPLEX”</th>
<th>“CARE”</th>
<th>“NEEDS” (i.e., for complex care)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Significant</td>
<td>Support</td>
<td>Exceptionalities</td>
</tr>
<tr>
<td>Additional</td>
<td>Help</td>
<td>Disabilities</td>
</tr>
<tr>
<td>Specialized</td>
<td>Services</td>
<td>Functional difficulties/limitations</td>
</tr>
<tr>
<td>Extra</td>
<td>Fiscal and human resources</td>
<td>Issues</td>
</tr>
<tr>
<td>Extraordinary</td>
<td>Placement</td>
<td>Health conditions</td>
</tr>
<tr>
<td>Extra</td>
<td></td>
<td>Problems</td>
</tr>
<tr>
<td>Beyond that required by children generally</td>
<td></td>
<td>Impairments (in one or more of health, cognition, communication, sensory-motor, social integration, emotional/behavioural, self-help)</td>
</tr>
<tr>
<td>Complicated</td>
<td></td>
<td>Life-threatening</td>
</tr>
<tr>
<td>Continuous</td>
<td></td>
<td>Medical fragility</td>
</tr>
<tr>
<td>Interrelated</td>
<td></td>
<td>At serious risk of harm</td>
</tr>
<tr>
<td>Interlocking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aggregation of issues</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Some descriptions/definitions also include information about outcomes of complex care, such as:

- Participation in daily activities/ordinary life
- Having access to services, activities, experiences
- Reducing functional status limitation
- Well being of self and family
- Quality of life
March 12 2013 Consensus meeting participants

CORE TEAM

1. **Debra Stewart (MSc OT Reg)**: Associate professor in the school of Rehabilitation Science at McMaster University; investigator with CanChild Centre for Childhood Disability Research (also at McMaster)

2. **Khush Amaria (PhD, C. Psych)**: Clinical and Health Psychologist, division of Adolescent Medicine, Hospital for Sick Children.

3. **Jan Willem Gorter (MD, PhD, FRCP(C) physical medicine and rehabilitation)**: Associate Professor, department of pediatrics; investigator at CanChild Centre for Childhood Disability Research (also at McMaster).

4. **Miriam Kaufman (BSN, MD, FRCPC)**: head of the division of adolescent medicine, Hospital for Sick Children; Professor of Pediatrics, University of Toronto

5. **Sherri Adams (MSN, NP-pediatrics, RN(EC), CPNP)**: Pediatric Nurse Practitioner, division of Paediatric Medicine; academic lecturer. Certified as a Nurse Practitioner in Canada and the US.

6. **Jan Burke Gaffney**: Mother of a child with high care needs; founder and Director of Hamilton Family Network and President of Family Alliance Ontario.
   - Hamilton Family Network is a growing organization of families who have a member with a disability and who seek to implement innovative strategies to support and strengthen families. Also a member of the Special Education Advisory Committee for the Hamilton-Wentworth Catholic School Board and former chairperson of the Residential Placement Advisory Committee which reviews the placement of a child with a developmental disability

7. **Matt Freeman**: PhD student in the school of Rehabilitation Science at McMaster University who also brings to the project the lived experience as someone living with cerebral palsy.

8. **Tram Nguyen**: PhD student in the school of Rehabilitation Science at McMaster University.
   - Research assistant for this project; conducted published literature reviews under supervision of Deb Stewart.

9. **Lisa Blenkhorn**: Research assistant for this project; conducted unpublished literature reviews under supervision of Deb Stewart.
10. **Jenna Doig (BHSc (Hon.), MD)**: Second year Pediatrics resident at the Hospital for Sick Children, training through the Postgraduate Medical Education program at the University of Toronto. Conducting the one-on-one interviews with patients and caregivers in phase II of this work.

11. **Jennifer Major**: Project manager

12. **Stephen Samis**: Senior Strategist and facilitator of the meeting.

**INVITED EXPERT CONSULTANTS**

1. **Eyal Cohen (MD, MSc, FRCP(C))**: Physician, Paediatrics, the Hospital for Sick Children; at University of Toronto: Associate professor in Paediatrics, core faculty for centre for patient safety, Institute for health policy, management and evaluation, and Lawrence S Bloomberg Faculty of Nursing; Scientist at CanChild Centre for Disability Research, McMaster University.

2. **Bruce Drewett**: Director Leadership Development Branch Ontario Ministry of Education. Led a tri-ministry (MCYS, MCSS, ED) advisory group to develop benchmarks for transition to adulthood for youth with developmental disabilities. Currently in his twenty-fifth year in the Ontario Public Service. During his career, Bruce has served in numerous provincial ministries, including: Community and Social Services, Citizenship, Management Board Secretariat, Cabinet Office, Agriculture, Food and Rural Affairs and for many years in Education, where he is currently the director of the Leadership Development Branch. In this capacity, he and his staff work with schools boards and professional educator associations to develop their leadership capacity for supporting better student achievement and well-being in Ontario schools. Bruce holds a Masters Degree in Public of Administration from Queen’s University and has served on the board of directors of many not-for-profit organizations. Also brings to the project the lived experience as someone with a disability.

3. **Peter Rosenbaum (MD, FRCP(C))**: Professor of Pediatrics, McMaster University; Canada Research Chair in Childhood Disability; Scotia bank Chair in Child Health Research.

4. **Jamie Brehaut (PhD)**: Senior Scientist, Clinical Epidemiology, Ottawa Hospital Research Institute; Associate Professor, Clinical Epidemiology and Community Medicine, University of Ottawa.

5. **Mary Vasilak**: Parent expert consultant. Mother of a 22 year old son who is medically fragile/technology dependent.
Appendix 2: Report on one-on-one interviews

Data collection and analysis
Six one-on-one interviews were conducted to explore the experiences and perceptions of caregivers of young people with complex care needs regarding the transition from pediatric to adult healthcare. All participants were parents of youth or young adults with complex care needs who were current or former patients of the Complex Care and/or Good 2 Go transition programs at The Hospital for Sick Children (SickKids), would be transferring or had transferred to adult care, and were within three years of their 18th birthday. Staff members of the aforementioned services were asked to identify families meeting these criteria. Individual interviews (in person or via telephone) were conducted following a semi-structured interview guide developed to better understand the transitional needs of their youth. Parents were asked to discuss their ideas about important outcomes of transition and their insights regarding services desired and required to improve satisfaction with their child’s care and health outcomes. These interviews were audio-recorded and transcribed. Computer software (NVivo 10) was used to manage the interview transcripts and to facilitate data analysis. Qualitative analysis was performed using a content analysis approach, aimed at identifying themes from within the text.

Results
Interviews ranged in length from approximately 30 minutes to over two hours. All participants were biological mothers. Further demographic details are provided in Table 1 below. Primary diagnoses included rare genetic and metabolic disorders in addition to more common issues such as cerebral palsy and global developmental delay. The majority of the young people had multiple additional diagnoses, including issues such as scoliosis, seizure disorders, recurrent aspiration pneumonias and autism. Medical technologies and aids used included G and GJ-tubes, PICC lines, TPN and feed pumps, walkers, wheelchairs, orthotics, commodes, hospital beds, Hoyer lifts, tracheostomies, home oxygen therapy, BiPAP, suctioning, and monitors (such as oximetry). Many different specialties and allied health professions were involved in providing medical care for these youth.

Dependence on care
The majority of the participants described their children as having “100%” dependence on care for activities of daily living, including feeding, toileting, dressing and personal hygiene activities. One mother, whose child was able to perform some of these tasks, described the process of trying to increase his independence. Care was provided by parents and professionals such as nurses and personal support workers, and was described as “a way of life.” The importance of routine in day-to-day care activities was emphasized. Dependence on care extended into the medical realm, with the majority of the young people having little to no involvement in managing their own medical needs and care. Most interviewees felt that their children would not know or be able to provide basic information about themselves, such as their birthdate, weight or diagnoses, let alone booking and attending medical appointments, filling prescriptions, accessing medical records or getting help in case of an emergency. In most cases, parents were primarily responsible for all medical management and decision-making.
One mother described this lack of independence for personal care in the context of transitioning into the adult healthcare system:

... Eighteen is sort of an arbitrary number, and they have to pick something, which is fine, but, you know, you send these kids into the ... adult medical world when they're not adults...
In terms of maturity, [my son is] not operating like an adult.

Table 1: Demographic information of interviewees and of their child

<table>
<thead>
<tr>
<th></th>
<th>Case 1</th>
<th>Case 2</th>
<th>Case 3</th>
<th>Case 4</th>
<th>Case 5</th>
<th>Case 6</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship to child</strong></td>
<td>Biological mother</td>
<td>Biological mother</td>
<td>Biological mother</td>
<td>Biological mother</td>
<td>Biological mother</td>
<td>Biological mother</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td>Married</td>
<td>Single</td>
<td>Married</td>
<td>Married</td>
<td>Common-law</td>
<td>Separated</td>
</tr>
<tr>
<td><strong>Health rating (self)</strong></td>
<td>5</td>
<td>7</td>
<td>8</td>
<td>5</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>University</td>
<td>University (Master's)</td>
<td>University (Master's)</td>
<td>High school</td>
<td>Some university</td>
<td>College</td>
</tr>
<tr>
<td>** Household income**</td>
<td>N/A</td>
<td>&lt;$40,000</td>
<td>&gt;$100,000</td>
<td>$61–99,000</td>
<td>$41–60,000</td>
<td>&lt;$40,000</td>
</tr>
<tr>
<td><strong>Persons in household with special needs</strong></td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>N/A</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Child's transfer status</strong></td>
<td>Pre-transfer</td>
<td>Post-transfer</td>
<td>Post-transfer</td>
<td>Pre-transfer</td>
<td>Post-transfer</td>
<td>Pre-transfer</td>
</tr>
<tr>
<td><strong>Child's gender</strong></td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Health rating (child)</strong></td>
<td>4</td>
<td>5–6</td>
<td>9</td>
<td>2</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Hospital admissions (past year)</strong></td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>
“Flying without a net”: Describing transition

The concept of transition was first raised as an issue for the participants' children between the ages of 15 and 17. In most cases, it was a healthcare professional who initiated the discussion. Resources used in the process included handouts and written information as well as referrals to a transition program. Few of the families had had an opportunity to meet with other families who had transitioned. Parents were divided on whether or not this would be helpful.

Parents reported feelings of denial and a reluctance to accept that their child would have to transition. The process was described as being psychologically and emotionally very difficult, with words such as “overwhelming,” “intimidating,” and “scary” used. Parents described feeling “lost” and “freaked out” and “sad” in addition to “overwhelmed” and “unprepared.” They mourned the “loss of a relationship” and likened the process of transition to being “kicked out,” “leaving the country” and “flying without a net.” Parents, especially those who had not yet transitioned, expressed feelings of uncertainty and “a lot of not knowing” in terms of what to expect in the future. They worried about having to “move and start all over again” after so many years spent developing teams and relationships in the pediatric system. One mother perceived transition as a “sigh of relief” on the part of her child's care providers that she had survived to transition and would now have to be looked after by someone else.

Of particular concern to many interviewees was the process of finding new healthcare providers to transition to. They described “searching for pieces of a puzzle that were elusive” in reference to trying to build a new team for their children. This was noted to be particularly difficult for children with complex care needs due to having “so many systems involved and so many different subspecialties” that they would have to transition between. The teams and relationships they had built in the pediatric system had already taken time and effort to develop and had followed their children for significant portions of their lives. One mother, whose son had transferred to the adult world nearly two years prior, related how “very difficult to put together” his team had been and how “it’s still not finished.”

Parents who had already transitioned shared stories, both positive and negative, of their experiences in the adult world and reflected back on the road they had travelled to get there. One mother characterized transition as a process of growing up—for both the child and the parent—and in retrospect was able to see the process as an important milestone for her daughter:

... Realizing that [my daughter] has lived in spite of everything, and that it was ultimately a huge triumph to celebrate the fact that she could turn 18 and become an adult, you know. It’s good to sort of ... realize this is huge that she’s even lived to this point in time and can move on.

Contrasting systems

Differences between the pediatric and adult healthcare systems were highlighted throughout the interviews. For one mother, whose daughter had not yet transferred, she felt that “it doesn’t really make [a] difference just because a child is older” and did not believe that there would be any major
differences in the adult system other than needing different medications and doses. One mother was unsure what to expect in the adult system, but worried that she would not be listened to regarding her child’s needs. She worried about him suffering and wanted him to have “good care—the same care he’s been having so far.” Another was also uncertain and described feeling “a little leery, a little scared” about moving on after 16 years in one system.

Pediatric care was described as being centralized within one hospital and “a lot more accessible.” Parents felt that SickKids emphasized “family-centred” and “cohesive, quality care.” Their team within the pediatric system was characterized as a “safety net” and a group they believed they could trust. They felt that healthcare providers in the pediatric system were more willing to “go out of the way ... to help” and that their child’s issues were viewed as more acute and dealt with quicker. They also felt that more accommodations were made for caregivers, including physical space (such as beds in the child’s room for parents to stay overnight) and more willingness to listen to caregivers and include them in the team. The pediatric system was described as being more “innovative,” and one mother spoke about SickKids as being “intimidat[ing] to adult hospitals.”

In contrast, parents felt the adult healthcare system to be less co-operative and more controlling. One mother described the system as expecting people to “absorb into the system the way the system is.” Another described adult hospitals as “incredibly disorganized,” inefficient, crowded and with long wait times. She felt that adult hospitals were “not really on the ball” and didn’t think her child would be well supported in an emergency. Other differences were reported, such as shared rooms in the adult system and different clientele. Parents also identified the lack of centralized care in the adult system as an issue. More than one parent identified major concerns regarding perceived “holes in the system,” mainly around medical technologies. They described difficulties accessing timely and appropriate assistance with their children’s PICC lines and G-tubes, and related concerns about lack of services between ages 18 and 20 for investigations such as bone density scans. A lack of knowledge of how to deal with rare pediatric diseases also arose as an issue, stemming from the recognition of their children as having unique conditions with unique needs that were “never textbook”:

People are just doing their best and they’re working with what they know. And unfortunately, these rare diseases have largely occurred in children who have been at SickKids who never made it to age 18 to move to a hospital, so the hospitals don’t have the experience of dealing with it. Now the kids are living longer and becoming adults, and it’s just a whole area of rare diseases that no one’s really quite sure what to do with in the adult setting.

Parents described the process of learning the adult system following transfer and were able to recognize some of the positives of the new system. They described people as having “been very kind” and the nurses as having “more time.” They saw it as a different system with a different mentality, but one that was “not so bad” once you started to learn it:
It's not necessarily a worse way of doing things, it's just a different way—it's a different system. And once adjusted to, it can work very well.

Recommendations
1) Care coordination
A central theme throughout all of the interviews was the need for a “point person” or care coordinator to aid in the transition from pediatric to adult care. This was felt to be crucial both in the pediatric system, in preparation for transfer, and in the adult system, as a “bridge” and person other than the parent to try to organize and manage the young person’s care. One mother recounted her frustration with the lack of care coordination in the adult system, stating:

Resources are highly wasted just because there is no point person that can move something into action right away and achieve the same results with the same people but using far fewer resources.

Parents spoke of wanting individualized care and transition advice, specific to their own child and family situation. They expressed the need for and utility of transition services, along with care coordination. Potential benefits of such services could include better communication and “handover” between the pediatric and adult systems, better communication with the family about new providers, opportunities for debriefing experiences in the pediatric system before moving on, and possibilities for visiting new clinics in the adult system prior to actual transfer. As well, such services could aid in cohorting care (transitioning all kids with a rare diagnosis to the same adult provider). Lastly, within care coordination, the potential role of the family physician was discussed. One mother suggested this:

I would like to advocate for the family doctors to be kept in the loop a little more than they are now, because they could be an invaluable source of help as a patient transitions from pediatric care to adult care.

2) Centralized care
The concept of centralized care was an important issue stemming from the interviews. This was seen as a positive aspect of the care in the pediatric system. Parents spoke of wanting to coordinate their child’s care within a central location, with one mother stating that she “dreamed” of having “all the subspecialties in one place or within one system.”

3) Plan for medical technologies
Parents raised concerns regarding a number of medical technologies upon which their children were dependent, including gastric tubes (G-tubes) and peripherally inserted central catheters (PICC lines) required for nutrition and hydration, which created issues following transfer into the adult system. They related stories of having to go through the Emergency Department to troubleshoot difficulties with these technologies, an inefficient and inappropriate use of resources. Timely and direct access to interventional radiology services in the adult world are crucial to ensure these life-
sustaining pieces of equipment are appropriately managed and maintained. Concerns were also raised regarding other medical technologies (namely bone density scans and lower radiation X-ray machines), which were reportedly unavailable to young people following transfer from SickKids (bone density scans being available only after age 20 as per one mother’s experience).

4) Recognition of the caregiver
The role of parents in the lives of children with complex care needs was emphasized in these interviews, highlighting them as advocates, care providers, coordinators, voices and lifelines for their children. Recognition of the important role they play in their child’s medical care is crucial to a successful transition because, as one mother put it, “if mom does well then the child will do well.” Despite their children growing older and preparing to transfer or having transferred into a new system, parents did not feel that their role would or did change. Possible ways mentioned of recognizing this role included accommodations to be allowed to room with their child during in-patient stays as well as respect and recognition for their expertise and crucial membership within the child’s medical team.

5) Other recommendations
Other recommendations included several suggestions made by parents to improve their experience following transfer. One idea stemming from these discussions was the possibility of offering single rooms for young people with complex care needs (both to accommodate additional family members who might need to stay with them, as well as to alleviate concerns regarding the additional sensory input, which might be problematic in some conditions, that came with multi-patient rooms). One mother reported that her child had requested an equivalent of Child Life specialists in the adult system. These people were noted to be “hugely important” to him and were non-existent following transfer. Lastly, the idea of a “grace period” was discussed by one mother as a period of time in which young people could still return to a pediatric care facility to receive required services if their needs could not be met in the adult system (for example, to deal with a piece of medical equipment).
Appendix 3: Pre- and post-roundtable surveys

Participants were surveyed before and after the roundtable to establish their highest priorities to promote successful transition to adult services for youth and young adults with complex care needs. Approximately sixty people attended the roundtable; of these, seven were parents of children with complex care needs and six had complex care needs themselves. The remainder had experience as acute care and mental health professionals providing service to youth and adults, ministry officials, employees with community organizations, or workers in research and education-related fields. Before the roundtable, participants were asked to complete a homework assignment that asked: “Please choose your first, second, and third priorities for strategies that are most needed to promote successful transition to adult services for youth and young adults with complex care needs who require care in the long term. If your first, second, or third priority strategies are not represented in the list, please type them in the "other" spaces available to include them in your ranking.”

Twelve potential transition practices and strategies were listed, and participants were also able to include their own suggestions. The strategies provided to choose from were these:

1. Service coordination and collaboration strategies put in place across multiple sectors/systems including government ministries, agencies and programs
2. Shared management approach adopted and supported through funding; collaboration and decision-making between families, clients, service providers and communities that strategically and explicitly include the family/client in the decision-making process
3. Establish community capacity-building programs that promote greater understanding within local communities of the assets of youth with disabilities to participate in employment, recreation, education and other community services.
4. Mental health assessment and support for all youth and families (irrespective of diagnosis/condition)
5. Expect/require continuity between pediatric and adult services—a seamless transfer process.
6. Enhance capacity of all service providers (in both adult and child/youth systems) in transition issues through education, training and research.
7. Develop strategies up front that promote the stability and maintenance of any new or existing transition program.
8. Funding supports needed for families and community-based services that are not part of the healthcare, social or educational systems (e.g. remuneration for providers and supports for families)
9. Peer support services set up across the province for youth and parents through funded mentorship programs/parent navigation programs in the community (not part of systems/agencies)
10. Direct funding options available and easily accessible (clear criteria and less wait time) to all families of youth with chronic conditions so families can make their own choices about the services they pay for

11. A central “place” for information about transition issues for youth, parents and service providers across Ontario that is non-categorical

12. Provision and print of online resources

13. Other suggestions

Results

Of the 60 people surveyed, the homework assignment received a 50% response rate. Based on the responses from these assignments (Figure 1 and Table 1), the top three priorities were:

1) Service coordination and collaboration strategies put in place across multiple sectors/systems including government ministries, agencies and programs
2) Expect/require continuity between pediatric and adult services—a seamless transfer process.
3) Enhance capacity of all service providers (in both adult and child/youth systems) in transition issues through education, training and research.

Nine “other” recommendations were made by participants, as follows:

- Extend the age for pediatric care of complex care needs (recommended by two people).
- Develop policy/legislative expectations and accountability frameworks and expectations that are monitored and incentivized for effective transition success.
- Accessibility planning, focus on attitudinal barriers/support in communities to be inclusive
- Develop complex care clinics where a nurse practitioner provides support on management, coordination and integration of different services and is continued.
- Finding care support once children have left school
- Give youth and families decision-making control regarding their transitions (recommended by two people).
- Funding equity between adult and pediatric services
Figure 1: Homework assignment results—graph

Table 1: Homework assignment results—table

<table>
<thead>
<tr>
<th>Potential practices/strategies</th>
<th>First priority</th>
<th>Second priority</th>
<th>Third priority</th>
<th>Total votes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service coordination</td>
<td>10</td>
<td>6</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Continuity between pediatric and adult services</td>
<td>2</td>
<td>6</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Enhance capacity of service providers</td>
<td>5</td>
<td>2</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Shared management</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Community capacity-building programs</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Direct funding</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Other suggestions</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Promote existing transition programs</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Peer support</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Funding support for families</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>A central &quot;place&quot; for information</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Mental health assessment</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
Respondents identified which potential practices and strategies they viewed as priorities, but very few expanded as to how these priorities could be achieved. Moreover, the potential for overlap between several of the proposed potential strategies could lead to a skewed analysis of the results because respondents might understand and interpret these different practices and strategies differently. Nevertheless, this survey suggested agreement on the need for improved service coordination and continuity, enhanced capacity of service providers (through training, for example), community opportunities, and funding models that give families greater power in selecting and accessing services.

Following the roundtable conference, participants were surveyed a second time, this time anonymously via an online survey tool. Participants were asked: “Please choose your first, second, and third priorities for strategies that are most needed to promote successful transition to adult services for youth and young adults with complex care needs who require care in the long term. If your first, second, or third priority strategies are not represented in the list, please type them in the "other" spaces available to include them in your ranking.”

The strategies proposed were revised versions of those sent during the pre-roundtable survey, based on feedback from the roundtable and from a re-analysis of the literature:

1. Enact processes to facilitate active collaboration within and across sectors among clients, families, service providers, communities, policy-makers and ministry officials to improve preparedness and efficiency of transition planning for everyone involved.
2. Increase availability and accessibility of medical, social and community-based services.
3. Further develop and strengthen supports that exist within communities to facilitate the participation of young adults in employment, recreation, education and other local community activities.
4. Improve information sharing during the transition from pediatric to adult services.
5. Enhance education and training of all service providers about transition issues (in both adult and child/youth systems).
6. Mandate mental health and addiction assessment and support for all youth and families with complex care needs irrespective of diagnosis/condition.
7. Ensure continuity and portability of funding so that it stays with the person as they move from pediatric to adult services (so funding never abruptly stops) and allows clients and families greater control and choice over the services they obtain.
8. Other (If selected, respondents were asked to expand upon their recommendations.)

The results of the post-roundtable survey are illustrated in Figure 2 and Table 2 below. Twenty-five of the 60 participants responded, creating a response rate of 41.6%. The top three priorities were:

1) Ensure continuity and portability of funding so that it stays with the person as they move from pediatric to adult services (so funding never abruptly stops) and allows clients and families greater control and choice over the services they obtain.
2) Enact processes to facilitate active collaboration within and across sectors among clients, families, service providers, communities, policy-makers and ministry officials to improve preparedness and efficiency of transition planning for everyone involved.

3) Increase availability and accessibility of medical, social and community-based services.

Five participants selected "other" as a priority, but only four made recommendations as to what these solutions should be.

Figure 2: Strategies to promote successful transition: Graph of post-roundtable survey results
Table 2: Strategies to promote successful transition: Data from post-roundtable survey results

<table>
<thead>
<tr>
<th>Proposed strategies</th>
<th>First priority</th>
<th>Second priority</th>
<th>Third priority</th>
<th>Total votes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuity and portability of funding</td>
<td>9</td>
<td>4</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td>Facilitate collaboration within and across sectors</td>
<td>4</td>
<td>6</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Increase availability of services</td>
<td>6</td>
<td>5</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Participation of young adults in community activities</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Improve information sharing during transition</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Enhance education and training of service providers</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Mandate mental health assessment and support</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

Participants specified the following other strategies as important in promoting successful transition to adult services:

- Mandate transitions for all pediatric agencies/services.
- Create regional transition navigators.
- Extend the age of access to pediatric supports to age 25 for all children and youth formally identified as having complex needs so that the age limit is inclusive of biological, social and psychological needs.

Because this second survey was anonymous, it is impossible to know whether the respondents comprised a balanced sample of parents, clients and providers or reflected the original comprehensive sample. Additionally, because of the lower response rate, it has the potential to be less reflective of the group opinion as a whole.