



CANADIAN ASSOCIATION OF PAEDIATRIC HEALTH CENTRES (CAPHC)  
ASSOCIATION CANADIENNE DES CENTRES DE SANTÉ PÉDIATRIQUES (ACCSP)

## Canadian Association of Paediatric Health Centres CAPHC

**Youth and Adults Working Together to Create Effective  
Transitions to Adult Care  
National Symposium  
October 20, 2009**

**CAPHC 2009 Annual Meeting**  
*Investing in Child and Youth Health in Tough Economic Times*

**October 18 – 21, 2009**  
**The Weston Nova Scotian**  
**Halifax, Nova Scotia**



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## About CAPHC

The Canadian Association of Paediatric Hospitals was co-founded in 1968 by the leaders of the Children's Hospitals across Canada.

Over the past two decades, child healthcare organizations have undergone fundamental structural changes. In 2001, as a result of an organizational renewal, The Canadian Association of Paediatric Health Centres (CAPHC) was created to better respond to emerging healthcare challenges and the shifting landscape of child and youth health service delivery in Canada.

Today, CAPHC is proud to support its forty-five member organizations, representing multidisciplinary health professionals that provide health service delivery to children, youth and their families within acute care hospitals, community health centres, rehabilitation centres and home care provider agencies across Canada.

All Children's Hospitals and their respective Children's Hospital Foundations in Canada are members of CAPHC, thereby providing strong linkages to clinical care, education and research.

CAPHC supports a Pan-Canadian communication network that enables knowledge transfer of leading-edge research and clinical care practice. Along with our members and partners, CAPHC is a strong national advocate for change and quality improvement to enhance the healthcare for all children and youth.

As a national organization representing health professionals and organizations across the continuum of care, CAPHC is uniquely positioned to influence system-wide change at a national level by advocating for child and youth health service delivery at key and influential tables. In addition, because a large part of CAPHC's membership is situated at the grass roots level, we are also able to effect change at the point of service delivery.

## A Voice for Child and Youth Health

Over the past several years, CAPHC has mobilized and successfully facilitated multiple national healthcare programs and has attracted the interest of other organizations, governments and federal and provincial agencies.

CAPHC has now laid the foundation for long-term collaborations in key health service delivery areas. This is predicated on the understanding that relevance, timeliness and good working relationships are critical factors for success.



CAPHC has created a significant national portfolio focused on key child and youth healthcare priorities. In addition, CAPHC has been a leader in engaging family advocacy groups to ensure a strong voice and leadership role in many of our national programs. Details of CAPHC programs are described on our website: <http://www.caphc.org/>

### CAPHC's Mission

The mission of the Canadian Association of Paediatric Health Centres is to support member and partner organizations in order to improve health service delivery for Canadian children and youth.

We do this by:

- Advocating for the unique character and importance of the health of children and youth;
- Identifying and responding to emerging issues and trends that impact our communities;
- Building a community of practice to share research, information, knowledge and expertise;
- Building strategic partnerships and facilitating collaboration;
- Leveraging opportunities to advance health service delivery priorities; and
- Promoting best practices in quality improvement and patient safety.

### CAPHC's Strategic Priorities 2009 – 2014

1. Establish programs and activities that address current and emerging child and youth healthcare priorities;
2. Advocate for transforming health service delivery for children and youth in Canada;
3. Connect service providers and key stakeholders to realize shared child and youth healthcare goals;
4. Foster research, broker knowledge, facilitate educational opportunities and enhance information exchange for members and stakeholders, within the child and youth healthcare community, as well as with external partners; and
5. Build capacity and enhance organizational health to ensure that CAPHC can realize organizational objectives and meet the needs of member organizations.

*Reference: CAPHC 2009 Annual Report & 2009 – 2014 Strategic Plan - <http://www.caphc.org/about.html#mission>*



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As a 2009 Annual Conference partner The Canadian Association of Paediatric Health Centres (CAPHC), would like to extend sincere appreciation to the Public Health Agency of Canada for its ongoing commitment to improving the health and well-being of children and youth and for your participation and support of the National Symposium entitled – ***“Youth and Adults Working Together to Create Effective Transition to Adult Care”***.

This national symposium was held on October 20, 2009 in Halifax Nova Scotia, during CAPHC's 2009 Annual Meeting. We are pleased to submit the proceedings of this symposium as follows:

***Youth and Adults Working Together to  
Create Effective Transition to Adult Care  
National Symposium Proceedings***

**Symposium Overview**

Successful transitioning of youth with special health care needs from paediatric to adult medical care is a critical component of patient safety. Evidence also demonstrates that coordination of services using a transitional model of care is a significant variable in optimizing patient outcomes.

Research suggests that a three phase approach is most effective: building self efficacy skills from early adolescence (readiness phase), systematically planning the transfer of care (transfer phase) and following the patient through to adult adjustment and integration (adjustment phase). This model incorporates recognition that transitional support needs can be best understood within a developmental framework.

In tough economic times we are told there is no extra funding for additional programs. This symposium challenged the audience to consider how they can improve the coordination, collaboration and communication required to incorporate more effective transition services into their daily practice. Building on the CAPHC 2008 World Café, stakeholders who represented a range of perspectives, best practices and evidence, shared various models of service, tools and resources designed to support youth and their families to grow, transfer and integrate into the world of adult services.



***National Symposium speakers were:***

Helen Healy, Consultant, Helen Healy & Associates, Toronto, Ontario;

Dr. Nick Kates, Professor and Vice-Chair of Clinical Services, Department of Psychiatry & Behavioural Neurosciences, Associate Member, Department of Family Medicine, Director of Programs, Hamilton Family Health Teams, Hamilton, Ontario;

Catherine Dunseith, Youth in Transition Program Coordinator, Alberta Children's Hospital, Alberta Health Services, Calgary Area;

*Symposium Chair* - Susan Fogg, Program Director, Child Health, Winnipeg Regional Health Authority, Director of Patient Services, Children's Hospital, Health Sciences Centre, Winnipeg, Manitoba; CAPHC Board of Directors.

**Symposium Presentations**

The voice of youth is critical to ensure appropriate services and programs are developed to support youth and their families and ensure continuity and that the bridge between paediatric and adult health care services is seamless. The *Youth and Adults Working Together to Create Effective Transition to Adult Care* session provided an overview of several approaches to transition from paediatric to adult services and explored ways in which coordination, collaboration and communication can be improved.

All presentations can be found on the CAPHC website ([www.caphc.org](http://www.caphc.org)).

***1. Youth and Adults working together to Create Effective Transitions to Adult Care  
Helen Healy, Consultant, Helen Healy and Associates, Toronto, Ontario.***

Helen Healy presented on the ***Living Independently and Fully Engaged Service Model*** (LIFEspan). This holistic model provides continuity to youth transitioning to adult services and is anchored in values of partnership, collaboration, communication and shared expertise.

It is critical that organizations recognize and work with partners to ensure continuity in transition. Organizational commitment, systems action and capacity building both within the paediatric and adult sectors, are enablers that provide greater continuity and can support more successful transitions to adult services.

The ***Growing Up Ready*** program at Bloorview Kids Rehab is a multi-faceted program which focuses on providing children, youth and families the tools and skills for transitioning into adult services.



The family-centred program begins at an early age and focuses on future orientation towards adulthood and adult services. The program focuses on individual needs and strengths. Education materials around transitioning are introduced to the family at an early stage to help prepare, educate and support the family through this process. Various tools within the service model act as triggers and points of discussion for families.

Part of the **Growing Up Ready** program includes *Developing the Skills for Growing Up Checklists*; culturally sensitive series of three checklists designed to assist young people and their families to develop skills and prepare for the future. The tools are not age specific, so families and youth can decide for themselves when to begin the process of preparing for transition. It is not a standardized assessment, but instead families set goals together and select items to work on, based on their priorities and situation. The Checklists have been introduced in school support services, clinics and inpatient rehabilitation.

The **Growing Up Ready** program helps supports youth transition into an adult rehabilitation centre with the support of a nurse practitioner who works with the client and family across both the paediatric and adult centres. In addition, a multidisciplinary team is in place at the adult centre. This team works together to ensure the smooth transition and clear communication. In 2007, this model was designated a leading process by Accreditation Canada and considered an excellent way to bring youth through the transition process.

The **MyHealth Passport** is another tool that has been developed for youth to assist in transitioning. The portable, customized document aims to provide patient education, create a sense of ownership and foster self-advocacy. Using the tool also provides opportunities for learning, as youth complete their own medical passport. Currently, the initiative is exploring ways which youth can upload and access data via cell phone.

The **LIFEsplan Model** of service delivery is a shift in philosophy and practice which embraces a chronic care model. It moves from episodic management of acute issues to a focus on management of chronic disease.

**2. Primary Care – The Forgotten Link for Transitioning Youth; Nick Kates, McMaster Department of Psychiatry and Behavioural Neurosciences, Hamilton Family Health Team, Hamilton, Ontario.**

Nick Kates provided an overview on the role primary care can play in bridging the gap between systems for youth transitioning to adult care, the challenges many youth with mental health issues experience when transitioning to adult care and recommendations for system change.



While healthcare providers, administrators and families all acknowledge that there are problems within the Canadian mental health system, there are not many opportunities to step back, look at the issues and discuss how to do address services and issues to address systems barriers and gaps.

Primary care is often the first point of contact for people when entering the health care system. The comprehensive services offered within primary care can foster enduring relationships between the healthcare provider and patients. While much of the focus for primary care is on health promotion, prevention and chronic disease management; future directions include the concept of medical home, where all services that an individual requires are either provided or linked to the primary care provider.

There are many opportunities for improvement of the primary care model to better serve youth. Such opportunities include ability to track and monitor a population or cohort on an ongoing basis, ensure individuals do not fall through the cracks when transitioning to adult services, provide student health services and monitor individuals at risk. Primary care is also well positioned for early detection, monitoring and identification of relapses and early intervention. Through monitoring over time, there is a greater likelihood of preventing relapses.

Youth transitioning to adult mental health services can face many challenges in accessing and maintaining care and services. Primary care needs to be involved in discharge planning to assist in this transition process. Often the primary care professional plays a continuing role in the youth's life into adulthood. It can be difficult to support and deliver appropriate services to youth who are discharged back to their family physician without a clear plan. By youth receiving a copy of the transition or discharge plan, supports can be put into place to hold the system accountable to a care plan.

There are fundamental shortcomings of the Canadian health system and how it is organized which perpetuate the challenges youth with mental health issues or mental illness experience. Through changes to the system design, resources can be maximized and these challenges addressed.

Better management and outcomes require changes in the way systems of care are organized and linked. The system needs to be redesigned to meet the needs of youth. Exploring collaborative models between primary care, mental health and paediatric services, resources can be better utilized. New roles for primary care can optimize the system and meet the needs of youth and families.

The role of family physicians and primary care can not be enhanced without the support, collaboration and partnership of specialized services. Through client-centred care, collaborative models of service delivery can be established to ensure youth and families receive the support and care needed.



Shared models of care, where youth and primary care professionals work together to ensure regular communication, make it easier to negotiate points of transition. Acknowledging a shared responsibility to ensure the care plan is in place and working needs to occur. These collaborative models of care will ensure that gaps in services are bridged.

Often primary care can be overlooked as part of the youth's treatment plan. However, by optimizing the role of primary care, we can improve the outcomes of youth and ensure continuity when entering adult services. This requires a different way of thinking, approaching services and building relationships between systems.

**3. *Implementing a Youth transition program in tough economic times: A Systems Approach; Catherine Dunseith, Youth In Transition Program Coordinator, Alberta Children's Hospital, Alberta Health Services, Calgary, Alberta.***

Catherine Dunseith presented on Alberta Children's Hospital's transition program. The presentation also provided delegates the opportunity to view three video vignettes related to transition. These digital story telling vignettes were created in partnership with the University of Calgary and provide different perspectives on transitioning practices.

The goal of transitioning is to *"provide comprehensive, developmentally appropriate health care in a coordinated and uninterrupted manner."* Client and family-focused transition to adult services acknowledge where the youth and his or her family is, builds on existing strengths and provides supports.

The ***Well on Your Way Program*** provides a key person or coordinator to oversee the transition process. While everyone plays a role in successful transitioning, a coordinator provides a bridge to assist in the process and ensure that teams involved are communicating and use the same language and goals. This ensures that the paediatric team has a clear outline of the process, can access resources and that the adult team is prepared for the new patient. It is essential that staff bridge the transition to adult services with the patient and stay in place until the full transition is complete. With collaboration and commitment from both the paediatric and adult teams, successful transition is more likely.

Information, communication and empowering patients and families are key elements of successful transition. Transition services and programs can not be linear, but instead need to be adaptable and flexible to meet the needs of the youth. This support will enable the youth to become their own experts.

There needs to be recognition that youth are not always going to need specialized care throughout their lifespan, therefore a need for ongoing communication between primary and specialty care.



Family physicians need to be supported. Specialists need to be encouraged not to provide primary care to their patients but instead, foster the relationship between the youth and the primary care physician and provide support to the family physician where possible. This will help to ensure that youth entering the adult system can access supports, services and appropriate care and not slip back into paediatrics.

Transition is not an enhancement program, but a safety issue. Safe transfers of youth into the adult system ensure continuity of quality care, as well as promote cost savings for the overall healthcare system. Paediatrics has a responsibility to ensure that youth are entering the adult care successfully and have safely adapted to the system.

### Symposium Discussion

Delegates were provided the opportunity to ask questions and bring forward issues around transitioning for panelists to respond to. Major themes of the discussion are summarized below:

- Student health programs situated in colleges and universities are excellent ways to address mental health issues in the youth population and for marginalized youth/students to access services that they would not necessarily access in their own community;
- Family practitioners are a key component in successful transitioning to ensure youth connect with the adult system. It is important for family physicians to remain involved with the overall care of a child throughout their development;
- Youth need to be the 'owner' of their own information. This empowers them to share it with appropriate practitioners and allows them to access health services regardless of location or context. Family physicians and consistent healthcare providers are not available to all youth and families, the use of technology, like USB memory sticks or data stored in cell phones, allow for youth to easily communicate their health history and ensure continuity of care;
- There is no standard for the make up of inter-professional teams for transitioning. Team composition is dependent on the culture and context of each clinic. There are criteria and key steps that must be achieved that teams should review to determine who should oversee the transition process. Each team needs to be realistic in what they can provide and what they will be able to track. Being up front about the commitments to the transition process will help to define roles; and
- There is a great deal of literature supporting the need for successful transitioning. Children with chronic physical problems have increased morbidity when not properly transitioned. When transitions are not supported, it can be dangerous, inappropriate and unethical. Transitions and transition plans are not a choice but a responsibility of our healthcare system.



## Conclusion and Summary

Transitioning programs and services do not necessarily require a great deal of financial resources. Success transitioning requires the commitment and support from the organization and individual healthcare providers. Respect for the role each player brings to the transition process and clear communication will help to ensure safe transitions are created.

As demonstrated in this national symposium, several tools are available to healthcare providers to support effective transition practices. Delegates were encouraged adapt these tools to meet local needs and settings, and utilize them in their respective centres to help ensure transitioning to adult services is successful. CAPHC is committed to posting all relevant links to the tools presented at the symposium on the CAPHC Knowledge Exchange Network (KEN).