Briefing Note: Transition from Pediatric to Adult Care at BCCH
ON TRAC Initiative Projects

Purpose: The Transition Initiative is a Provincial initiative supported by Child Health BC and 4 partner projects. The goal is to facilitate transition, preparation and transfer, for youth with chronic health conditions and disabilities (CHC/Ds) to adult care and ensure that transfer is successful, with youth engagement and appropriate continued attachment to primary care and specialist adult services.

Background: The Transition Initiative developed from concern regarding the increasing numbers of youth with CHC/Ds surviving beyond the pediatric age group and requiring long-term care, and challenges for all stakeholders as transfer occurred. The BCMA policy Statement- Closing the Gap, Youth Transitioning to Adult Care in BC, December 2012 has 10 recommendations regarding improving transition services within British Columbia.

Projects: While each project has a unique specific mandate, the Initiative is collaborative, with the goal that synergy between projects will decrease costs, streamline services and avoid duplication. British Columbia Medical Association Shared Care and Specialist Services projects follow the Triple Aim Framework- improve patient and provider engagement, reduce costs and improve health outcomes. All projects are aligned to be synergistic, and will have significant crossover, particularly with some of the critical themes that have emerged. These include patient engagement, understanding complex health care needs and the support required, access to relevant information in a timely manner, recognition of the patient population and their needs, effective communication strategies and integration of cross jurisdictional care.

Shared Care Youth in Transition Project: 2012-2015

First Year Accomplishments: Current transition and transfer practices from specialist pediatric care to the health regions and community were identified as well as opportunities to improve services. A Medical Transfer Summary (MTS) was developed as a communication tool between primary and specialist (pediatric and adult) providers.

Second year projects include:

1) ***Improving attachment of youth who age out of pediatric care with their Family Practitioner and Adult Specialist(s)***. The Division of Family Practice, North Shore (Vancouver Coastal Health) has agreed to participate in this project. Requests are being made to Northern Health Authority, and the Division of Family Practice, Abbotsford, (Fraser Health) to participate as well. The projects will assess the utility of the information, such as the MTS, to support ongoing care and health service provision issues and opportunities to improve attachment and service provision, including the involvement of Allied Health for complex patient management.
2) ***Improving Attachment to the Family Physician.*** Identifying FP interested in managing youth with CHC/Ds: We plan to engage the 31 Divisions of Family Practice and the Health Authorities to develop strategies to identify and encourage Family Physicians to accept unattached patients. We will also seek to develop organized relationships between the BC Children's Hospital (BCCH) and the attachment/home health initiatives that are supported by the Health Authorities.

Recent changes in the MSP billing structure provide opportunities to encourage Family Practitioners to take on complex patients. We will work with the BCMA and the Divisions to develop guidelines and identify opportunities to improve attachment.

Specialist Services Committee: Jan 2013- June 2015
This project is designed to improve specialist services and continuity of care for youth/young adults with CHC/Ds. Pediatric and adult specialists, working with primary care providers and allied health, will co-develop condition-specific long term care plans to help ensure that youth with CHC/Ds who age out of tertiary paediatric care have access and attachment to appropriate specialist care as young adults. Prototypes will be developed for youth with cardiac, neurologic (including neuromuscular) and rheumatologic conditions, and will identify differences in management based on patients' disease complexity, cognitive abilities, psychosocial needs, or access barriers.
The long term care plans will lead to: 1) development of training modules and other training tools for adult specialists and family practitioners to support implementation and provision of youth-friendly care; 2) identification of system improvements (e.g., billing codes, information systems, etc.) to facilitate appropriate care; and 3) identification of strategies and mechanisms for providing allied health support to adult specialists managing young adult patients' complex conditions. The project will develop strategies for knowledge translation and scalability to other conditions, and will estimate ongoing costs for updating care plans and providing allied health support to ensure sustainability.

Vancouver Foundation Youth Voice Project: January 2013-July 2014
Partners include Check Your Head (Youth advocacy social justice NGO), Impact BC (a MOH supported patient advocacy network), McCreary Centre Society and condition-specific camps and organizations. This project brings an active and empowered patient voice (age 14-24years) to the Transition Initiative through genuine community-based youth engagement. Healthy outcomes for youth will be actualized when youth are involved, active participants in their health care. Youth ON TRAC will directly engage youth with CHC/Ds in all processes to create a new, relevant, meaningful, effective, authentic youth health advocacy voice through skills-building training, online social mentorship, education and collaboration. Youth friendly health promotions materials and tools will be developed with Emily Carr University of Art and Design. New skillsdeveloped by youth participants with CHC/D will lead to leadership and mentorship of younger youth entering the transition period and creation of a Provincial Youth Advisory Council (YAC) within Impact BC to ensure sustainability .This project is community based and external to BCCH. This project will inform health care decision makers on youth-friendly health care by guidelines, presentations at meetings and workshops.

Clinical Practice Guidelines: BC Children's Hospital (BCCH) Jan 2012- December 2015
This project has a Provincial mandate and extends from 12 to 24 years after youth have been discharged from pediatric care in partnership with adult services. Clinical Practice Guidelines (CPGs) and clinical tools have been created using the ImProve system and Agree II format. The CPG recommendations and tools will be trialed in pediatric, adult and community settings, supported with education tools for youth, families and health care providers such as safety plan, personal health care summary/planner, readiness tools (youth and parents), and extended resources for youth with complex transitional requirements. A Referral Network of services and teaching resources will be developed for youth with complex care needs in partnership with nursing, CYSN, adult and community based agencies. This project will educate and support clinical teams and allied health providers in pediatric, adult specialty and community services to identify strengths and gaps in developmentally-appropriate care, transition preparation of simple and complex patients, and processes for completion of transfer into adult care.