



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

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Definitions

- YSHCN
 - Children and youth who have or are at increased risk for a chronic physical, developmental, 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)
- Transition
 - The purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult oriented health care (Blum, 2002)
- Transfer of Care
 - A one time event that occurs at the time the child is transferred out of the child health system (PCMCH, 2009)

Background and Rationale

- Advancement in modern medicine has allowed for earlier diagnosis and prolonged life expectancies
- Transitions in care become inevitable
- Stark contrast between pediatric and adult environments
- Transition planning is associated with:
 - adherence to treatment
 - clinical outcomes
 - E.g. depression, graft loss in kidney transplants
 - participation & satisfaction

Nova Scotia Context

- Youth under the age of 20 made up nearly 20% of population in 2014
- Only 6.9% of youth had at least one chronic disease, yet accounted for 16.7% of health care services used by all youth
- Disability rates in general are higher in NS compared to the national average, including those 0-14 years of age and those 15-24
- Data out of date and difficult to find

Purpose

- To explore the current state of transitions from pediatric to adult based services in Nova Scotia for Youth with Special Health Care Needs (YSHCN)
- Objectives:
 - 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

- Literature Scan
- Program & Policy Review
- Stakeholder Consultations
 - *Continuing Care* (Council, HCN, Care Coordinators, VPs Community)
 - *Primary Care* (Family Physicians, VPs Community, You're in Charge program)
 - *Community Services* (ARC/RRCs, and Adult Service Centres)
 - *Acute & Tertiary Care* (Provincial Programs, VPs Clinical)
 - *Government Departments* (branches of DHW- primary care, acute and tertiary care, continuing care, and mental health and addictions and children's services, SPD through DCS, and DOE)
 - *Provincial and National Initiatives and Programs* CAPHC, ON TRAC SickKids' Good 2 Go program, and Ontario's PCMCH
- Family Physician Survey

Methods

- Caveats:
 - Predominant health focus
 - Low survey response rate
 - Lack of consultation with youth and their families

What we Heard: System Level Themes

- ***Collaboration & Communication between sectors and providers***
 - 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.
 - particular focus should be paid to clarifying the roles and relationships between the following services and providers
 - community services and health services
 - family physicians and specialists (pediatric and adult).
 - education and health sectors while YSHCN are at school

Recommendation: System Level Themes

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.

What we Heard: System Level Themes

- ***Provincial Child and Adolescent Health Focus***

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

- ***DHA Role Clarity***: 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
- ***Tertiary Services*** role should be to support primary and secondary care providers who also care for these patients
- ***Health System Restructuring***: Opportunity to examine what the roles of the IWK and the new HA are in provision of care to this population.

Recommendation: System Level Themes

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, including the role of tertiary services in supporting primary and secondary care providers.

What we Heard: System Level Themes

- ***Lack of Data, Information & Planning***
 - Demographic data on YSHCN for needs based planning
 - Flow of information between service providers and sectors
 - Lack of involvement from those on the receiving end of transition until the youth is “on their doorstep”

Recommendation: System Level Themes

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.
- 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.

What we Heard: System Level Themes

- ***Age Specifications & Limitations***

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

- Different age of transfer for mental health services (19 vs 16) confusing for patients and care providers
- Finding the “right” age
 - Align with other provinces, and other “natural” transitions (18)
 - Younger (e.g. 16) appropriateness of child health settings
 - Older (eg 21-25) incorporate “emerging adulthood”. Adolescent brain still developing
 - Rigidity of using age as a criteria for transfer

Recommendation: System Level Themes

Recommendation 4: As recommended through 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

What we Heard: System Level Themes

- ***Knowledge & Skills to Appropriately Care for YSHCN***
 - Adolescence as a Speciality or Transitional Stage
 - Distinctive physical and psychosocial needs
 - Adults with Autism and other Developmental Disabilities
 - Increasing population (magnitude unknown)
 - Family Physicians & Adult Specialists
 - Having a knowledgeable and competent provider on the receiving end of transition and throughout the lifespan

Recommendation: System Level Themes

Recommendation 5: Create training opportunities and build knowledge and skills for service providers to appropriately care for YSHCN within the three identified areas:

- **Adolescence**
- **Adults with Autism and DD**
- **Family Physicians and Adult specialists**

This can be done through undergraduate curricula and CE opportunities and identifying and tapping into existing resources and pockets of expertise (Nova Scotia Autism Centre, Breton Ability Centre)

What we Heard: System Level Themes

- ***Use of Navigators***

- “Band-Aid” solution?
 - Focus should be on making system less complex
- Placement and scope of navigators is key
 - e.g. primary care, cross-sector navigator
- A key element of navigation is having and being aware of resources to navigate.

Recommendation: System Level Themes

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.

What we Heard: System Level Themes

Differences between Child and Adult Care Environments

Lack of collaborative teams and more “organ” focused in adult care

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

Joint CDHA-IWK Steering Committee on Transition Needs of Youth and Families recommended the establishment of a joint CDHA-IWK adult complex care clinic

Recommendation: System Level Themes

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.

This should be done with provincial focus, and should model should be well linked to health and support services the patient can access in their local community if they are from a another part of the province.

What we Heard: System Level Themes

Youth & Family Inclusion

- Involvement in the planning process and in the determination of transition related policies and programs is imperative
- E.g. You're in Charge Program relied on a youth and family advisory council which helped shape the location and delivery of the program.

Recommendation: System Level Themes

Recommendation 9: Include youth and parent representatives in the planning and design of transition initiatives and services to ensure they are person/ family-centred (e.g. youth and family advisory committees, active engagement with patients/clients etc.).

What we Heard: Primary Care

- Key primary care issues for transition
 - Self-management & Self Advocacy Skills
 - Involvement of Family Physicians

What we Heard: Primary Care

- Self-management & Self Advocacy Skills
 - Pre-requisite skills for adult based care
 - Need opportunities for parents and youth to practice these skills and understanding consequences early on
 - You're in Charge Program
 - Building a Better Tomorrow Together

Recommendation: Primary Care

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.

What we Heard: Primary Care

The Role of the Family Physician

- Family physician survey (n=25) and follow-up interviews (n=2)
 - *Role Clarity.* gap between what FPs believe their role should be and what their current role is; specifically that they should be more involved than they currently are.
 - 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.
 - *Capacity :*
 - 48% disagreed they had the necessary **knowledge**
 - 53% felt they did not have the necessary **time**
 - 74% felt that access to **community resources** is lacking (e.g. home support, respite, vocational opportunities, etc.)
 - 76% did not feel they were adequately **compensated**

Recommendation: Primary Care

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.

What we Heard: Acute & Tertiary Care

- ***The Role of Tertiary Services***
- ***Provincial Programs***
 - Felt to be an enabler where they exist
 - *Moving on ... with Diabetes*
 - *Comprehensive guide/ resource for youth with diabetes transitioning to adulthood*
 - *Illness related*
 - *Social relationships (friends, intimate)*
 - *Alcohol*
 - *Grocery lists*
 - *Sick time from work etc.*

Recommendation: Acute & Tertiary Care

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.

What we Heard: Mental Health & Addictions

- ***Previous and ongoing work on transition***
 - 2010 Auditor General Report
 - DHA policies (variation in scope and implementation)
 - Staying Connected Mental Health project which focuses specifically on the transition from pediatric to adult based mental health services

What we Heard: Continuing Care & Community Services

- Greater need for community based supports (e.g. respite, adult day, vocational programs)
- Planning and preparation for those on the receiving end of transition.
 - ARC/RRCs involvement with youth earlier
 - ASCs more planning and practical skills needed before the adolescent leaves a school environment
- Relationship between community and continuing care services: there needs to be greater clarification around boundaries

What we Heard: Continuing Care & Community Services

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.

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)

Conclusion

- There are several system and sector level barriers to a seamless transition from pediatric to adult based care YSHCN
- There is ongoing work and pockets of innovation addressing this issue
- There are opportunities to translate these pockets of work into a provincial approach as we strive to do the same for our health system