Provincial Council for Maternal and Child Health
Child and Youth Advisory Committee

Transition to Adult Healthcare Services Work Group

Terms of Reference

Background:
Regardless of the clinical condition, the need for a planned approach to transition from paediatric to adult healthcare services for youth with a chronic and/or complex physical, developmental and/or mental health condition has become more pressing over the past decade and a half. Significant improvements to diagnostic and treatment techniques have enabled many with congenital and acquired conditions to survive well into adulthood; many of these conditions previously resulted in mortality during infancy, childhood and adolescence. There has not, however, been a corresponding growth of adult services aimed at congenital or acquired conditions including, but not limited to, childhood cancer, congenital heart disease, cerebral palsy, sickle cell disease, cystic fibrosis, inborn errors of metabolism and those who have required a solid organ or tissue transplant.[1,2] For the purpose of these terms of reference, healthcare transitions are defined as the purposeful, planned movement of youth with chronic and/or complex physical, developmental and/or mental health conditions from child/youth/family-oriented to adult-oriented care.[3]

Although the transition to adult healthcare services is a critical part of the transition to adult life for youth with a chronic health condition and their families, reports from families indicate this is often not addressed in an organized, timely, and planned manner. In many instances, paediatric healthcare providers experience issues in finding qualified adult healthcare providers willing to accept patients with chronic and/or complex conditions and/or disabilities.

Both the Canadian Paediatric Society and the American Academy of Pediatrics state that the goals of planned healthcare transitions are to ensure high-quality, developmentally appropriate, psychologically sound healthcare that is continuous, comprehensive and coordinated, before and throughout the transfer of youth into the adult system.[4,5] In doing so, youth and their families can learn to advocate effectively for themselves, maintain good health behaviors and use healthcare services to maintain their health and prevent secondary disability.[6]

Transition to adult healthcare services is a ***process*** that begins prior to the actual transfer and does not stop once the transfer has occurred. Youth, their families, paediatric healthcare providers and adult healthcare providers all have an important role to play in the shared responsibility of patient care prior to and following the transfer of care.

Purpose:
The TAHS-WG will make recommendations regarding a provincial approach to transition to adult services for youth with a chronic and/or complex clinical condition including physical, developmental and/or mental health conditions. The recommendations will be generic rather than site and/or condition specific so that they can be adapted to each patient, patient population and the unique characteristics of an organization.

Underlying principles for the recommendations include:
1. Provision of healthcare that is:
    a. High quality, co-ordinated, continuous
    b. Patient/family-centred, age and developmentally appropriate and culturally competent
    c. Flexible, responsive and comprehensive with respect to all persons involved
2. Promotes skills in communication, decision-making, assertiveness and self-care, self-determination and self-advocacy for youth, their families and/or substitute decision makers
3. Enhances the young person's sense of control and independence
4. Provides support and guidance for the parent/carer of the young person
5. Maximises life long functioning and potential[7,8]

Goals:

- To identify current issues in transition to adult healthcare services, both from a paediatric and adult healthcare provider perspective
- To identify current best practices in transition to adult healthcare services
- To identify and clarify the roles of paediatric and adult teams in relationship to transition to adult healthcare services
- To recommend strategies to ensure a seamless interface between paediatric and adult healthcare providers
- To gain consensus regarding a framework of transition to adult healthcare services
- To prioritize strategies based on both importance and cost/ease of implementation
- To make recommendations regarding knowledge transfer strategies including opportunities for partnering across the continuum of care and across sectors
- To look at opportunities for partnering with and/or leveraging existing technologies
- To make recommendations regarding evaluation of the impact related to implementation of the recommendations

Accountability:
The TAHS-WG will report to the Child and Youth Advisory Committee (CYAC) of the Provincial Council for Maternal and Child Health (PCMCH).

Membership:
In order to ensure a comprehensive approach, TAHS-WG members will be chosen from paediatric and adult care. Membership will be LHIN-based and balanced by profession and organizational type.

Members:

- Paediatricians or paediatric sub-specialists (hospital-based)
- Adult sub-specialists (hospital-based)
- Family physicians and/or nurse practitioners
- RNs from both paediatric and adult settings
- Allied health (i.e. Social Work, Psychology)
- Physiatry (specialist in physical medicine and rehabilitation)
- Transition Programs from both paediatric and adult settings

Given the focused nature of the group's work, alternates will not be permitted. The PCMCH Secretariat will provide support to the TAHS-WG.

Decision Making Process:
Members share accountability for decisions. There should be open and direct communication based on honesty, respect and transparency, to ensure that all perspectives are heard. Decisions should be evidence or most-promising practice based. Decisions will be made by consensus whenever possible. If voting is required, all members will have one vote.

Conflict of Interest:
Members of the TAS-WG shall disclose, to the co-chairs of their group, without delay, any actual or potential situation that may be reasonably interpreted as either a conflict of interest or a potential conflict of interest.

Communication and Confidentiality:
TAHS-WG material should be treated as confidential. It will be clearly stated when TAHS-WG material is no longer confidential.

Meeting Schedule:
February 2012 to September 2012

[1] Holland Bloorview Kids Rehabilitation Hospital. ***LIFEspan clinic helps youth with disabilities transition to adulthood.*** Retrieved from: http://www.hollandbloorview.ca/resourcecentre/growing_up/life_span_clinic.php

[2] Provincial Council for Children's Health. ***Transition: A Framework for Supporting Children and Youth with Chronic and Complex Care Needs as they Move to Adult Services.*** November 2009. Retrieved from: http://www.pcmch.on.ca/LinkClick.aspx?fileticket=UR0dMj5YS8E%3d&tabid=65

[3] Blum, R.W.; Garell, D.; Hodgman, C.; Jorissen, T.; Okinow, N.; Orr, D.; and Slap, G. ***Transition from child-centered to adult health-care systems for adolescents with chronic conditions.*** Journal of Adolescent Health 1993;14(7):570-576.

[4] Adolescent Health Committee of the Canadian Paediatric Society. ***Policy Statement on the Care of Adolescents with Chronic Conditions.*** Paediatr Child Health 2006;11(1):43-8; Reaffirmed January 2011. Retrieved from CPS http://www.cps.ca/english/statements/AM/ah06-01.htm#transfer

[5] American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. ***Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home.*** PEDIATRICS Vol. 128 No. 1 July 2011, pp. 182-200. Retrieved from: http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;128/1/182?rss=1

[6] Adolescent Health Committee of the Canadian Paediatric Society.

[7] McDonagh, J. E, & Kelly, D. A. (2003). ***Transitioning care of the pediatric recipient to adult caregivers.*** Pediatric Clinics of North America, 50(6), 1561-1583.

[8] McDonagh JE. ***Growing up and Moving on. Transition from pediatric to adult care.*** Pediatric Transplantation 2005;9:364-72