Transitions from Pediatric to Adult Based Services for Youth with Special Health Care Needs: A Nova Scotia Perspective

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Preamble

This is the third iteration of Board Leadership Topics. Initiated in 2011, the Health Association Board of Directors identified the development of thought leadership papers as a strategic area where the Health Association could support its members to address pressing health issues and challenges beyond the nuances of the day to day concerns, using a systems lens.

The intent is that these papers be used as a platform for advancing these issues with key stakeholders and that they provide evidence-informed recommendations for Health Association members and other potential implementers to instigate and evoke change on the selected topic.

At the September 2013 meeting, Board members decided on Transitions from Pediatric to Adult-Based Services for Youth with Special Healthcare Needs (YSHCN) as its leadership priority for 2013/14. This paper is timely as there is significant work on this topic being done nationally, across provinces and locally. Namely, transition of medical care has been a priority topic for the IWK and CDHA. Through this work, a need for a provincial approach to transitions for this population was identified, and brought forward to Health Association’s Board of Directors. Representatives from CDHA, IWK and Health Association met to clarify scope and ensure the two projects are complementary and avoid duplication of effort. From that meeting it was determined that the Association’s role would be to provide a provincial lens of the current status of transitions from pediatric to adult based services. The agreed upon deliverable was a discussion paper that would provide a foundation upon which a common provincial approach to effectively transition Youth with Special Health Care Needs can be built.

While the scope of this work is intended to be broad, it focused primarily on health services for these youth. In recognition of the broad range of community, social and educational services and resources that are also required to support this population as they age, consultations were conducted with stakeholders outside of the health system (e.g. education, community services, adult service centres etc.), but not to the extent to which health services and providers were consulted. It is recognized that these consultations merely scratch the surface of this complex issue that spans a multitude of services and sectors. As such, this report should not be interpreted as a comprehensive review of all services that impact this population, or an in depth analysis of all of the issues facing this population and the sectors which serve them. Rather, this report should be used as a platform to foster discussion and identify further opportunities and solutions to improve the lives of youth with special health care needs as they age.
Key Messages

• Advancement in modern medicine has allowed for earlier diagnosis and prolonged life expectancies of many childhood disorders. This means many patients with chronic conditions and disabilities are being diagnosed in childhood, and living well into adulthood, making transitions in care inevitable.

• There are marked differences between child and adult based health and community based services. A lack of continuity between child and adult services can lead to negative consequences for these vulnerable youth (e.g. such as failure to meet developmental milestones, poor adherence to treatment and poor clinical outcomes).

• There are several transition initiatives and programs that exist nationally, in other provinces and locally, however a provincial lens has yet to be applied to this topic in Nova Scotia.

• The following system level themes regarding transitions from pediatric to adult based services for youth with special health care needs were identified through stakeholder consultations
  o There needs to be greater collaboration and relationship building in order to enable a person-centre, holistic approach to care and service delivery
  o As a province, there needs to be greater clarity around the roles of the IWK, the future health authority and of tertiary services with respect to how YSHCN are cared for and supported.
  o There needs to be a single, agreed upon age of transfer for YSHCN
  o There needs to be more opportunities for training and skill building to support this population as they age
  o There needs to be consensus across providers, illness trajectories and sectors around the placement and scope of navigator functions
  o Services and supports that exist for YSHCN need to be widely known and easily accessible for referring providers.
  o There needs to be an adult complex care clinic which can provide continuity of care for those with multiple and complex conditions.
  o Youth and parents need to be included in, and help directly in the planning and design of transition initiatives and services

• The following sector specific themes were identified through stakeholder consultations
  o Primary care
    ▪ There needs to be greater focus on building self-management skills in YSHCN
    ▪ Family physicians should take on a greater role in the care of YSHCN and barriers to doing so need to be addressed (e.g. knowledge, compensation etc.)
  o Acute & Tertiary Care
    ▪ Speciality specific transition initiatives can be enabled through provincial programs and modeled after the Moving On... With Diabetes initiative.
  o Continuing Care & Community Services
    ▪ There needs to be sufficient and appropriate resources in the community and continuing care sector for YSHCN and youth with disabilities, especially once they've aged out of the school system
Executive Summary

Advancement in modern medicine has allowed for earlier diagnosis and prolonged life expectancies. This means many patients with chronic conditions and disabilities are being diagnosed in childhood, and living well into adulthood, making transitions in care inevitable. There are marked differences between child and adult based services. These differences, combined with fragmented and discontinuous service delivery can negatively impact the transition from child to adult based services for Youth with Special Health Care Needs (YSHCN), including poor adherence to treatment and negative clinical and system outcomes.

In recognition of the importance of transition for this vulnerable population, several transition initiatives have been developed, nationally, in other provinces, and locally. However, this issue has yet to be examined through a provincial lens in Nova Scotia. Our purpose was to provide that lens and create a foundation upon which a common provincial approach to effectively transition YSHCN can be built. In order to fulfill that purpose a broad stakeholder consultation, including interviews and focus groups were completed with stakeholders who span the continuum of care and services accessed by YSHCN.

There were several common themes that emerged regardless of service or sector we consulted. The most salient message across all stakeholder groups was the need to take a collaborative approach to service delivery for this population. The need and importance of service delivery that is person-centred, which takes into account individual preferences, goals and unique circumstances, was widely recognized. However it was felt that siloed approaches to sectors and service delivery undermined the ability to provide person centred care and services, and as such, there needs to be greater collaboration across the continuum of care and services commonly accessed by this population.

Role clarity of sectors, services and providers was identified as a requirement to facilitate smooth transitions from child to adult based services. Specifically, the roles of the IWK, future health authority and of tertiary services in supporting primary and secondary services were identified as key priorities, especially as the health system in Nova Scotia is restructured. There was also concern expressed around the role of the education sector in caring for YSHCN while they are attending school.

A lack of knowledge and skills in caring for YSHCN was felt to be barrier to a smooth transition, especially when the provider or service on the receiving end of transition has limited experience and skills with this population. Specifically it was noted that there needs to be more providers with knowledge around YSHCN in general, and the unique needs of adolescents. While there is some expertise within the Services for Persons with Disabilities sector, adults with autism and other disabilities was a commonly noted knowledge gap for those within the health sector. Other system level issues included having a single agreed upon age of transfer, and the use and scope of navigator functions.

Sector specific themes included the need for self-management skills and training programs, as well as family physician involvement identified through primary care. The need for sufficient and appropriate continuing care and community based services (e.g. respite, adult day programs etc.) was also
recognized, as was the importance of provincial programs, namely the Diabetes Care Program of Nova Scotia, in facilitating transitions from pediatric to adult based services for YSHCN. There was also recognition for the progress in transitions in mental health and addictions which has been a topic of focus for many districts and at a provincial level over the past few years.

Given the diversity and complexity of this population and of the services they access, there is not a panacea to this issue. However recommendations to address these concerns were made based on the input and solutions suggested through our consultation and the evidence where it existed. While many of the recommendations made are dependent on behavioural and cultural changes, an abundance of work in this area has already been done and there exists a window of opportunity to translate this work into change as we as a province restructure our health system.
### List of Recommendations

#### System Level Recommendations

**Recommendation 1:** Build a model of service delivery that is person-centred, holistic and based on collaborative relationships between services and providers (in particular, community services and health, family physicians and specialists and education and health sectors while YSHCN are at school).

**Recommendation 2:** Enable a provincial approach to transitions from pediatric to adult-based care for YSHCN through clarified roles of the IWK and the future Health Authority.

2.1. The Senior Leadership Teams of the IWK and the future health authority, when established, meet to build consensus and define what their respective roles and responsibilities are in the provision of health services to YSHCN, particularly as they transition from pediatric to adult based care. This should also include defining the role that tertiary services play in supporting primary and secondary care.

**Recommendation 3:** Gather and use data on YSHCN to optimize early planning and seamless service delivery on a system and case level basis.

3.1. Establish a method to gather, track and monitor the rates, diagnoses and geographic locations of YSHCN.
3.2 Include services and providers on the receiving end of transition early in the planning process.
3.3 Ensure timely and efficient flow of information between services providers through the use of interoperable information systems and streamlined consent processes where applicable.

**Recommendation 4:** As recommended through previous reports and reviews, streamline the age of transfer across all specialities and ensure that age is communicated to necessary stakeholders.

**Recommendation 5:** Create training opportunities and build knowledge and skills for service providers to appropriately care for YSHCN. Priority topics and providers identified were:

5.1 Build pockets of adolescence expertise.
5.2 Build knowledge and skills for providers of adults with autism
5.3 Build knowledge and expertise of YSHCN within family physicians.

**Recommendation 6:** Build consensus across providers, illness trajectories and sectors around the placement and scope of navigator functions.

**Recommendation 7:** Establish a directory of services available to pediatric specialists, family physicians, navigators and any other referring provider or organization.

**Recommendation 8:** Implement the previous recommendation made by the Joint IWK-CDHA Steering Committee on Transition Needs of Youth and Families to create a model of service delivery that appropriately cares for adults with complex care needs.

**Recommendation 9:** Include youth and parent representatives in the planning and design of transition initiatives and services.
**Primary Care Recommendations**

**Recommendation 10**: Further promote programs and resources that build self-management skills in YSHCN, and that educate health care providers on how to promote these skills in their patients.

**Recommendation 11**: Review Family Physician compensation for this population.

**Acute & Tertiary Recommendations**

**Recommendation 12**: Illness specific transition initiatives use the Diabetes Care Program “Moving on... with Diabetes” initiative as an example or framework for addressing the transition needs of YSHCN on a holistic level.

**Continuing Care & Community Services Recommendations**

**Recommendation 13**: Advocate for and ensure there are sufficient and appropriate resources in the community and continuing care sector for YSHCN and youth with disabilities, especially once they’ve aged out of the school system (e.g. adult day program, adult service centres, inclusive employment opportunities).

- 13.1 Ensure sufficient and appropriate respite options exist for parents and caregiver of YSHCN.
- 13.2 Incorporate consideration for the additional allied health and psychosocial supports that may be required for YSHCN in continuing care settings.
- 13.3 Review and explore funding mechanisms which may enable more community based supports for this population (e.g. ARCs/ RRCs providing outreach services, appropriate residential services, funding for YSHCN to access more practical job skills training and coaching).
Background

Advancement in modern medicine has allowed for earlier diagnosis and prolonged life expectancies. This means many individuals with chronic conditions and disabilities are being diagnosed in childhood, and living well into adulthood. For example 90% of children with disabilities live beyond 20 years of age (Blum, 1995). As of 2011, nearly 60% of all Canadians with cystic fibrosis, an illness typically diagnosed in childhood, are adults (Cystic Fibrosis Canada, 2011). Furthermore, the five-year survival rate for childhood onset cancer is 82% (Childhood Cancer Canada Foundation, 2011). Therefore transitions in care for these patients become inevitable. Transitions in care are particularly important for patients moving from pediatric to adult health services, as the process can influence how these youth interact with the health system, and how they manage their conditions for the rest of their lives. This is especially important for those with complex chronic conditions, developmental disabilities and co-morbidities. A lack of continuity of care can lead these vulnerable patients to fall through the gaps that often exist in a siloed health system and support services.

It has been suggested that pediatric and adult services differ greatly in their approach and environments (Kaufman, M., Pinzon, J, & Canadian Paediatric Society Adolescent Health Committee, 2007) (see Table 1). Furthermore, the transition period typically occurs during adolescence and young adulthood which brings their own unique issues that may influence the transition process and therefore require particular attention. It has been suggested that transition planning should start early, and in some as cases, as early as diagnosis (Kaufman et al., 2007). Given these disparities it is important that Youth with Special Health Care Needs (YSHCN)\(^1\) and their families are informed about the changes they can expect, are given the education and tools to prepare for those changes, and are engaged as a partner in the transition planning process.

Table 1: Differences between Pediatric & Adult Health Environments

<table>
<thead>
<tr>
<th>Pediatric Health Services</th>
<th>Adolescent &amp; Young Adult Issues</th>
<th>Adult Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Focused</td>
<td>Increasing independence</td>
<td>Patient Focused</td>
</tr>
<tr>
<td>Developmentally appropriate care</td>
<td>Changing health behaviours</td>
<td>Requires autonomy</td>
</tr>
<tr>
<td>Input from parents</td>
<td>Sexual and reproductive issues</td>
<td>Self-management</td>
</tr>
<tr>
<td>Multidisciplinary team approach</td>
<td>Consent and capacity</td>
<td>Fewer interdisciplinary resources</td>
</tr>
<tr>
<td>Family based income decisions and insurance coverage</td>
<td></td>
<td>Individual based income criteria and insurance coverage</td>
</tr>
</tbody>
</table>

\(^1\) YSHCN are defined as: Children and youth who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.
It is important to distinguish between transition, and transfer of care. Transition is the purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult oriented health care (Blum, 1995). Transfer of care is the one time hand off from pediatric to adult services (see Appendix A: Terms & Definitions). While a transfer of care may occur, inadequate planning may result in poor transition (i.e. fragmented, discontinuous, and or developmentally inappropriate care), which may negatively impact the health and well-being of the individual.

“The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound before and throughout the transfer of youth into the adult system”

Kaufman et al., 2007, p. 786.

Although YSHCN represent a relatively small proportion of the population they account for a disproportionate amount of health and other services. For example, in Nova Scotia 6.9% of youth with one or more chronic disease accounted for 16.7% of health care services used by all youth (Manos, Talbot, MacKenzie, Hennen, MacDonald, & NSYOUTHS Research Group, 2007). Furthermore, with earlier diagnosis and continued medical advancements, it is reasonable to expect that this small, yet high needs population will grow. As such, it is important to take a proactive approach to identifying and reducing barriers for YSHCN to experience an effective and seamless transition to adult based services.

Purpose

The purpose of this work was to explore the current state of transitions from pediatric to adult-based services for YSHCN in Nova Scotia, and identify key issues and opportunities for improvement. More specifically, the following objectives have been identified:

- To determine the processes, barriers and opportunities that exist around transitions from pediatric to adult-based health services across the province
- To engage key stakeholders in the process to obtain the information above, and facilitate change and improvement
- To share knowledge and experiences from across the province
- To work towards a common provincial approach to effectively transition patients from pediatric to adult-based services
Methods

In order to fulfill this purpose, the Policy Communications and Decision Support team of Health Association Nova Scotia undertook a broad stakeholder consultation. Interviews and focus groups were conducted and a survey for family physicians was administered over the period of January 2014 to June 2014 (for full stakeholder list see Appendix B). Stakeholders were representative of the full continuum of health services as well as relevant non-health services, and some provincial and national initiatives outside of Nova Scotia. The specific sectors represented include:

- **Continuing Care sector** including nursing home and home care agency administrators, care coordinators, VPs Community, Medical Directors of Continuing Care, District Directors of Continuing Care
- **Primary Care** including Family Physicians, VPs Community and the You’re in Charge program
- **Community Services** including Adult Residential/ Regional Rehabilitation Centre and Adult Service Centres
- **Acute & Tertiary Care** including Provincial Programs, VPs Clinical and a Program Manager for Speciality Services
- **Government Departments** including branches of the Department of Health and Wellness (primary care, acute and tertiary care, continuing care, and mental health and addictions and children’s services), Services for Persons with Disabilities through the Department of Community Services, as well as the Department of Education.
- **Provincial and National Initiatives and Programs** including the Canadian Association of Pediatric Health Centres, BC ON TRAC (Transitioning Responsibly to Adult Care) Program, SickKids’ Good 2 Go program, and Ontario’s Provincial Council for Maternal and Child Health.

A scan of academic and grey literature was also completed to determine best practices where they exist and support development of recommendations. A scan of Nova Scotia specific programs, policies and reports that directly or indirectly influence transition was conducted to understand the history and current context of the issue and to avoid duplication of effort.

Interview and focus group data was synthesized and analyzed using a recursive abstraction method. The survey was conducted and analyzed using Select Survey. Significance testing was not done due to low response rates.

The scope of this work excluded data collection from patient/parent groups. While it was recognized that this is a key stakeholder group, as they themselves are the recipients and managers of care, it was not feasible due to time and resource constraints. Attempts were made to solicit information from this group through mailed interview questions, however none were returned. Although tertiary care services are provided for some patients outside of NS, only in-province stakeholders were consulted. The transition process for healthy, typically developing youth was not included.

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2 Given the significant work done through CDHA and the IWK a broader consultation process including pediatric and adult specialists was not conducted so as to not duplicate effort.

3 Potentially interested patients and families were identified through Caregivers Nova Scotia. No direct patient or family contact information was given to Health Association Nova Scotia
What We Know

A Scan of the Literature on Transitions from Pediatric to Adult-Based Health Services

In order to shape interview, focus group and survey questions, a scan of academic and grey literature was conducted to determine predictors of successful and unsuccessful transitions, and to identify promising and leading practices where they exist. A scan of literature and existing programs revealed several factors which influence the transition process and outcomes. The consulted literature converged on several main influencing factors (see Table 2). Furthermore, the importance of many of these factors was corroborated through our stakeholder consultation process.

Table 2: Factors Influencing Transition from Pediatric to Adult Based Services

<table>
<thead>
<tr>
<th>Influencing factor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Readiness &amp; timing</td>
<td>Timing of transition should be agreed upon by patient, family and providers, and should occur during a time of stability. While varying ages are suggested for the initiation of transition planning and actual age of transfer, readiness is a more important factor than chronological age.</td>
</tr>
<tr>
<td>Preparation &amp; education</td>
<td>In order to ensure readiness, there are pre-requisite skills that youth should have, and have had time to practice in order to successfully transition to adult oriented services (e.g. patients have knowledge of their condition, self-management and advocacy skills, awareness of program changes, such as funding, eligibility criteria etc.).</td>
</tr>
<tr>
<td>Provider attitudes and training</td>
<td>Pediatric providers are able to cede control to patients, family physicians and adult providers. Adult providers and family physicians feel confident to care for these patients. All providers are able to provide developmentally appropriate care, have realistic expectations and are comfortable with dealing with adolescent specific issues as they may relate to the illness.</td>
</tr>
<tr>
<td>Attitudes of parents</td>
<td>Parents encourage independence of youth as appropriate and are aware of their role as their adolescent ages, including issues with consent and information sharing.</td>
</tr>
<tr>
<td>Supply of health care providers</td>
<td>There may not be an equivalent adult provider for patients to transition to, especially for “childhood diseases”. The youth is able to find a family physician willing to take them on, and preferably was involved in their care prior to aging into adult system.</td>
</tr>
<tr>
<td>Supply of supportive programs</td>
<td>There may not be equivalent or adequate programs for young adults as they transition or eligibility criteria may change from childhood to adult based programs (e.g. finding adult day services, changes in insurance and funding criteria for certain programs or services).</td>
</tr>
<tr>
<td>Collaboration, communication and information flow</td>
<td>The services providers, including those outside of health, which serve this population work collaboratively to meet the needs. This collaboration is enabled through regular communication and information flow (e.g. joint meetings, electronic records etc.).</td>
</tr>
<tr>
<td>Involvement of patients and families</td>
<td>All care and decisions involve the patient and the family as appropriate, ensuring their preferences and needs are incorporated into the transition plan.</td>
</tr>
</tbody>
</table>

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4 This table is based on the following: Callahan, Feinstein Winitzer & Keenan, 2001; Rosen et al, 2003; Betz, 2004; Kaufman et al., 2007; and Paone & Whitehouse, 2011.
and are developmentally appropriate.

<table>
<thead>
<tr>
<th>Administrative and Policy Support</th>
<th>Having formalized tools such as checklists, policies, registries (e.g. knowing how many individuals and who will be transitioning over a given period of time), having compatible age and eligibility criteria across services and sectors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual level factors</td>
<td>Ability to self-manage, engage in care, risk taking behaviours, diagnosis (e.g. those with more complex conditions or those affecting the nervous system have less successful transitions) also influence the transition process.</td>
</tr>
</tbody>
</table>

**Outcomes of Transition Initiatives**

Although research and outcome evaluations of transition planning and programs are limited, there is evidence to suggest that inadequate transition planning is associated with poor patient and system outcomes. For example:

- **Developmental milestones**
  - Those without a specific intervention may differ from healthy peers in achieving milestones for adult life, such as graduating college, being employed, having lower incomes and increased odds of receiving public assistance (Bloom, Kuhlthau, Van Cleave, Knapp, Newacheck & Perrin, 2012).

- **Poor adherence to treatment**
  - 50% of young adults with complex congenital heart defects did not successfully transfer to adult care (Reid, Irvine, McCrindle, Sananes, Ritvo, Siu & Webb, 2004)
  - Only 40% of asymptomatic patients with ulcerative colitis who were transferred adhered to their medication schedule (Watson, 2000)

- **Poor clinical outcomes**
  - Higher depression scores (Bloom et al., 2012)
  - Unexpected graft loss in 35% of kidney transplant patients within 3 years of transition (Watson, 2000)

Conversely, positive outcomes for various transition interventions have been documented.

- **Continuity of care**
  - Graduates of a Kentucky based transition program were more likely to report a usual source of care and less likely to be uninsured (Bloom et al, 2012)
  - Those who were introduced to a diabetes specialist before transition had more regular clinic attendance 2 year post transition (Bloom et al, 2012)
  - The use of a system navigator reduced the adult care dropout rate from 40% to 11% for youth with diabetes (Van Walleghem, MacDonald & Dean, 2008).

- **Reduced anxiety about transition process**
  - Patients who were introduced to adult clinic before transfer reported significantly fewer concerns about leaving their pediatric provider (Bloom et al., 2012).
  - The Good 2 Go program reports patients and families have decreased anxiety regarding their transfer to adult care (Canadian Foundation for Healthcare Improvement, 2013, SickKids, 2014).
Clinical outcomes
- Those who attended a young adult clinic for diabetes had decreased HbA1c levels and lower hospital admission for ketoacidosis (Bloom et al., 2012)

Uptake and satisfaction
- The Young Adult Rheumatoid Diseases (YARD) clinic had a 94% attendance rate (LaBrie, Kiefer, Miettunen, Fahlman, Johnson, Crawford & Lupton, 2008)
- 85% of Lifespan clinic attendees use the Growing Up Ready tool, with high satisfaction rates (95%) (GTA Rehab Network, 2010).

As demonstrated above, there are several positive outcomes associated with transition planning. However there is limited information available on the long term impact of specific transition programs and initiatives. Many programs that do exist are in the early stages of evaluation and primarily focus on process and output measures. Furthermore, causal relationships between initiatives and successful transition are relatively unknown (Betz & Smith, 2010). As transition programs are developed, evaluation must be a key focus from the beginning, with defined evaluation questions and program goals. Furthermore, expected outcomes must also be reasonable for the particular condition and its trajectory.

Leading Practices & Current Initiatives

In the absence of empirical evidence, clinical and subject matter experts have developed consensus on what constitutes best practice in transition planning (Hamdani, Kingsworth, Healy, 2006); these are:

- Organizations should adopt a formal transfer approach & process
- Establish a clear procedure for transferring youth.
- Establish methods for communication & information sharing.
- Develop skills & knowledge of youth & families for engaging in adult services.
- Provide support for youth & parents in preparation for transition.
- Prepare & support youth, families & organizations for a shared management approach in transition planning.
- Support parents & service providers in respecting the role of youth as they take on more responsibility.
- Transfer knowledge about best practices for transition to professionals.

While these are broad in nature, they provide a foundation for those working with YSHCN or developing transition initiatives. There is a multitude of initiatives and approaches around transitions for YSHCN, nationally, in other jurisdictions and locally. Many of such programs are at the hospital or institution level (see Appendix C for an overview of transition programs and initiatives). Given that the purpose of this particular work is to provide a provincial lens to the issue, particular attention has been paid to broader initiatives at a community or provincial level.
Nationally

Our work regarding transitions for YSHCN is timely given this has been identified as a priority topic at a national level. The Canadian Association of Pediatric Health Centres is currently working towards national guidelines with the input and expertise of stakeholders across jurisdictions. The intent of the guidelines is to be high level enough to be applicable across illnesses and across the continuum of care, but still be specific enough to be useful.

Provincial Approaches to Transition

Ontario

Ontario’s Provincial Council for Maternal and Child Health has identified transitions as a priority topic. A working group has been convened with the mandate to make recommendations to the Council for taking a provincial approach to the transition to adult services for youth with chronic and/or complex clinical conditions. The recommendations are intended to be foundational, so that they can be adapted and built upon for particular patient populations, organizations, geographies etc. The recommendations focus on early planning with emphasis on YSHCN building self-management skills and acquiring knowledge about their illness and the adult healthcare system (Gorter & Weaver, 2013) (see Appendix C for full set of recommendations). In conversation with representatives from the council it was noted that, although the recommendations may seem conspicuous, they are still necessary as these actions are still not fully implemented at a provincial level.

Alberta

Similarly, Alberta has established a Policy Framework for Children and Youth with Special and Complex Needs (Alberta Children and Youth Initiative Partners, 2003). The Framework, developed by several government ministries (Children's Services, Health and Wellness, including Alberta Mental Health Board, Learning, Community Development, Persons with Developmental Disabilities), identifies four broad policy directions in order to promote collaborative, coordinated and consistent service delivery and long term care planning for children and youth with special needs, and their families (see Appendix C). Although developed over a decade ago, it is not clear the degree to which this framework was implemented or has influenced the transition process for YSHCN.

British Columbia

In British Columbia, a Cross Ministry Transition Planning Protocol for Youth with Special Needs was developed in 2009 (Government of British Columbia, 2009). The protocol consisted of nine government organizations as signatories, including six ministries and BC Housing, Community Living BC, and the Public Guardian and Trustee. The protocol was developed to improve access and coordination of services and establish agreed upon roles and responsibilities of signatories to support the transition of youth with special needs (aged 14-25) to adulthood (See Appendix C for the protocol). While encouraging, concern has been expressed that its potential is not being realized as it is not clear if and how the protocol is being implemented (Inclusion BC, 2011).

The On TRAC (Transitioning to Adult Care Responsibly) program in BC is also provincial in nature. This is
likely in part due to the provincial delivery of specialized health and disability services through the Provincial Health Services Authority. The program uses a developmental transitional framework which articulates appropriate developmental issues and goals based on different stages (early, middle and late adolescence, and recently, emerging adulthood, covering the years of 10-24) (Paone & Whitehouse, 2011). Work is currently being conducted to implement clinical practice guidelines in pediatric and adult community settings, There is ongoing collaborative work with BC Medical Association (BCMA) and the BC Ministry of Health focused on attaching youth and young adults with Family Practitioners who have the interest and capacity to provide a Medical Home for complex youth who present with high-intensity care demands (On TRAC, 2013).

**Nova Scotia Context**

*Demographic Profile*
While Nova Scotia’s demographic is typically better known for its aging and senior population, youth under the age of 20 made up nearly 20% of population in 2014 (Statistics Canada, 2014). Although YSHCN comprise a small proportion of the overall population, they account for disproportionately high service utilization. For example, according to a 10-year audit covering 1995-2004, only 6.9% of youth had at least one chronic disease, yet accounted for 16.7% of health care services used by all youth (Manos et al., 2007). Of those 6.9%, the specific illness breakdown can be seen in Table 3. Furthermore, disability rates in general are higher in NS compared to the national average, including those 0-14 years of age and those 15-24 (Disabled Persons Commission, 2008). As can be seen in Table 4 rates of disability in NS youth appear to be increasing. Anecdotally, this has been attributed to earlier diagnosis and intervention.

*Table 3: Illness Profile of Youth (12-24) with Chronic Conditions in Nova Scotia*^5^

<table>
<thead>
<tr>
<th>Illness</th>
<th>Percentage of youth with chronic conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>25.0%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>2.0%</td>
</tr>
<tr>
<td>Congenital Heart Disease</td>
<td>8.7%</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>0.6%</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>40.6%</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>17.9%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>9.5%</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>5.2%</td>
</tr>
</tbody>
</table>

*Table 4: Disability in NS Children & Youth*

<table>
<thead>
<tr>
<th>Age</th>
<th>Year 2001</th>
<th>Year 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>3.5%</td>
<td>4.5%</td>
</tr>
<tr>
<td>15-24</td>
<td>5.3%</td>
<td>6.5%</td>
</tr>
</tbody>
</table>

^5 These figures represent the illness category of those youth living with one or more chronic condition, not of the entire youth population.
Although the data are informative about the prevalence and diagnoses of youth (see Table 3), they are over a decade old. Anecdotal evidence from stakeholder consults suggests that illness profile of this population has been changing (e.g. fewer cases of spina bifida, and more cases of autism). However finding up to date data on this population is challenging; a sentiment echoed throughout our stakeholder consults. In order to adequately plan for YSHCN as they age, it is integral to know the prevalence and incidence of this population, their diagnoses and where they reside.

Policy & Program Review

The concept of transition planning for YSHCN and its importance is not new in Nova Scotia. Several reports and strategies spanning various government departments and interest groups have acknowledged and expressed concern around this issue and/or made recommendations (see Appendix D). While the majority of efforts have been illness or sector based, several of these report recognize the need to align policies and integrate service delivery across the continuum of care and support through which this population receives services.

A scan of Nova Scotia policies and practices currently in place regarding transition for this population was conducted. A request was made through the provincial OP3 group (One Province, One Policy, One Procedure) to gather any district specific polices around this population. Departments of Health and Wellness, Community Services and Education websites were also searched for relevant reports and policies. For a full review of provincial policies and initiatives that directly or indirectly influence transition for this population, see Appendix E).

District-based policies and guidelines that exist around transition are currently all specific to Mental Health and Addictions, with the exception of the IWK transition policy and procedure (in draft) which is not disease specific (see Box 1). However, not every district reported having relevant policies, or other guidelines or tools around transition of this population, and the ones that do are at varying levels of implementation. All that do exist speak to the importance of patient readiness and that a collaborative approach is taken with service providers, patient and family. However there are variations across policies with respect to involvement of family physicians, and the specific timing and ages of transition specific meetings and referral to adult services (e.g. 4-6 months before 19\textsuperscript{th} birthday), while others do not specify. The impetus for these policies is likely, in part, attributable to the 2010 Auditor General Report which recommended that DHW have a policy around this issue (Office of the Auditor General, 2010). The Department’s response was to direct the DHAs to adopt a formal policy process around this issue. Throughout our consultation process it was suggested that the next time the Mental Health Standards are reviewed, having a formal process in place will likely become a Standard. In addition to the mental health district based polices, a five year project is being implemented in HRM focused on transition from pediatric to adult mental health services, in addition to partnering with universities (see Staying Connected Mental Health Project in Appendix E).

\footnote{This review is not intended to be a comprehensive review of all transition related policies, programs or initiatives that exist; but rather a scan of the work that has been done previously to provide context and history of the issue.}
**Box 1. Highlights from IWK’s Policy: Transition from Paediatric to Adult Health Care**

- Shared Management Model
- A focus on engagement of both current and future providers
- One healthcare provider must hold specific responsibility for the broader context of care coordination and health care planning through the transition
- Includes the following tools
  - Readiness checklist
  - Transfer checklist
  - Early, Middle and Late Transition Plan Templates

IWK Policy (in draft), N.D.

**Provincial Programs and Services** that address transition include a focus on self-management skills, as well as a comprehensive transition handbook with several resources and tools for transition from pediatric to adult services for diabetes. Resources provided in the handbook are broad in scope, including information and tips for school work and social issues. The You’re in Charge program for youth 13-15 with a chronic disease aims to prepare youth and their families for transition and focuses on building self-management skills. While not directly related to transition, Building a Better Tomorrow Together workshops, funded through the primary care branch of DHW provide education to health care providers and collaborative teams on a variety of topics, one of which is focused on chronic disease self-management.

**Continuing Care** policies and programs that exist have some age stipulations, while others are provided across the lifespan. Specifically, home care, home oxygen, IADL support and the community bed loan programs do not have age stipulations that may impact this population as they transition. Similarly the LTC placement policy does not have age requirements. The exception to this would be Evergreen Home for Special Care, which offers continuous care across the lifespan; however has a separate specialized facility for children, in addition to an adult nursing home. Although some of these programs do not have age based stipulations, it has been suggested that seeing younger populations in continuing care settings is rare relative to geriatric clients, and as such, facilities or services may be limited in the care they can provide to this population. Programs and services which do have age stipulations are the Self-Managed Care Program (clients must be 19 or over and have cognitive capacity) and the Supportive Care Program (clients must be 65 or older and lack cognitive capacity). The Adult Protection Policy covers those over the age of 16.

**Services for Persons with Disabilities**, through the Department of Community Services also provide a number of supports for those with intellectual, developmental and physical disabilities and dual diagnoses. The Direct Family Support program provides funding for children and adult children living at home with their families. The main differences between the child and adult programs are eligibility criteria and some funding parameters. Both are income tested, however the children’s program is based on family income, whereas the adult program is based on individual income. The children’s program may provide funding for child care costs for those over the age 12; the intent is to provide support for
costs associated with the child’s disability, not the costs that would typically be incurred raising a child. The Adult program also may provide a personal allowance which is not offered through the Child program. Residential care is also offered through DCS for those with disabilities who meet the criteria.

Given the overlap of both home and facility based services for those ongoing care needs between DHW Continuing Care and DCS Services for Persons with Disabilities, it was noted several times throughout our consultation process (see What We Heard), that there is need for clarification and collaboration from both departments. As can be seen from Table 5, there are programs and services with age stipulations which has the potential for someone with ongoing needs across the lifespan to be bounced between both departments. Respite services in particular have been identified as critically important to this population and their caregivers, especially as they age. As can be seen in Table 5 there are multiple access routes to accessing respite, however it may not be clear as to which is the most appropriate.

There is a joint DCS and DHW funding arrangement whereby the (DCS) Care Coordinator identifies the sources of funding and services available through DHW and ensures there is no duplication of funding or service for those who are receiving assistance from both departments.

Table 5: Continuing Care and Services for Persons with Disabilities Across the Lifespan

<table>
<thead>
<tr>
<th></th>
<th>Child</th>
<th>Adult</th>
<th>Lifespan (no age stipulations)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Individual living support program (up to 65)</td>
<td>Home Oxygen</td>
</tr>
<tr>
<td></td>
<td>Home based respite (Through DFS)</td>
<td>Home based respite (Through DFS)</td>
<td>IADL Program</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Community Bed Loan</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Home Based Respite (Through Home Support Services)</td>
</tr>
<tr>
<td><strong>Residential</strong></td>
<td>Evergreen (Through DHW Placement Policy)</td>
<td>ARCs/RRCs</td>
<td>Long Term Care Placement Policy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Residential Care Facilities</td>
<td>Small Options Home(^7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community Homes</td>
<td>Facility based respite (Through LTC Placement Policy)</td>
</tr>
<tr>
<td><strong>Educational/ Vocational</strong></td>
<td>School based services and supports (Special Education Policy: Schools to Community transition planning begins in Junior High. Many stay in the school system until 21)</td>
<td>Adult Services Centres (Include vocational training and adult day programming)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adult Day Programs (offered through DCS Licensed facilities)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adult Day programs offered through DHW licensed facilities and home care agencies)</td>
<td></td>
</tr>
</tbody>
</table>

This table was created based on the current Provincial Home Care Policy, Long term Care Placement Policy, Services for Person with Disabilities Program Policy, and Special Education Policy.

\(^7\) While at a provincial level there are no age stipulations for small options homes, some service providers have youth and adult specific homes.
The Education sector also provides support for transition planning through their Special Education Policy. According to section 2.7 of the policy, school to community transition planning should begin in junior high. Transition outcomes are incorporated in the student’s Individualized Program Plan (IPP) or cumulative student record if an IPP does not exist. While not specific to transition planning for YSHCN, Youth Health Centres and Schools Plus exist in many schools across the province to coordinate and deliver health and support services. Youth Health centres provide health education, health promotion, information and referral, follow-up and support, as well as some clinical services in a school setting. Schools Plus helps coordinate services delivery across government departments for youth and their families.

What We Heard

System Level Themes

Throughout our discussions with stakeholders, there were several system level themes with broad impact that became evident regardless of who we spoke with, or the sector they were representing.

Collaboration and Communication

By far the most commonly mentioned influencing factor identified in the transition process was the importance of establishing relationships and collaboration amongst the different health care providers (e.g. Family Physician, pediatric and adult specialists etc.) and sectors (e.g. Health Authorities, Continuing Care, Community Services, Education, etc.) that the individual and their family must navigate. Most important was each of those providers establishing relationships with the individual and their families in order to deliver care and services based on their needs, and individual preferences. It is these relationships that are the necessary pre-requisites for the communication and collaboration required to plan, navigate and deliver the appropriate services for YSHCN. Relationships that were most commonly acknowledged as needing concerted and strategic focus were between health and community services sectors, between family physicians and specialists (pediatric and adult), and between health and education sectors. Collaboration was discussed as it relates to person-centred care and service delivery. It was often noted that collaborative relationships with a mutual understanding of one another’s role in the transition process, are a pre-requisite to person-centred care and service delivery. Conversely, it was noted that where these relationships do not exist, person-centred care is impeded. As one stakeholder put it:

“If we’re truly doing patient-centred care, this [transitions] shouldn’t be difficult”
-Consultation Participant

Recommendation 1: Build a model of service delivery that is person-centred, holistic and based on collaborative relationships between services and providers. There needs to be a mutual understanding of one another’s services and priorities between the providers and services delivered to this population (e.g. health, community services, and education). Based on stakeholder consults, particular focus should be paid to clarifying the roles and relationships between the following services and providers:

- community services and health
Provincial Child and Adolescent Health Focus

“*We don’t have a provincial maternal and child focus, we have an IWK focus*”
- Consultation Participant

A broader underlying topic that several stakeholders commented on was a perceived lack of a provincial focus on child and adolescent health in general. Several stakeholders expressed uncertainty as to what the role of health authorities and other service providers, especially those outside the IWK, are in child and adolescent health. It was further noted that, in general, there needs to be more of a “kid-specific” lens applied to program and service decisions. It was felt that this lack of focus and lack of role clarity hinders the transition process for YSHCN.

Tertiary Services

While the specialized role of the IWK was highly commended and appreciated, some frustration was expressed over a lack of collaboration and support in the community for YSHCN. Some described this as being excluded from the care of this population, thereby limiting the ability for other service providers to build skills and relationships necessary to care for and support this population when they are no longer under the auspices of the IWK. Many tertiary services, including those at the IWK, are provincial in nature, and it was felt that part of that role should be to support primary and secondary care providers who also care for these patients. It was suggested that having a concentration of expertise in one area of the province, while helpful, has in some ways limited the development of local expertise needed to care for these youth. Furthermore, several stakeholders from primary and continuing care indicated that having timely access to a specialist is a critical factor for them to be able to assume the care or support of YSHCN.

Volume & Critical Mass

Many stakeholders outside of tertiary services (e.g. primary care, continuing care, rural districts) acknowledged that seeing relatively low volumes of YSHCN was a barrier to providing care to this population. However it was also noted that transitions may be less complex outside of the IWK and Capital Health as the pediatric or child service provider likely works in the same building or may even be the same person in smaller areas with fewer specialized services.

Health System Restructuring

Multiple stakeholders questioned what the impact of the health system restructuring in Nova Scotia will be on this particular issue. As the existing nine district health authorities are merged into one, with the IWK remaining separate, several opportunities and threats of this transformation were identified. It was suggested that this may provide an opportunity for child and adolescent health to become more of a focus in the province, by providing a more “level playing field” for the IWK. It also may provide a window...
of opportunity to examine what the roles of the IWK and the new health authority are in child and adolescent health, and more specifically transition to adult health. Having fewer administrative structures may also enable better collaboration between the IWK and the rest of the health system. However there were some doubts expressed over the restructuring and its likelihood of improving the transition process for this population. It was suggested that by keeping the IWK separate, there may continue to be a dichotomy between child and adult health services in the province. Furthermore, it was noted that restructuring may be more of a hindrance to the issue as time and focus is dedicated to the transformation, at the expense of other issues.

**Recommendation 2:** Enable a provincial approach to transitions from pediatric to adult-based care for YSHCN through clarified roles of the IWK and the future Health Authority. Specifically, the following actions should be taken:

2.1. The Senior Leadership Teams of the IWK and the future district, when established, meet to build consensus and define what their respective roles and responsibilities are in the provision of health services to YSHCN, particularly as they transition from pediatric to adult based care.

2.2. The IWK, future Health Authority, and representation from Department of Health and Wellness, Acute and Tertiary and Primary Care branches, and other stakeholders as appropriate, define the role that tertiary services play in supporting primary and secondary care.

In defining roles and scope of the IWK, the new Health Authority and tertiary services in supporting primary and secondary care, the relatively simplified transition process that currently occurs in smaller districts should not be overlooked.

**Lack of Data, Information & Planning**

As previously mentioned, a commonly identified barrier to smooth transitions is a lack of data and information available about this population, and where it does exist, barriers to sharing information. Several stakeholders indicated that the relative numbers and location of youth that will require ongoing care throughout their lives is not readily known or easily accessible. It was also identified that on a broad, system level, having this data is important for planning current and future services and their location. Where data and information does exist on an individual level, several stakeholders indicated that flow of information between service providers was an issue. For example, it was noted that information flow between family physicians and specialists was sometimes a barrier and that follow-up appointments might occur before the information had been received by the family physician. As noted in several reviews of transition, having interoperable electronic health records (EHRs) was noted as an enabler to transition. With cases that transcend the health sector, the Personal Health Information Act, while generally recognized as positive in protecting privacy, was noted as a barrier to information sharing by some.

The vast majority of stakeholders on the receiving end of transitions noted that they are often not involved with this population until they are “on their doorsteps”, whether it be an Adult Residential Centre, Nursing Home, Adult Service Centre, or even the Family Physician after having limited involvement with the patient while in the pediatric system. Where there were examples of advanced
planning, it was often noted that it was a facilitator in the transition process for both the individual, family and the care providers. Those on the receiving end of transition without advanced involvement expressed frustration over their lack of ability to appropriately prepare for the individual, which sometimes may require additional staff training or equipment.

**Recommendation 3:** Gather and use data on YSHCN to optimize early planning and seamless service delivery on a system and case level basis. Specifically, the following actions should be taken:

3.1. Establish a method to gather, track and monitor the rates, diagnoses and geographic locations of YSHCN. Ideally this would be done through one central agency, or as a collaborative effort between several agencies (i.e. IWK, DHW, DOE, DCS, Youth Ombudsman etc.) with one main access point.

3.2 Include services and providers on the receiving end of transition early in the planning process. This should happen on a case by case basis (e.g. school and adult service centre, pediatric specialist and nursing home), as well as an aggregate level to facilitate systems planning (e.g. school board shares number of students who will require community services supports after they exit the school system).

3.3 Ensure timely and efficient flow of information between services providers through the use of interoperable information systems and streamlined consent processes where applicable. For example, Schools Plus developed a common Consent Form which streamlined the administration of consent across the various service providers involved in Schools Plus. Furthermore, legislation has been passed in New Brunswick which will make it easier for some government departments to share personal information with other government departments for the purpose of integrated service and delivery.

**Age Limitations & Specifications**

Regardless of who we spoke with, clarity and appropriateness of age cut-offs for pediatric services was brought up. There was particular concern expressed around the different age cut-off for mental health services compared to other services. Currently, the age of transfer in Nova Scotia is 16; however the age of transfer for mental health services is 19. This has created confusion for many providers and patients, especially for those caring for individuals with mental health comorbidities. This leaves a potential three year gap where these youth may get bounced between pediatric and adult services, during times of great vulnerability. Furthermore, it was suggested that having two different ages of transfer created uncertainty amongst providers. For example, an adult specialist working in a physical specialty may not see a seventeen year old because they are under the impression that the transfer age is 19.

“*kids 16-19 can really get lost in the system*”

-Consultation Participant

In addition to having two different age cut-offs, another common concern was around what the “right” age of transfer is and, if age was even an appropriate determining factor. Across provinces the age of transfer is typically 18. Some stakeholders felt it would be prudent to align age with other provinces and also “natural” transitions that often occur around 18 (e.g. transitioning from high school to university).

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9 An Act Respecting the Delivery of Integrated Services, Programs and Activities
However, others felt doing so would create too much chaos during that period, and that the pre-requisites to actively engage and manage their own care, requires more advanced reasoning and decision-making skills that may not present until later adolescence. As such, older cut-off ages were also suggested (e.g. 21 or 25). Some expressed concern that a specific age of transfer may be too arbitrary and rigid, and there should be more flexibility to allow transfer to occur when the patient is ready. There are currently limitations to such an approach, such as performance measurement structures (e.g. reducing “over-age” patients at the IWK), and physician billing criteria (e.g. a pediatrician who sees a 17-year-old can only bill at the lower rate of a family physician). A report from the Pediatric Complex Care Coordination Expert Panel in Ontario specifically recommended that the Ministry of Health and Long-Term Care allow pediatric patients to access specialized child- and youth-focused services beyond 18 years of age, depending on the needs of the youth and family (Rosenbaum, 2008). Specifically, it was suggested that needs could be met through a dedicated program of care during the transition years, defined as 16-25.

**Recommendation 4:** As recommended through previous reports and reviews, streamline the age of transfer across all specialities and ensure that age is communicated to necessary stakeholders. While having a specific age of transfer can reduce confusion and standardize processes, some flexibility should be applied when it is in the best interest of the patient without punishing the patient or care providers.

**Knowledge & Skills to Appropriately Care for YSHCN**

A common underlying theme suggested by stakeholders was a paucity of knowledge and skills to appropriately care for YSHCN. There were several areas in particular that were suggested by stakeholders as having current knowledge and skill gaps that need to be addressed.

**Adolescence as a Speciality or Transitional Stage**

In congruence with concerns around age specifications, many stakeholders identified the distinctive needs of adolescents in general and even more so for those with special health care needs. It was suggested that adolescence is unique enough to warrant special attention around this period, and that lumping this period within children’s health or adult health services may not be appropriate. Many adult based health care providers may not feel comfortable or have the knowledge to treat this age group which has needs, distinctive from more mature adults. In addition to unique psychosocial needs, it was also suggested that there are important physical differences, namely that brain development is ongoing during adolescence which warrants a different approach or expectations of care and self-management. It is also important that care providers are able to distinguish between illness related behaviours and adolescent related behaviours. Some regions have developed adolescent medicine as an independent sub-specialty. Further, some approaches to transition planning are based on having a separate transitional stage for adolescence and recognize “emerging adulthood” (18-24) as a separate developmental phase (e.g. On TRAC, Young Adult Rheumatic Diseases Clinic). Regardless of different potential strategies to care for adolescents, it was acknowledged that this is a current knowledge gap for many care providers which need to be bridged in order to provide developmentally appropriate care.
**Autism and Developmental Disabilities**

Adults with autism and other developmental disabilities are an emerging population that many stakeholders across the continuum of care and support have expressed concern about. It was felt that there needs to be more preparation and planning for this population as they age, including knowing the magnitude of this population. There was an identified need for intensive skills and training for this population as they age, particularly for challenging behaviours. Although there is an abundance of work and strategies to address challenging behaviours for seniors with dementia, it was suggested that this population warrants further research and a distinctive approach, especially given the safety implications as these individuals are typically physically stronger than seniors with behavioural issues.

**Family Physicians & Adult Specialists**

Generally, it was suggested that those on the receiving end of transitions need to have the knowledge and skills to care for YSHCN as they age. This was particularly true for family physicians and adult specialists who take on these patients. Several stakeholders commented on the importance of having family physicians that are knowledgeable and comfortable providing care for YSHCN throughout the lifespan. Despite this importance nearly half of family physicians who responded to our survey disagreed that they have the necessary knowledge to care for YSHCN (see What We Heard: Primary Care p. 28). It was also specifically identified that there needs to be support for advanced level training of FPs in developmental disabilities.

**Recommendation 5: Create training opportunities and build knowledge and skills for service providers to appropriately care for and support YSHCN. Priority topics and providers identified were:**

5.1 **Build pockets of adolescence expertise.** While it may not be feasible or sustainable to treat adolescent medicine as a sub-speciality in and of itself within Nova Scotia, having designated providers across the continuum of care who can either directly care for this population, or act as a resource to their care providers. This can be facilitated through ensuring this period is adequately covered in undergraduate and training curriculum of health providers, and through providing specific continuing professional education on this topic.

5.2 **Build and share knowledge and skills for providers of adults with autism**

This can be done through the creation of educational opportunities and through sharing of existing knowledge and expertise in the province (E.g. Nova Scotia Autism Centre, Breton Ability Centre).

5.3 **Build knowledge and expertise of YSHCN within family physicians and adult specialists.**

This could be done through incorporating education about YSHCN and transitional care in undergraduate training as well as continuing medical education opportunities. One stakeholder suggested a model similar to maternal care. Although not every family physician will deliver babies, they can refer to a family physician that will. A similar set up for YSHCN could facilitate the development of a pool of family physicians who will care for these patients.

**Navigators**

The concept of having a designated navigator or coordinator function was commonly identified as a potential enabler of transitions. However there was divergence amongst stakeholders with respect to what that role should look like, and the degree to which it is useful. While most had a positive reaction...
to the concept, a few felt that this is a “Band-Aid” solution which does not address the underlying complexity of the systems and services that must be navigated. It was also suggested that, where and how this role is positioned, will influence the impact. For example, it was suggested that primary care might be the best location for such a position, rather than having specialty specific navigators, in order to ensure navigation is across the continuum of care. Further to this point, it was recognized that many YSHCN are receiving services or programs through other sectors, such as community services or education, and consequently, having the ability to streamline navigation across those sectors would be beneficial. There was also concern that adding navigators may result in another layer of complexity to the process, especially for those with multiple providers in multiple sectors. The underlying sentiment expressed is that navigation of services and supports should be easier for youth and their families. It was also recognized there is an inherent injustice that those who require the most services, and are likely the most vulnerable face the greatest barriers to accessing those services due to their siloed nature. Generally the literature supports using a navigator. For example, the Maestro program which uses a navigator has seen decreases in adult dropout rates following transfer (Van Walleghem, MacDonald & Dean, 2008). However this is one outcome of one illness. The Society for Adolescent Medicine (Rosen et al., 2003) recognizes that having a designated professional who takes responsibility for the process as a principle of successful transition. However it does not imply that this necessarily has to be an added function; it could be someone who is already providing services. Having a transition coordinator was also identified as a best practice in BC’s Cross Ministry Transition Protocol (Government of British Columbia, 2009), however the definition used explicitly identifies that this role should be at a systems level.

**Recommendation 6:** Build consensus across providers, illness trajectories and sectors around the placement and scope of navigator functions. Having a separate navigator function may be necessary between some services, or opportunities may exist where such a function is built into a pre-existing role (e.g. family physician, care coordinator). Opportunities should also be identified where such a role can ensure a system or cross-sector lens.

A key element of navigation is awareness of the resources and supports that already exist for this population. Several stakeholders commented on the need to know what resources currently exist locally and provincially for this population, particularly during the transitional phase, and after transfer to adult based health and other services. The Community and Healthcare Resource Directory in BC is a province wide referral resource of physicians which has been described as “one-stop shopping” (Abbott, 2011). Having a similar resource for this population available to family physicians, pediatric specialists and anyone fulfilling a navigator role could be beneficial and ensure that potential resources and supports do not go untapped. It would be ideal to be able to link health, community, educational and vocational support available for this population, with identifiers of providers and services that have capacity to take on new patients or clients, and those that have particular expertise or interest in key areas (e.g. adolescence, developmental disabilities etc.).

**Recommendation 7:** Establish a directory of services available to pediatric specialists, family physicians, navigators and any other referring provider or organization. In order to capitalize on existing
infrastructure, there may be opportunities to build upon the 211 service that currently exists in NS.

**Differences between Child and Adult Service Environments**

The differences between child and adult care settings have been well-documented in the literature and corroborated through our stakeholder consults. The design and culture of adult services was noted by several stakeholders; particularly the lack of collaborative teams compared to those that exist in pediatric care, and the high degree of silos between different specialities. It was also noted that adult services tend to be more speciality or organ focused, whereas pediatric services tend to be more holistic in their approach. Recent work from a Joint CDHA-IWK Steering Committee on Transition Needs of Youth and Families (2012) recommended the establishment of a joint CDHA-IWK adult complex care clinic to serve the needs of those with developmental disabilities and complex co-morbidities, and help address this gap.

“We’re transitioning individuals with diseases, not the disease itself”

-Consultation Participant

**Recommendation 8:** Implement the previous recommendation made by the Joint IWK-CDHA Steering Committee on Transition Needs of Youth and Families to create a model of service delivery that appropriately cares for adults with complex care needs. While it was suggested this be a joint venture between CDHA and the IWK, namely pediatric and adult specialists and family physicians, this should be done with provincial focus. While a lack of critical mass may prohibit the replication of such a model outside of HRM, this model should be well linked to health and community services the individual can access in their local community if they are from another part of the province. Further, there should be telehealth capabilities to allow for the individual’s local family physician to take part.

Differences were also noted outside of the health sector, with several stakeholders indicating that going from a school based environment to community settings can be a stark contrast. Specifically, it was felt that there are fewer resources and supports on the adult side to fill the gap where these young adults would have gone to school. It was acknowledged that Adult Service Centres which help fill this gap are a beneficial, yet limited resource which youth, parents and other service providers may not even be aware of. A contrast between child and adult based residential services was also noted. The inclusiveness of schools was also contrasted to the labour market and the community in general, which is typically not as inclusive as the school system which these youth have become accustomed to. Part of the Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program is to address these labour market gaps (Department of Community Services, 2013). Of course the most concerning scenario is when the youth does not have a service or provider to go to on the adult side.

**Youth & Family Inclusion**

Evidence from Ontario found that, from the perspective of those who are transitioning, or have successfully transitioned, there were several barriers to care; namely, lack of access to specialists and allied health on the adult side (Young, Barden, Mills, Burke, Law & Boydell, 2009). It was also noted that
even when an adult provider exists; there is typically a sense of loss associated with leaving the pediatric provider. A salient finding from Young et al. (2009), which was echoed from our stakeholder consults, was the feeling of transitioning to nothing. A lack of professional knowledge and sufficient information was commonly noted as a barrier to transition, and contributing to uncertainty and anxiety around the transition.

“There’s no point in putting all that money into kids if you’re not going to continue it with adults”

-Parent of a YSHCN as cited in Young et al. (2009).

As with the other providers involved in their care, the youth and families need to have collaborative relationships with care providers. Firsthand information from patients and families was solicited through a mailed survey sent out by Caregivers Nova Scotia, however there were no respondents. While we were unable to obtain firsthand information from patients and Families, several stakeholders emphasized the importance of their involvement in the planning process and in the determination of transition related policies and programs. For example, the “You’re in Charge Program” relied on a youth and family advisory council which helped shape the location and delivery of the program.

**Recommendation 9: Include youth and parent representatives in the planning and design of transition initiatives and services to ensure they are person/family-centred**

**Sector Level Themes**

While the majority of issues and potential solutions we heard were system level in nature and common across stakeholder groups, there were several challenges and opportunities around transition for YSHCN which were unique to different stakeholder groups and sectors.

**Primary Care**

“There needs to be in general, more funding for upstream. If not, it will come back into the system when these kids are 20 and haven’t been taking care of their condition and haven’t been accessing the system”

-Consultation Participant

Given it is the front door to the health system, primary care plays an integral role in the overall health and wellbeing of individuals, even more so for those with chronic and complex conditions. Having consistent primary care throughout the lifespan is critical to smooth transitions. Stakeholders from the Primary Care branch of the Department of Health and Wellness, Family Medicine, You’re in Charge Program and VPs Community were consulted. The main concerns expressed around primary care were the development of self-management skills and involvement of family physicians.
Self-management & the Right to Risk

The importance of developing self-management and advocacy skills, before the youth transition to adult services was commonly noted across stakeholders. Those on the receiving end of transition felt as though this is something that needs to be developed far in advance of them receiving the client. The reluctance of both family members, and sometimes pediatric providers, to relinquish control and let the youth become more involved in their own care, was identified as a barrier to self-management. For example, a parent may want to continue to go to appointments or receive information about their child, who as a mature minor with capacity has the right to limit that involvement. Further to this point, as a mature minor with capacity, these individuals also have the right to risk which may negatively influence their care and health outcomes. It was felt that to reduce the impact of behaviours that could negatively affect one’s health (e.g. not going to follow-up appointments, not taking medications etc.), both parents and youth need to understand early on, and have opportunities to practice and be comfortable with youth taking on a more prominent role in their care, and to understand the consequences of not doing so. There are currently two initiatives that are specifically working to address the issue of self-management for this population at a provincial level

- **You’re in Charge Program.** This program, delivered in partnership between DHW Primary care, IWK and Dalhousie School of Occupational Therapy, is for early adolescents (13-15) with chronic health conditions and their families to help prepare everyone for transition. The program, which is designed to develop a foundation for self-management skills, typically takes place as a weekend camp, however the program has been adapted to one day workshops. The program focuses on four main self-management skills: being able to give a brief health history, recognizing warning signs, managing illness, and general wellness (e.g. sleep, physical activity etc.). Staff are available to participants for four weeks after the program to provide support. Parents are also involved and are able to discuss with one another and a facilitator relevant issues, such as distinguishing between illness related behaviours and adolescent behaviours. While the program has not been in place long enough measure to long term outcomes or effect on the actual transfer of care, early outcomes have been positive. The program has shown statistically significant improvements on behaviour domains for youth and knowledge domains for parents (Versnel, 2013, 2014). Qualitative findings indicate satisfaction, some behaviour changes and increases in knowledge and awareness. Despite being free for participants and having positive outcomes, the biggest barrier identified was a lack of uptake and difficulty recruiting participants.

- **Building a Better Tomorrow Together.** This is a continuing education program for health care professionals and teams which deliver a series of workshops. The main focus is to help providers learn new skills and increase confidence to collaborate with other professionals. One of those workshops is dedicated to chronic-disease self-management support. There are facilitators of these workshops around the province and there are fee-for-service codes that allow physicians to participate (Province of Nova Scotia, 2014).
The Role of the Family Physician

Both the importance and ambiguity of the family physician role in the transition process for this population was highlighted across stakeholder groups, including those outside of the health system and Family Physicians themselves. Given they often act as a gatekeeper to services, and have an ongoing relationship with patients across the lifespan, family physicians play an integral role in the care of their patients; even more so when care needs are higher and more complex. However, it was routinely noted that family physicians are often not optimally engaged with this population while they are receiving care from pediatric specialists. This becomes even more troublesome as these patients age out of the pediatric system into the adult system which tends to be more difficult to navigate, may have waitlists, and may not even have the specialist expertise required for the most complex patients.

A survey of family physicians (n=25) was conducted as were follow up interviews (n=2). While the survey was intended to be provincial in nature, the vast majority (72%) of respondents were practicing in CDHA. The most common themes emerging from family physicians are outlined below.

- **Importance of Transition.** 100% of survey respondents agreed that the transition process plays a critical role in the overall health and wellbeing of YSHCN. Further, over half of respondents (53%), indicated that they often think about how the process can be improved. Sixty-two percent indicated that they would be willing to take on new YSHCN as patients, however less than half of respondents (48%) indicated that they have the capacity to do so.

- **Role Clarity.** One of the most salient findings from both survey and interview data was a gap between what FPs believe their role should be and what their current role is; specifically that they should be more involved in the care of YSHCN than they currently are. For example:
  - The most common role descriptor for FPs in the transition process was as a passive recipient of information (43%), whereas the vast majority (96%) felt as though their role should be a collaborator on a multidisciplinary team.
  - 61% indicated that currently the pediatrician is typically the Most Responsible Practitioner, but 57% indicated that the Family Physician should be.
  - The majority (70%) of respondents indicated that they has never attended a transition clinic or joint appointment with a pediatric and adult provider to discuss transition.

Several respondents, as well as many other stakeholders outside of family practice, described a common scenario: when children are diagnosed and referred to specialty care, it is often to the exclusion of the family physician, until they age out of the pediatric system and require adult care. At this point the family physician has had limited contact with the patient and ability to establish a relationship and get to

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10 Response rates varied for different questions

**Recommendation 10:** Further promote programs and resources that build self-management skills in YSHCN, and that educate care and support providers on how to promote these skills in their patients. Specifically, promotion of You’re in Charge can be targeted to Youth Health Centres in schools and the Schools Plus Program.
know their care needs and preferences. It was also suggested that sometimes specialists may take over some primary care tasks that really should be delivered by the Family Physician. The value-add of family physicians to the transition process was also noted, as they typically have an abundance of knowledge about the family and the community. It was recognized that exclusion of the family physician is not necessarily intentional on the FP or specialist’s part, but rather, there needs to be a mutual willingness to have greater family physician involvement.

“Patients often get dumped out of IWK around age 19 and sent back to family doctors who have never managed the complicated medical needs of these patients, and there is really no place in the adult system for these patients to be managed in one place”

-Consultation Participant

• **Capacity.** Despite recognition of the importance of family physician involvement in this process, there were several barriers that were identified through the survey. For example:
  o 48% disagreed they had the necessary knowledge
  o 53% felt they did not have the necessary time
  o 48% did not feel that they could easily answer questions that patients and families had about the transition process
  o 74% felt that access to community resources is lacking (e.g. home support, respite, vocational opportunities, etc.)
  o 64% indicated that patient or illness specific factors (e.g. cognitive ability) were barriers to facilitating the transition process.
  o 76% did not feel they were adequately compensated to facilitate the process
  ▪ Billing codes and compensation processes were commonly identified as a barrier (69%). Specifically it was noted that this has improved for developmental disabilities, as there has been a recent 50% premium implemented in recognition of the extra time required for assessments for these patients. It was also noted that it would be helpful to have billing codes for the additional paperwork that typically has to be done, especially for those with developmental disabilities or cognitive impairments which may limit their ability to respond on their own. As part of the collaboration between the On TRAC program and the BC Medical Association focusing on attaching YSHCN to a family physician, a comprehensive review of billing codes was conducted (McCall, Campling & Conly, 2014). A similar process in Nova Scotia may be helpful to identify where gaps may exist, or where billing codes which allow for these exceptions may exist, but are not widely known.

| Recommendation 11: Review Family Physician compensation for this population. This could include a billing code review for Family Physicians to determine codes that currently exist, or should be developed in order to attach YSHCN to family physicians. Alternative funding arrangements for family physicians who take on youth and young adults with complex needs could also be explored (e.g. salary, risk-adjusted capitation models etc.). This should include representation from Doctors Nova Scotia, Department of Health and Wellness Partnerships and Physician Services branch, as well as interested |
Family Physicians.

When asked about particular tools or resources used to facilitate transition, nearly half (48%) of respondents reported using nothing. Multiple comments suggested a lack of awareness that tools (e.g. guidelines, policies, checklists etc.) exist. Similarly, a desire for tools, guidelines, assessments and inventories of community supports in one location (i.e. website) was previously expressed through a survey of 18 Capital Health family physicians that care for those with developmental disabilities (Pyra Management Consulting Service Inc., 2009). In alignment with recommendation 7, having a central repository of tools and assessments available for YSHCN as they transition would be helpful. Several of these are already accessible through the Developmental Disabilities website, and are provided or linked through the IWK transition policy, which is currently still in draft.

Another common resource that family physicians felt was important to caring for YSHCN is reliable and timely access to specialist support. Specifically, it was noted that having someone who knows the particular patient and their condition would be preferable to a general on-call doctor focused on getting the patient through the next 24 hours. It was felt that without this specialized backup support, many of these patients will end up in the Emergency Department. Implementation of this specialist backup can be further developed through recommendation 2 which is to define the role that tertiary services plays in supporting primary and secondary care.

“With specific instruction and rapid access to specialty care as required, family physicians should generally be able to care for these patients”.

-Consultation Participant

- **Collaboration & Communication**. As with every other stakeholder group consulted, interprofessional collaboration and communication was identified as an important influencing factor on transitions. Family Physicians were specifically asked about their communication with various stakeholder groups. According to survey results:
  - Communication with adult specialists was overall rated as neutral with 28% of respondents indicating they had good communication with adult specialists involved in their patients’ care, and the same percentage disagreeing, with the vast majority responding neutral. However it was noted that communication was not open (53%), nor was it timely (58%) or reciprocal (58%)
  - Communication with pediatric specialists was most commonly rated as neutral or higher, with only 21% disagreeing. More specifically 68.5% indicated that they have clear communication with pediatric specialists and they have no difficulty understanding the information they receive from them.
  - Communication with parents or guardians was generally rated positively with 63% agreeing the had good communication with parents/guardians
  - Communication with YSHCN was generally rated positively with 47% agreeing that they had good communication, 37% felt neutral and only 16% disagreed.
As previously indicated in recommendation 1, communication and collaboration between family physicians and specialist providers should be a strategic area of focus.

**Acute & Tertiary Care**

Stakeholders consulted from acute and tertiary care included representatives from the Acute and Tertiary Branch of the Department of Health and Wellness, District VPs Clinical, Provincial Programs and a specialist provider\(^{11}\). The key issues identified from this sector are outlined below.

*The Role of Tertiary Services*

Access to specialized backup and support was identified as being critically important to be able to care for this population by both primary care and continuing care sectors primary care. As previously discussed, it was suggested that the role of tertiary services defined in supporting other levels of care needs to be mutually agreed upon and defined (see Recommendation 2).

**IWK Pediatric Medical Clinics**

Previous work initiated by a CDHA and IWK Joint committee consulted pediatric medical clinics on their transition practices. Nine of the 15 medical clinics reported transition planning activities, with varying approaches (e.g. overlap/joint appointments; nurse or social worker to provide transition counselling). Pediatric providers indicated that an overarching transition strategy for the IWK would be helpful, as well as an agreed upon transition age, and more adult specialists and general practitioners willing to take on these patients (Joint IWK-CDHA Steering Committee, 2012). (These suggestions can be addressed through recommendations 2, 4 and 5).

**Provincial Programs**

There are currently nine provincial programs which act in an advisory role to the Department of Health and Wellness and health care providers across the province\(^{12}\). The programs were borne out of an identified need based on the most pressing health issues for Nova Scotians. Provincial programs, where they exist were identified as enabler to transition from pediatric to adult based care. It was noted that having the dedicated resources and focus on these particular health issues has allowed for significant improvement. The Diabetes Care Program in particular has done significant work on transitions and have developed multiple resources for youth and families as they transition, including handbooks, checklists and even a mobile application. The work done by the Diabetes Care program is holistic in nature, offering sources and information on a wide variety of topics pertinent to young adulthood, including grocery shopping, alcohol consumption and intimate relationships, in addition to disease management. The *Moving on... with Diabetes* initiative suggests a phased approach beginning in early

\(^{11}\) A broader consultation process with pediatric and adult specialist was not conducted as there has been significant ongoing work within CDHA and IWK on this topic. To avoid duplication of effort we have included previous work from CDHA & the IWK which consulted pediatric specialists.

adolescence, where the individual increasingly takes on more responsibility for their care in increasing their knowledge and self-management skills (Diabetes Care Program of Nova Scotia, 2013).

Recommendation 12: Illness specific transition initiatives use the Diabetes Care Program “Moving on... with Diabetes” initiative as an example or framework for addressing the transition needs of YSHCN on a holistic level.

Mental Health & Addictions
Stakeholders from the Mental Health, Addictions and Children’s Services branch of DHW, Mental Health Speciality Services and District VPs of Community were consulted. Further several other stakeholders commented on the transition process for mental health as it relates to differing age ranges. As previously stated having differing ages of transfer for mental health and physical health creates confusion and inconvenience for those who have both physical and mental illnesses and needs to be addressed. It was also felt that issues around consent and capacity were more sensitive for this patient population. For example, a mature minor with mental illness may not want information shared with a parent, who may find this distressing.

There has been significant focus on transitions from pediatric to adult mental health services in recent years. For example, recommendations have been made by the Auditor General as well as an external review of Child and Adolescent mental health and addictions service in HRM. As the result of those reviews, initiated in part from tragic cases of teen suicide, there has been progress in this area. For example, most districts have a transition policy for mental health services (see Appendix E) and a large donation has funded the five year Staying Connected Mental Health project which focuses specifically on the transition from pediatric to adult based mental health services. It was noted that progress in transitions for mental health and addictions, particularly in taking a provincial approach, has been in part due to the Mental Health Standards.

Continuing Care & Community Services
Interviews and focus groups were conducted with representatives from the continuing care sector, including the Provincial Continuing Care Council, Evergreen Home for Children, Arborstone Young Adult Unit, Home Support Network, District Medical Directors of Continuing Care, Care Coordinators (n=2), District Directors of Continuing Care, VPs Community and DHW Continuing Care Branch. Representatives from the Community Services sector were also consulted, including ARC/RRCs, Department of Community Services, Services for Persons with Disabilities Branch, and Adult Service Centres. There were several opportunities and challenges identified by these stakeholders unique to continuing care and community services settings.

\[13\] While having a transition policy from pediatric to adult based mental health services is not currently written in the standards, it was noted that it is monitored in the same manner and is anticipated to be fully incorporated the next time the standards are reviewed.
Appropriateness of care setting.
For those requiring ongoing care in a nursing home it was widely recognized that the care and psychosocial needs of this population differ greatly from seniors who comprise the majority of nursing home residents. There are long term nursing home options designed specifically for children and young adults to age in place available through Evergreen and the young adult unit at Arborstone. Evergreen indicated that despite being a children’s facility, a significant proportion of their residents are actually over the age of 18. There is currently no waitlist so having “overage” residents has not been an issue. It is relatively rare for a resident to transition out of Evergreen children’s facility, however there have been a few residents which have moved to more traditional nursing home settings or back home with respite and home support. While Arborstone has a young adult unit, many of the residents are in their 40s or 50s; however there are still some younger adults that transition to the facility, often from community settings. Despite having a dedicated unit to younger populations, there were still several barriers identified to serving the population in a long term care setting. It was noted that this population tends to have different lifestyles altogether, such as the desire to go out more often, wanting more time spent on physical appearance, the need for privacy to carry on relationships, even differences in food preferences. This issue was also recognized from a home support perspective as well; specifically that the Home Care Policy may be limiting in its ability to deliver activities that young populations may prefer doing (e.g. outings). Several continuing care respondents also commented on the differing allied health needs for younger populations, indicating that often these needs are higher. Specifically it was suggested that need for occupational therapy in particular is usually higher than what might be provided in a long term care setting. Arborstone’s young adult unit has an extra recreation programmer and an extra social worker, which was noted to be helpful, but insufficient to meet the unique needs of younger populations.

Appropriateness of care provider
The role of the CCA in providing care for this population was mentioned by several continuing care representatives. While the CCA curriculum includes content specific to children’s needs within a lifespan approach, it was suggested that because volume is so low, there are limited opportunities to use and maintain these skills. There are unclear boundaries with scope of practice for certain nursing tasks (e.g. ventilators and tubes), skills that often times parents or caregivers are trained to take care of, but CCAs cannot. For example, a CCA doing an overnight respite but may need to wake up parents to take care of a ventilator or tube issue. Given the importance of respite to keep the client at home, having respite workers who can perform tasks for the more complex cases is important.

Despite some of the challenges continuing care faces in supporting and caring for this population, there were several unique attributes and programs that are potential opportunities to facilitate seamless care for this population as they age.

- Not age specific. It was noted that for many continuing care services, age is not a determinant of access, and so continuity of care is built into the service. The only significant change as a client ages is ability to consent and make decisions for their own care.
Based on functionality. It was suggested that continuing care in nature is based on functionality rather than a particular disease, which may provide a model or learning opportunities for youth with multiple chronic conditions.

Self-managed care. The self-managed care program through DHW Continuing Care was recognized as being a potentially beneficial and underutilized option for this population as they age. The program allows eligible adults with physical disabilities to self-manage funds from DHW to hire and purchase their own care. The criteria for self-managed care also allows for the client to appoint a care manager on their behalf; this is a recent amendment to the program which was thought to have addressed some gaps. The self-managed care program may be an appropriate resource for some young adults that allows them to take a proactive role in their care.

Community Services & Supports for those with Disabilities

Those who work with youth and adults with disabilities, particularly developmental disabilities, noted several unique challenges and opportunities that exist in serving this population as they transition from child to adult based services. Similar to other stakeholder groups on the receiving end of transition, representatives from the ARC/RRC sector expressed that often they had limited involvement with these clients before they are referred. They described what is often a crisis situation where a well-intentioned care provider is reaching burnout. It was felt when there were opportunities to engage with families sooner (e.g. through outreach programs) and establish a relationship, the transition from community to facility goes much smoother. It was noted that DCS has a gatekeeper role for the ARC/RRCs which may limit their earlier involvement. Similarly, from an Adult Service Centre perspective, it was felt that more planning is needed before the adolescent leaves a school environment. For example, more practical job skills such as resume writing or even on the job training opportunities should be a focus, rather than traditional classroom learning. These gaps can begin to be addressed through recommendation 3.

As previously discussed, more providers with knowledge and skills to care for adults with autism & other developmental disabilities are required (see recommendation 5). It was noted that particularly with autism there is a marked decrease in supports as children age. This has been acknowledged in a previous review of the Lifespan Needs for Autism (Province of Nova Scotia, 2010), which recommended more
opportunities and supports for adults with autism; however many stakeholders reported that there are still gaps in services for this population. Namely, respite and meaningful opportunities (e.g. vocational) for this population after they leave school were identified as necessary to appropriately serving this population. Access to respite will become even more important as there is reduced reliance on facilities, such as ARCs/RRCs in the future (Nova Scotia Joint Community-Government Advisory Committee, 2013).

Although the need for greater community based supports was identified, several stakeholders noted that there are funding barriers to providing those community supports. For example, as ARCs/RRCs are funded on a per diem basis, it limits their ability to provide non-residential services, such as outreach to this population. It was also suggested that as a student with a developmental disability transitions from a school environment to an Adult Service Centre environment, that funding should follow that individual. It was felt that doing so would allow for more job based training and coaching opportunities that may be difficult to deliver in the traditional education system; namely the non-traditional work hours of the jobs that those with developmental disabilities typically work, and rigidity of collective agreements for teacher and teaching assistant roles limiting their ability to work within those hours.

**Recommendation 13:** Advocate for and ensure there are sufficient and appropriate resources in the community and continuing care sector for YSHCN and youth with disabilities, especially once they've aged out of the school system (e.g. adult day program, adult service centres, inclusive employment opportunities). Specifically, the following actions should be taken to begin to address this:

13.1 Ensure sufficient and appropriate respite options exist for parents and caregiver of YSHCN. Specifically, review and clarify the potential respite workers that can perform certain tasks for YSHCN (e.g. ventilators, feeding tubes, etc.). This should be done with a caregiver lens, in order to ensure they are able to receive genuine respite.

13.2 Incorporate consideration for the additional allied health and psychosocial supports that may be required for YSHCN in continuing care settings.

13.3 Review and explore funding mechanisms which may enable more community based supports for this population (e.g. ARCs/ RRCs providing outreach services, funding for YSHCN to access more practical job skills training and coaching, greater promotion and access to the Self-Managed Care Program)

**Relationship between Community & Continuing Care Services.**

“Without this relationship, it is very difficult to do good transitions”

-Consultation Participant

As previously mentioned, the collaborative relationship between community and health services was commonly noted as a barrier where it didn’t exist and an enabler where there was collaboration. Given the similarities in clients and services between DCS Services for Persons with Disabilities, and the
Continuing Care branch of DHW, it was felt that there needs to be greater clarification around boundaries of services so potential gaps can be identified and addressed (see Recommendation 1). It was suggested that collaboration needs to happen at a provincial level (e.g. DCS, DHW, DOE) to better enable local collaborations (e.g. school boards, health authorities, ARCs/RRCs, Adult Service Centres etc). It was also noted that differing geographic boundaries between sectors can create barriers to collaboration. While the overall picture was one of fragmentation, there were specific examples of purposeful collaborations that were recognized as being both successful and opportunities for expansion (e.g. Strait to Work Program, Access to Community Education and Employment- see Appendix E).

“Where there’s been collaboration, we’ve seen success”
-Consultation Participant

The Role of Schools
Given that education is a basic human right to which everyone is entitled, concern was expressed around those with highly specialized medical and care needs and the ability of school staff to ensure their health and safety while at school. It was noted that for youth with very complex and specialized care needs, there needs to be greater clarity around the boundaries of what school staff can do and what requires a health professional to come in and do. Similar to the CCA role, clarifying scopes of practice and liability of certain tasks will better clarify the role of schools while YSHCN are under their supervision. Scenarios were also described where services provided through Community Services or Health (e.g. hearing and speech) are terminated when the child enters school and subsequently receives the same, or a similar services directly through the school. Once the child finishes school, so do their services and they must then access them through the appropriate department (e.g. health, community services etc.). This was recognized as a barrier to transition and to continuity of care.

As previously mentioned Schools Plus and Youth Health Centres exist in several schools. An evaluation of Youth Health Centres found positive effects in creating access to health services (Research Power Inc., 2009), and Schools Plus has recently expanded services across the province. While generally these initiatives have been perceived as positive, there was concern expressed around setting up a parallel system in schools which may be done so to the exclusion of the community and primary care services; thereby potentially hindering transition when students finish school. It was suggested that these services should act more as a liaison and connector service rather than a replacement for services provided within the tradition health system. Similarly, a disconnect between university based health services and the rest of the continuum was also recognized. This is a concern given university typically begins around the age of transfer, depending on the service. As reflected in recommendation 1, these concerns suggest the need for greater role clarity of school based services for YSHCN, and warrant a more in depth analysis of the issue.
Conclusion & Recommendations

The move from youth to adult based services for YSHCN involves several barriers to a seamless transition. YSHCN represent one of society’s most vulnerable populations and as such they are owed a high level of diligence in the design and provision of services, across health, community and education settings. While many of the recommendations made throughout this report are dependent on behavioural and cultural changes, an abundance of work in this area has already been done and there exists a window of opportunity to translate this work into change as we as a province restructure our health system. Although, there may not be a panacea to this issue, there are necessary conditions. As one stakeholder put it:

“A [system] expectation of collaboration between settings and service providers... how else are we going to be able to do it?”

-Consultation participant

Recommendations

System Level Recommendations

Recommendation 1: Build a model of service delivery that is person-centred, holistic and based on collaborative relationships between services and providers. There needs to be a mutual understanding of one another’s services and priorities between the providers and services delivered to this population (e.g. health, community services, and education). Based on stakeholder consults, particular focus should be paid to clarifying the roles and relationships between the following services and providers

- community services and health
- family physicians and specialists (pediatric and adult).
- education and health sectors while YSHCN are at school

This should be done with a patient/client focus to ensure a common lens and reduce service, provider centric policies and decisions.

Recommendation 2: Enable a provincial approach to transitions from pediatric to adult-based care for YSHCN through clarified roles of the IWK and the future Health Authority. Specifically, the following actions should be taken:

2.1. The Senior Leadership Teams of the IWK and the future district, when established, meet to build consensus and define what their respective roles and responsibilities are in the provision of health services to YSHCN, particularly as they transition from pediatric to adult based care.

2.2. The IWK, future Health Authority, and representation from Department of Health and Wellness, Acute and Tertiary and Primary Care branches, and other stakeholders as appropriate, define the role that tertiary services play in supporting primary and secondary care.

In defining roles and scope of the IWK, the new Health Authority and tertiary services in supporting primary and secondary care, the relatively simplified transition process that currently occurs in smaller districts should not be overlooked.

Recommendation 3: Gather and use data on YSHCN to optimize early planning and seamless service
delivery on a system and case level basis. Specifically, the following actions should be taken:

3.1 Establish a method to gather, track and monitor the rates, diagnoses and geographic locations of YSHCN. Ideally this would be done through one central agency, or as a collaborative effort between several agencies (i.e. IWK, DHW, DOE, DCS, Youth Ombudsman etc.) with one main access point.

3.2 Include services and providers on the receiving end of transition early in the planning process. This should happen on a a case by case basis (e.g. school and adult service centre, pediatric specialist and nursing home), as well as an aggregate level to facilitate systems planning (e.g. school board shares number of students who will require community services supports after they exit the school system).

3.3 Ensure timely and efficient flow of information between services providers through the use of interoperable information systems and streamlined consent processes where applicable. For example, Schools Plus developed a common Consent Form which streamlined the administration of consent across the various service providers involved in Schools Plus. Furthermore, legislation has been passed in New Brunswick which will make it easier for some government departments to share personal information with other government departments for the purpose of integrated service and delivery.

Recommendation 4: As recommended through previous reports and reviews, streamline the age of transfer across all specialities and ensure that age is communicated to necessary stakeholders. While having a specific age of transfer can reduce confusion and standardize processes, some flexibility should be applied when it is in the best interest of the patient without punishing the patient or care providers.

Recommendation 5: Create training opportunities and build knowledge and skills for service providers to appropriately care for YSHCN. Priority topics and providers identified were:

- 5.1 Build pockets of adolescence expertise. While it may not be feasible or sustainable to treat adolescent medicine as a sub-speciality in and of itself within Nova Scotia, having designated providers across the continuum of care who can either directly care for this population, or act as a resource to their care providers. This can be facilitated through ensuring this period is adequately covered in undergraduate and training curriculum of health providers, and through providing specific continuing professional education on this topic.

- 5.2 Build knowledge and skills for providers of adults with autism

- 5.3 Build knowledge and expertise of YSHCN within family physicians and adult specialists. This could be done through incorporating education about YSHCN and transitional care in undergraduate training as well as continuing medical education opportunities. One stakeholder suggested a model similar to maternal care. Although not every family physician will deliver babies, they can refer to family physician that will. A similar set up for YSHCN could facilitate the development of a pool of family physicians who will care for these patients.

Recommendation 6: Build consensus across providers, illness trajectories and sectors around the placement and scope of navigator functions. Having a separate navigator function may be necessary between some services, or opportunities may exist where such a function is built into a pre-existing role (e.g. family physician, care coordinator). Opportunities should also be identified where such a role can ensure a system or cross-sector lens.

Recommendation 7: Establish a directory of services available to pediatric specialists, family physicians, navigators and any other referring provider or organization. In order to capitalize on existing infrastructure, there may be opportunities to build upon the 211 service that currently exists in NS.

Recommendation 8: Implement the previous recommendation made by the Joint IWK-CDHA Steering Committee on Transition Needs of Youth and Families to create a model of service delivery that
appropriately cares for adults with complex care needs. While it was suggested this be a joint venture between CDHA and the IWK, namely pediatric and adult specialists and family physicians, this should be done with provincial focus. While a lack of critical mass may prohibit the replication of such a model outside of HRM, this model should be well linked to health and support services the patient can access in their local community if they are from another part of the province. Further, there should be telehealth capabilities to allow for the patient’s local family physician to take part.

**Recommendation 9:** Include youth and parent representatives in the planning and design of transition initiatives and services.

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<td><strong>Recommendation 13:</strong> Advocate for and ensure there are sufficient and appropriate resources in the community and continuing care sector for YSHCN and youth with disabilities, especially once they’ve aged out of the school system (e.g. adult day program, adult service centres, inclusive employment opportunities). Specifically, the following actions should be taken to begin to address this:</td>
</tr>
<tr>
<td>13.1 <strong>Ensure sufficient and appropriate respite options exist for parents and caregiver of YSHCN.</strong> Specifically, review and clarify the potential respite workers that can perform certain tasks for YSHCN (e.g. ventilators, feeding tubes, etc.). This should be done with a caregiver lens, in order to ensure they are able to receive genuine respite.</td>
</tr>
<tr>
<td>13.2 <strong>Incorporate consideration for the additional allied health and psychosocial supports that may be required for YSHCN in continuing care settings.</strong></td>
</tr>
<tr>
<td>13.3 <strong>Review and explore funding mechanisms which may enable more community based supports for this population (e.g. ARCs/ RRCs providing outreach services, funding for YSHCN to access more practical job skills training and coaching, greater promotion and access to the Self-Managed Care Program)</strong></td>
</tr>
</tbody>
</table>
Caveats and Limitations

There are several limitations to this work and caveats to its interpretation. While our survey results echo the anecdotal evidence of the role of family physicians in transition, the response rate is very low, and as such the results should be interpreted cautiously. While many stakeholders were consulted across the continuum of care and sectors, there are several others impacted by this issue, including youth and families themselves; however time and resource constraints precluded a broader consultation process. While representatives from other sectors were consulted, the scope of consultations primarily focused on health services and providers. Despite these limitations, it is our hope that this work provides a foundation upon which service providers and sectors can come together to address this issue to facilitate a smooth transition from pediatric to adult based services.
Appendix A: Terms & Definitions

Developmentally-appropriate Care
Improving health outcomes for young people requires that health professionals have an understanding of adolescent development and broaden their medical perspective to incorporate the developmental perspective. Satisfactory progress through developmental tasks contributes to the adolescent’s self-confidence and self-worth (Paone & Whitehouse, 2011).

Self-management
Self-management refers to an individual’s ability to manage the symptoms, treatment, physical, psychosocial, and lifestyle changes inherent in living with a chronic condition (Johnston, Liddy, Ives & Soto, 2008).

Self-managed Care Program
People with physical disabilities to hire their own care providers and develop their own care plans, which gives them control over the services they need and the providers they choose (Province of Nova Scotia, 2014).

Shared Management Model of Care
The Shared Management Model of care is one in which focuses of the early development of a therapeutic alliance between children/youth, families and health-care providers which gradually shifts leadership for care from the health professional to the parent and then ultimately to the youth (Kiechefer & Trahms, 2000).

Transfer of Care
A one-time event that occurs at the time the child is transferred out of the child health system (Provincial Council for Maternal and Child Health, 2009).

Transition
The purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult oriented health care (Blum, 1995).

Youth with Special Health care needs (YSHCN)
Children and youth who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson, et al., 1998).
Appendix B: Stakeholder List

Stakeholders representing the following organizations, services and sectors were included in our consultations

<table>
<thead>
<tr>
<th>Primary Care</th>
<th>Family Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>You’re in Charge Program</td>
</tr>
<tr>
<td></td>
<td>Department of Health and Wellness, Primary Care Branch</td>
</tr>
<tr>
<td>Acute &amp; Tertiary Care</td>
<td>Provincial Programs</td>
</tr>
<tr>
<td></td>
<td>Department of Health and Wellness, Acute &amp; Tertiary Care Branch</td>
</tr>
<tr>
<td></td>
<td>A Program Manager of Specialized Services</td>
</tr>
<tr>
<td></td>
<td>VPs Clinical</td>
</tr>
<tr>
<td>Mental Health and Addictions</td>
<td>Department of Health and Wellness, Mental Health, Addictions &amp; Children’s Services</td>
</tr>
<tr>
<td>Continuing Care</td>
<td>Department of Health and Wellness, Continuing Care Branch</td>
</tr>
<tr>
<td></td>
<td>Continuing Care Council</td>
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<td></td>
<td>Home Care Networks</td>
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<td></td>
<td>District Medical Directors of Continuing Care</td>
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<tr>
<td></td>
<td>Care Coordinators</td>
</tr>
<tr>
<td></td>
<td>Evergreen Home for Special Care, Children’s Centre</td>
</tr>
<tr>
<td></td>
<td>Shannex Arborstone, Young Adult Unit</td>
</tr>
<tr>
<td>Community Services</td>
<td>Department of Community Services, Services for Persons with Disabilities Branch</td>
</tr>
<tr>
<td></td>
<td>Adult Residential Centres and Regional Rehabilitation Centres</td>
</tr>
<tr>
<td></td>
<td>DirectioNS (Adult Services Centres)</td>
</tr>
<tr>
<td>Education</td>
<td>Department of Education</td>
</tr>
<tr>
<td>Provincial/National Initiatives</td>
<td>Ontario Provincial Council for Child and Maternal Health</td>
</tr>
<tr>
<td></td>
<td>Sick Kid’s Good 2 Go Program</td>
</tr>
<tr>
<td></td>
<td>British Columbia’s On TRAC program</td>
</tr>
<tr>
<td></td>
<td>Canadian Association of Pediatric Health Centres</td>
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</tbody>
</table>
## Appendix C: Transition Program Review

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
<th>Outcomes</th>
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</thead>
</table>
| **Sick Kids Good 2 Go**  | **Goal:** to prepare all adolescents with chronic health conditions to graduate with the skills and knowledge needed to succeed in the adult-oriented health care system.  
**Acts as an in hospital resource for other departments and clinics**  
**Based on a shared management model**  
**Focuses on 4 main areas**  
  - Education/KT transition needs and importance  
  - Consultation and staff support  
  - Resource/tool development  
  - Research and quality improvement initiatives | - Increases in patient, parent and health care provider knowledge on transitions  
- Transition events highly rated  
- Will be reviewing the number of patients leaving by age 18 before and after implementation of transition program  
- Increased knowledge around transitions (every ambulatory program has at least 1 transition tool in place and over 50% have sought support or education of G2G resources).  
- Transfer clinics have had over 250 participants in past 6 years, patients and parents report being better prepared  
- Uses My Health passports, majority have found it useful and most carry it most or some of the time  
- Some specific programs have seen an increase in their disease specific knowledge and plans to change lifestyle (Sick Kids, 2014, Grant & Pan, 2011) |
| **BC On TRAC**           | **On TRAC** is a Province-wide multifocal initiative to ensure successful planning, preparation and transfer of youth with chronic health conditions or disabilities from pediatric care to adult care, with a focus on attachment to primary care and specialist services. | No formal evaluations, however this is a currently a strong focus for the program as it has developed to a provincial initiative (CFHI, 2013, Grant & Pan, 2011).  
**Anticipated Outcome of using a Clinical Pathway** (Paone & Whitehouse, 2011)  
1. Improved continuity of care and coordination of care throughout the adolescent period that incorporates the roles of all stakeholders involved.  
2. Improved documentation of patient knowledge and skills in transition issues, variances of care, and a mechanism for quality of care review.  
3. Increased youth and young adult health-promoting and health-maintaining behaviors.  
4. Increased youth and young adult involvement and participation in decision-making and treatment plans.  
5. Improved goal setting, identification of readiness to transfer and realization of personal progress. |
| **Maestro (Winnipeg Regional Health Authority)** | - A type 1 diabetes specific transition program  
- Teens have access to a system navigator  
- Focuses on working closely with community based resource centres and enhancing community based resources. | Lowered adult dropout rate from 40% to 11% for those that had system navigator versus those that did not, also less difficulty and frustrations in establishing regular follow up with adult providers (CFHI, 2013, Grant & Pan, 2011, Van Walleghem, MacDonald & Dean, 2008) |
| Young Adults with Rheumatic Diseases (YARD) | Transition clinics for youth 18-23 to facilitate transition. Youth see pediatric and adult rheumatologists together in the clinic which also provides some career counselling, helps arrange services in new city (e.g. going away for school), etc. | Clinics well attended (94% attendance rate) 96% of patients are attending educational institutions or working (CFHI, 2013, Grant & Pan, 2011, LaBrie, Kiefer, Miettunen, Fahlman, Johnson, Crawford & Lupton, 2008). |
| Be Your Own Boss (BYOB) | 1st adaptation of the Stanford Chronic Disease Self Management Program. Community based peer led program 6 week program collaborative participatory workshops include RNs psychologists and “Master Trainers” led by young adult lay leaders. Focuses on transition planning communication skills, symptom management and healthy lifestyle choices | No formal evaluation, however the CDSMP itself has been evaluated and has seen increases in self-promoting behaviours, maintaining or improving health status, decreasing hospitalization, decreased health distress and improved self-perception of self-efficacy (CFHI, 2013, Grant & Pan, 2011) |
| Toronto Congenital Heart Disease Taskforce | A program that aims to facilitate transition between pediatric to adult care for those with congenital heart disease. Developed a taskforce which is a mix of adult and pediatric providers from various backgrounds (e.g. doctors, nurses, psychologists etc.). Uses several educational initiatives: o My health passport o Condition specific Timelines- o 3 sentence summary- age, diagnosis, brief medical history, treatment plan, questions to discuss in clinic visit o Patient and family educational events Includes a transfer of care algorithm which clarifies the nature of referrals for all referring pediatric providers (different subspecialty clinics, level of complexity takes into consideration), and a patient transfer database. | My health passport was formally evaluated – passport was easy to use and create had an educational element, facilitated communication and was carried by most users. (CFHI, 2013, Kovacs et al, Wolfstadt, Kaufman, Levitin & Kaufman, 2011). |
## Appendix D: Nova Scotia Reports with Recommendations or Implications for Transitions

<table>
<thead>
<tr>
<th>Report</th>
<th>Date</th>
<th>Recommendation(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Call for Greater Interdepartmental Delivery of services to youth and Families in Nova Scotia</td>
<td>2010</td>
<td>Appoint an interdepartmental commission to develop the organizational framework for integrating programs and services on a province wide basis. Establish, through policy and action, effective interdepartmental delivery of integrated services to children, youth and families in Nova Scotia (Nova Scotia School Boards Association, 2010).</td>
</tr>
<tr>
<td>Action Plan for the Organization and Delivery of Chronic Pain Services in Nova Scotia</td>
<td>2006</td>
<td>At age 16, the pediatric chronic pain patients are supposed to be transitioned to adult care, but often this transition is not ideal, the reasons are twofold: 1.) IWK specialists are reticent to release their patients who have received regular, timely care to the PMU where they would be placed on a 5 year waiting list. 2.) A key focus in adult pain programs is rehabilitative and a return-to-work. The occupational issues facing most of the adult pain population are not relevant to the population who is still school-aged. The IWK and the Department of Health need to review the age limit for treating these chronic pain patients (Nova Scotia Chronic Pain Working Group, 2006).</td>
</tr>
</tbody>
</table>
| Auditor General report                      | 2010 | **Recommendation 4.12**  
The Department of Health should develop a formal policy to ensure youth transferring to adult services are treated in a consistent manner in all areas of the province. This policy should ensure patients have continued access to services either in the youth or adult system (Office of the Auditor General, 2010)  
**Department’s response**  
The DOH will direct the DHAs/IWK to establish a formal policy for a process for youth to adult service transfer without service interruption. The policy will be documented and monitored by DOH |
| Autism Spectrum Disorder Action Plan        | 2011 | **Current government initiatives to address lifespan needs for persons with ASD**  
As part of the Special Education Policy, all school boards currently support transition from high school for students with Autism Spectrum Disorder. This service is provided through positions in Student Services; i.e., student services coordinators, program planning teachers, and transition teachers.  
**New Actions Government will take to Address Lifespan Needs for Persons with Autism**  
Support transition planning as a required component of the individualized program planning process outlined in the Special Education Policy. Several other actions which continue to fund and to explore educational, vocational and life skills options for adults with ASD such as day programs, Labour Market Agreements and enhancing post-secondary options for those with special needs (Province of Nova Scotia, 2011) |
<p>| Child and Adolescent Mental Health and      | 2013 | Integrate all health care for children and youth up to age 19 at the IWK. For youth who have experienced physical and/or sexual assault |</p>
<table>
<thead>
<tr>
<th>Source</th>
<th>Year</th>
<th>Summary</th>
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<tr>
<td>Addiction Services in the Halifax Regional Municipality</td>
<td></td>
<td>or abuse and the associated mental health sequelae, the current divide creates serious barriers to care, including discontinuity of care and unnecessary delays in receiving timely and appropriate treatment (Davidson &amp; Coniglio, 2013)</td>
</tr>
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</table>
| Choice, Equality and Good Lives in Inclusive Communities             | 2013 | Person-directed Planning/ navigation- establish person directed planning and navigation as a process available to all individuals with disabilities and their families across the lifespan.  
Increased access to competitive employment- adopt an employment focused framework for SPD funded service providers delivery day programs and employability supports  
Recommends to establish a disability supports program that replaces current DFSA and DFSC (funding levels that apply equally to children and adults and equally applicable for use within family home or by individual in own home outside of nuclear family. Rationale: Disabilities Support Program (DSP) should be designed to enable people with disabilities to transition to adulthood and independence according to their own aspirations. (The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013) |
| Come Together: Report and Recommendations of the Mental Health and Addictions Strategy Advisory Committee | 2012 | Implement effective plans for timely and seamless continuity of care between services and across the life-span (e.g., from youth to adult services or from adult to specialized senior services; from inpatient to community-based care). Plans for such transitions should include written discharge plans, briefing those who will provide care in the next step of treatment (family and other service providers including shelters and transition houses), case conferencing and other coordinating tasks as required  
2.2 Align the age of transition from youth to adult services across government departments, especially DHW and DCS (Mental Health and Addictions Strategy Advisory Committee, 2012) |
| Department of Education Special Education Policy 2.7                 | 2008 | School-to-community transition is the crossover from youth to adulthood and carries with it expectations of independent living, employment, and recreational pursuits.  
Transition planning takes into consideration all major aspects of each student’s life experiences and assists in determining appropriate resources and programming.  
School-to-community transition planning should begin when a student enters junior high school. Transition outcomes must be documented and incorporated in the student’s IPP and filed in the student’s cumulative record. If a student does not have an IPP but has special needs that may necessitate transition planning (e.g., physical/mobility/transportation needs), the transition plan should also be stored in the student’s cumulative record. School-to-community transition planning should address any area necessary for students to participate successfully in post-secondary training or employment: leisure/recreation, living arrangement, personal management, personal family relationships, health/medical services, financial planning, transportation, advocacy/legal services, or other |
<table>
<thead>
<tr>
<th><strong>Lifespan Needs for Persons with Autism Spectrum Disorder</strong></th>
<th><strong>2010</strong></th>
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<tbody>
<tr>
<td>The Department of Education should give targeted funding to each regional school board to support the position of Transition Facilitator. This position would work collaboratively with high schools, government departments, and community organizations to support successful transition out of public school. Opportunities should be created for recreational/leisure programming for individuals with ASD 21 years and older (Province of Nova Scotia, 2010).</td>
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<tr>
<th><strong>Transition of Medical Care from Youth to Adulthood: The Challenge for Capital Health and the IWK</strong></th>
<th><strong>2012</strong></th>
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<tbody>
<tr>
<td>1. The described “Guiding Principles and Values” are adopted</td>
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<tr>
<td>2. CDHA and IWK develop a collaborative practice model engaging family physicians, subspecialists and other health professionals to guide transition of care for all chronic conditions.</td>
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<tr>
<td>3. CDHA and IWK jointly establish transition coordinator functions to support youth as they enter the adult care system.</td>
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<tr>
<td>4. CDHA and IWK jointly establish an adult complex care clinic</td>
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<tr>
<td>5. Identify and/or recruit clinical faculty with special interest in transitional care and a clinical academic leader in Adolescent Medicine.</td>
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<tr>
<td>6. Academic departments in appropriate faculties are asked to review and update their curriculum.</td>
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<tr>
<td>7. Academic Funding Plans and fee-for-service guides reviewed regularly for the adequacy of physician remuneration in primary and consultative care to persons with developmental disabilities.</td>
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<tr>
<td>8. CDHA and IWK jointly establish and sustain common website portals that guide transition care planning for youth with chronic conditions and further develop the “Developmental Disabilities” website portal.</td>
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<tr>
<td>9. Information disseminated to the general public and particularly to youth with chronic conditions and their families to announce the implementation of this transition strategy as a CDHA-IWK collaboration.</td>
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<tr>
<td>10. An oversight group be established jointly by CDHA and IWK to monitor and improve transition services (Joint IWK-CDHA Steering Committee on Transition Needs of Youth and Families, 2012)</td>
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<tr>
<th><strong>Vocational and Day Program Services for Adults with Disabilities in Nova Scotia</strong></th>
<th><strong>2008</strong></th>
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<tbody>
<tr>
<td>Historically, Adult Service Centres developed programs for individuals with disabilities who are age 21 and over. This has left a gap in service development for individuals who are graduating from high school at age 18.</td>
<td></td>
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<tr>
<td>Recommendation 6.1 Address Priorities: The second priority issue should be the development of programs to provide services to the 18 to 21 year old group. Partnerships with the Department of Education, Adult Service Centres, the Nova Scotia Community College and other community agencies should be explored in this regard (Department of Community Services, 2008).</td>
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</table>
### Appendix E: Nova Scotia Transitions Policy & Program Review

<table>
<thead>
<tr>
<th>Policy/ Program/ Guideline</th>
<th>Description/Excerpts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DHA Based Policies</strong></td>
<td></td>
</tr>
<tr>
<td>SWHA</td>
<td>Not Available</td>
</tr>
<tr>
<td>SSDHA</td>
<td>Transition of Client Care from Child &amp; Adolescent Service to Adult Service (Draft). Applies to mental health and addictions. Does not stipulate age criteria, rather the decision is made between the client, clinician and family (where appropriate).</td>
</tr>
<tr>
<td>AVDHA</td>
<td>MH services youth to adult policy: Throughout the transfer the youth is considered a shared client of the Child &amp; Youth Team and The Adult Team. Transfers are guided by the youth’s readiness, stage of development, needs, and the complexity of the case. Transfers engage all relevant people including, but not limited to, the youth, their family, the transferring and receiving clinicians, and the primary care physician.</td>
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<tr>
<td>CEHHA</td>
<td>Not Available</td>
</tr>
<tr>
<td>CHA</td>
<td>Not Available</td>
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<tr>
<td>PCHA</td>
<td>Process: Transfer of 19 year-olds to Adult Outpatient Mental Health Services (Child/Adolescent Outpatient Mental Health Services). Process: A client being seen in the Child/Adolescent Service who is four (4) months away from their 19th birthday will trigger a Clinical Case Review</td>
</tr>
<tr>
<td>GASHA</td>
<td>Defined Process for the transfer of 19 year olds for Mental Health Services. Joint Adult / Child Clinician Intervention Session. Gradual ‘weaning’ and transfer sessions with defined time lines up to six (6) months after nineteenth (19th) birthday. On a case-by-case basis it may be determined that in the best interest of the child (based on diagnosis, need and where client is in the treatment process) a transfer should not occur.</td>
</tr>
<tr>
<td>CBDHA</td>
<td>Policy &amp; Procedure: Transitioning Youth to Adult Mental Health Services. A transition to Adult MHS will occur during a time of stability. An evaluation following the transition to assess the effectiveness of the transition.</td>
</tr>
<tr>
<td>CDHA</td>
<td>Guide. Transition of youth to Adult Mental Health and Addiction Services. For those requiring ongoing care, a referral to CDHA services made by the age of 18.5. May receive treatment at IWK up to 19.5., if referral is not anticipated collaboration with their primary care physician continues.</td>
</tr>
<tr>
<td>IWK</td>
<td>See Box 1.</td>
</tr>
<tr>
<td><strong>The Provincial Diabetes Care Program</strong></td>
<td>Work around transition began in 2006 and has since developed several tools and material for healthcare providers and patients to prepare adolescents to transition from pediatric to adult based care, including flow charts and checklists and a transition summary form for providers, and a comprehensive transition handbook for patients, which includes many adolescent relevant topics regarding university, drugs, alcohol, sexual and reproductive issues,</td>
</tr>
</tbody>
</table>
grocery lists and dealing with sick time at work, all as it relates to their diabetes.

| **Staying Connected Mental Health project** | A five-year project entering its second year funded through donation. The aim of the project is to culturally shift how youth and families transition from pediatric to adults based mental health services, and build closer partnerships with universities in Halifax. Elements of the project include:
  - Teen primer for adult Clinicians- providing education and training to adult clinicians on working with teens and young adults
  - Development of a Mental Health and Addictions Services Landscape Map- to help IWK identify services and pathways available
  - A transition coordinator position that will be housed at CDHA
  - University specific initiatives – e.g. electronic mental health literacy resources, education for faculty, peer support etc. |

| **You’re in Charge Program** | This program, offered through IWK, DHW, and the Chronic Disease Self-Management research group through the School of Occupational Therapy at Dalhousie is aimed at 13-15 year olds with any chronic condition to help teens and parents get ready for adult care. Include an annual camp (at Brigadoon), and also workshops. A one year evaluation of the You’re in Charge program indicate positive gains in readiness for behavioural change for the youth participants, furthermore parents who participated in the program showed significant improvements in the knowledge after the program. Long term effects of this program and how it influences impacts the transition process are still unknown (Versnel, 2013). |

| **Continuing Care** | **Challenging Behaviours Manual** - primarily targeted to older adults, but acknowledges that sometimes this may apply to younger adults and supports in this program may be of assistance
  - Facility placement policy- no age specifications (exceptions: Evergreen and Arborstone)
  - Adult Protection Policy- 16 year or older at risk of harming themselves or being harmed. When young adults require longer term placement, work with DCS if require nursing care at a later date, work with continuing care
  - Self-Managed care- for those 19 and over who have a chronic and medically stable condition
  - Supportive care- For those 65+ with long term cognitive impairments, SDM applies on their behalf (double check)
  - Home care-not provided in in DHW or DCS licenced facilities, except for acute stabilization of a med/post surg condition. No Age specifications
  - Home Oxygen- no age specification
  - Community Bed Loan program- no age specifications
  - IADLS- no age specifications |

| **Department of Community Services** | **Direct Family Support Program**- One program with two components- adult and child, for children and adults with disabilities who live at home with their families. Has a home first focus. One of the articulated purposes of this program is to “establish a smoother transition ad seamless transition between children’s and adult’s supports and services). Provides funding for respite or to |
compensate caregivers for supporting their family

DFS- Children’s program. Funding to support the family with an assessed, unmet need associated with their child’s disability (e.g. respite, medications, transportation, equipment, child care costs for those 12 and over- 12 and under would be paying child care costs anyway etc.)

DFS- Adult funding for assessed unmet need of an adult with a disability who lives at home with family, including shelter, food, clothing, transportation, a personal use allowance

Both are income tested. Other eligibility criteria

<table>
<thead>
<tr>
<th>Children</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 19</td>
<td>19-65 (65+ DHW)</td>
</tr>
<tr>
<td>Lives at home</td>
<td>Lives in Family home</td>
</tr>
<tr>
<td>Diagnostic criteria</td>
<td>Diagnostic criteria</td>
</tr>
<tr>
<td>Meets income guidelines</td>
<td>Meets income guidelines</td>
</tr>
<tr>
<td>Family agrees to participate in assessment process</td>
<td>Applicant and family agree to participate in assessment process</td>
</tr>
</tbody>
</table>

Ineligibility

| In Care of Minister, no clinical diagnosis, can carry out activities of normal living, requires on-going type II nursing care, family do not agree to participate in assessment process | Over 65, does not reside in family home, no diagnosis/ unmet needs, does not meet financial criteria, will not participate in assessment process |

Joint DCS/ DHW funding (part of DFS program)

When an individual receives services through both departments, the DCS care coordinator identifies sources of funding through DHW, contacts DHW (now DHAs) care coordinator to determine amount/ source of funding and ensure no duplication, determine if exceptional circumstances- e.g. respite funding for family if family only ones who can manage, efforts to find a respite caregiver are not successful). Over 2200/ mo.- extraordinary support needs, extreme behaviours, no appropriate day program for adult, single caregiver with sole responsibility for supporting the client. EOL issues in either client or caregiver, addition short term respite if caregiver is sick, family emergency, short term deterioration in the mental or physical health of caregiver or individual, unusual short term distress.

Individual living support program

- No more than 21 hours of support required a week (e.g. maintain a household, laundry shopping, banking, meal prep).
- Under 65 (no lower limit specified)
- Can manage medication
- Can participate in decisions about their activities

Licenced homes for special care

- Small Options (live in/ shift model)
- Group Home or Developmental Residence (4-12 person)- primary serve younger
- RCFs (4+ adults with disabilities who require minimal
<table>
<thead>
<tr>
<th><strong>Adult Service Centres</strong></th>
<th>provide employment skills training and day programs</th>
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</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
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<tr>
<td><em>Schools Plus</em></td>
<td>A collaborative interagency approach to supporting the whole child and their family within the school as the center of service delivery. This approach will make it easier for professionals to collaborate with each other on behalf of children, youth, and families</td>
</tr>
<tr>
<td><em>Youth Health Centres</em></td>
<td>provide young people with health education, health promotion, information and referral, follow-up and support, as well as some clinical services</td>
</tr>
<tr>
<td><em>Special Education Policy</em></td>
<td>Has requirements with respect to planning for transition from school to community</td>
</tr>
<tr>
<td><em>Strait to Work</em></td>
<td>Helps high school graduates with disabilities to prepare for full-time employment and independent living and academic and social skills</td>
</tr>
<tr>
<td><em>Access to Community Education and Employment</em></td>
<td>In the Halifax area, the Departments of Community Services and Education and the Halifax Regional School Board fund the ACEE program, which offers job readiness, life skills training and job coaching to students with special needs who have completed their high school education</td>
</tr>
<tr>
<td><strong>Provincial Initiatives</strong></td>
<td></td>
</tr>
<tr>
<td><em>Ontario’s Provincial Council for Maternal and Child Health- Transition to Adult Health Services Work Group Recommendations</em></td>
<td>All healthcare providers begin, early in adolescence, the process of facilitating the following: Knowledge related to their medical condition and the adult healthcare system</td>
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<td>Once transferred to the adult healthcare system, healthcare providers continue to foster knowledge acquisition and self-management skills within the young adult</td>
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<td>A combined transition readiness/risk assessment tool be developed and piloted to identify those who would benefit from a more intensive approach during the transition process and, if indicated, to determine a plan of care</td>
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<td>A formal and planned discharge discussion occurs with every patient/family on or near their last appointment in the paediatric setting</td>
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<td>For patients/families assessed through the transition readiness and risk assessments as needing a more intensive approach to transition, a joint discharge/transfer meeting/discussion occurs at which the patient, family/caregiver(s) and/or members from paediatric, adult, primary and/or community-based (i.e. CCAC) multi-disciplinary healthcare teams, as appropriate, are present</td>
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<td>Every specialist involved in the provision of care to youth who are transitioning to an adult healthcare provider/setting include standardized information on the discharge/transfer summary for every patient</td>
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<td>Gorter &amp; Weaver (2013).</td>
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BC’s Cross Ministry Transition Planning Process for Youth with Special Needs

1. Initiate the Transition Planning Process
2. Establish the Transition Planning Team
3. Identify the Transition Coordinator
4. Gather Transition Planning Information
5. Develop the Transition Plan
6. Implement the Transition Plan
7. Monitor and Review the Transition Plan

Government of British Columbia, 2009

Alberta Policy Framework for Children and Youth with Special and Complex needs:

- **Management of Integrated Service Delivery for Children and Youth with Complex Needs and their Families** (e.g. Formalization of an integrated case management model)
- **Cross-ministry Collaboration for Children and Youth with Special Needs and their Families**
- **Sustainability of Services/Transition Planning**. (i.e. Formal transitional planning for children and youth with special and complex needs will begin 24 months prior to a youth turning 18 years and resulting in the development of a transitional plan 12 months before the youth turns 18 years. The transitional plan will address issues such as placement, educational, social and other pertinent needs.).
- **Cross-ministry Information Sharing**. (i.e. development of information sharing guidelines and training tools for delivery staff; regularly updated resource information for families; and steps to improve ministry and regional information systems to identify common language, definitions, diagnostic and prognostic coding., all within the provisions of privacy legislation

Alberta Children and Youth Initiative Partners (2003).
References:


Canadian Foundation for Health Improvement (2013). Programs that aim to improve transition from pediatric to adult services: A snapshot.


Gorter & Weaver (2013). Transition to Adult Healthcare Services. [PPT slides].


Joint CDHA-IWK Steering Committee on Transition Needs of Youth and Families (2012). Transition of Medical Care from Youth to Adulthood.


McCall, Campling & Conly (2014). Family Physician Billing for Patients with Chronic Conditions and


Statistics Canada (2014). Table 051-0001 - Estimates of population, by age group and sex for July 1, Canada, provinces and territories, annual (persons unless otherwise noted), CANSIM (database).


